

I SURVIVED. THANKS TO MY DAUGHTER:
A STUDY OF ELDERLY WOMEN'S EXPERIENCE IN HOSPITAL.

by

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ABSTRACT

This research examined how the needs of elderly women are being met in the hospital setting. Qualitative data were gathered through in-depth interviews with eleven women between the ages of 70 and 93 who had had a hospital stay in the previous year. Data analysis revealed that the system failed to attend to participants' age specific needs. This failure created gaps in care which were particularly troubling for elderly female patients whose frailty made them susceptible to additional health problems. Participants received inadequate care in such areas as bathing, walking assistance and help with eating. Hearing impairments and denture issues were at times overlooked. These gaps in care caused participants to view a hospital stay as a matter of survival. Participants developed strategies to cope with gaps in care which included lowering their expectations, developing support networks and relying on family members to meet their basic needs and advocate on their behalf. Recommendations for change include identifying elderly women as a vulnerable patient population and defining the problems they face as structural issues as opposed to individual problems.

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PREFACE

For the last four years I have worked as a geriatric social worker in a variety of health care settings. The majority of my clients are elderly women, which reflects the demographics of the aged population. In my work in the hospital setting, I have observed a communication breakdown between elderly women and health care professionals. Elderly women seem to have a particularly hard time making their needs known. Health care professionals in turn appear to have difficulty tuning into the needs of this group. Much is missed and misunderstood. I wished to know why this was and what could be done about it.

In examining this issue, I turned first to the literature. The literature depicts elderly women as plagued by chronic illness, poverty and loneliness. Many of today's senior women were raised in a time when the medical profession was considered all knowing and one deferred to authority. The concept of patients' rights is foreign to many of these women. These descriptive accounts suggest that elderly women bring their own issues to the health care system. However, the literature contains little information on elderly women's perspectives on their needs in later life, in general, and with the health care system in particular. Given the increasing numbers of elderly women who will be entering hospitals an examination of older women's perspectives on their experience in hospital is essential to ensuring that their future care is based on real

not assumed need.

The purpose of this qualitative study is to hear from elderly women about their experience in hospital and make recommendations for their care based on their insights. The research question that guided this study was “How do elderly women experience being in hospital?” To this end, I interviewed 11 women over the age of seventy who had had a hospital stay in the last year. Unstructured interviews were conducted in participants’ homes and focused on understanding the women’s thoughts and feelings about their hospital experiences.

Data analysis revealed that a successful hospital stay is viewed as a matter of survival. Participants’ experiences alert us to the fact that the system is failing to respond to their age specific needs. To cope with gaps in care participants developed three survival strategies.

This thesis is organized in the following manner. Chapter one sets the stage for this study. This chapter discusses the demographics of today’s elderly women and examines what we know about their experiences with the health care system. Gaps in understanding are highlighted.

Chapter two outlines the methodology of the study. It provides a detailed account of how hermeneutics, structural social work theory and feminist research principles guided the study’s design. It contains a description of the study’s participants and discusses the interview process. The analytic process is described and evaluated.

Chapter three presents the findings of the study. This section chronicles the

major themes that emerged from the data.

Chapter four examines how the study's findings complement or challenge our existing knowledge base about the needs of elderly women. Implications for social work practice are discussed.

For me, this study highlighted how vulnerable elderly women can feel in the hospital. It alerted me to the need to help elderly women strategize ways in which they can bring their concerns to the attention of health care professionals. In particular, this study opened my eyes to the responsibility families' shoulder when an aged female member is admitted to hospital. It helped me frame the problems elderly women face in hospital as structural issues rather than individual problems. Most importantly, this study highlighted the need to develop structures that would help the system, patients, and their families work in partnership. We have a long road ahead. However, reviewing the literature and conducting this study has given me hope that we are pointed in the right direction.

CHAPTER 1 SETTING THE STAGE

"To put it bluntly the future is elderly and female."

(Kaveny, 1998:15)

It is well documented that elderly women make up, and will continue to make up, the majority of today's rapidly expanding senior population (Beckett & Schneider, 1992; Gundy, 1992; Kaveny, 1998). In fact, women aged seventy-five and over are the fastest growing age group in society today (Gundy, 1992). The U.S. Census Bureau predicts that by the year 2030 one in five Americans, and one in four American women, will be over 65 (Kaveny, 1998). In British Columbia it is projected that by the year 2021, eighteen percent of the population will be over the age of sixty-five with women making up the majority (Seniors' Advisory Council, 1998). Problems associated with aging, such as a greater risk of chronic illness, reduced economic resources, social isolation, and an increased need for care and institutionalization, affect women more dramatically than men (Beckett & Schneider, 1992; Gundy, 1992; Goynea, 1992). These demographics point to an increasing reliance by elderly women on the health care system. However, elderly women's opinions are rarely sought as a basis for providing care (Roberts, 1985; Sidell, 1992; Aronson, 1994). One area that has been overlooked is the experience of older women in hospital. For many older women a hospital stay is a new experience that requires the confrontation of complex health problems.

Until recently, studies of the aged adopted a unisex stance assuming women's

reality was the same as men's (Lewis, 1985; Doress-Worters & Laskin-Siegal, 1994). Feminist writers maintain that society has treated elderly women as invisible and myths and neglect have obscured the realities of their lives (Calasanti & Zajicek, 1993; Jorgensen, 1989; Lewis, 1985; Ward-Griffin & Ploeg, 1997). Scholars who have identified this vacuum as a problem have started to study how women cope with old age (Aronson, 1994; Boner, 1994; Evers, 1985; MacLean, Houlahan, Barskey, 1994). These studies found that older women worry about being a burden to their families (Aronson, 1994; Boner, 1994; MacLean et. al, 1994). A woman's life history also plays a role in how she copes in her later years (Evers, 1985). In addition, meaningful connections with others was found crucial to maintaining good health (MacLean et al, 1994). While these studies are a step in the right direction, we still have much to learn about older women's experiences, particularly in regard to their experiences in hospital.

A hospital admission is a critical event in an older woman's life. A review of the literature on elderly women and the health care system indicates that there are gaps in our understanding about the needs of this group in the hospital setting. For one, studies examining elderly women's experience with the health care system are limited. Secondly, ageist and sexist practices impact the delivery of health care services to elderly women. In an attempt to address these issues my study explicates elderly women's experience in hospital and makes recommendations for their care based on their insight. The following section will examine how ageist and sexist practices impact the delivery of health care services to elderly women. In addition, I will highlight where gaps in our understanding about older women's experience with the hospital system

occur.

Elderly Women Today

Research has yet to examine how an elderly woman's life history interfaces with her experience in hospital. However, in order to make sense of the experiences of elderly women in hospital it is important to understand the context of their broader lives. This section explains why.

Today's elderly women were born around the time of World War I. They lived through the Depression, World War II, the Cold War, Vietnam, and the Women's Movement. These women grew up in a time when infectious disease and epidemics took many lives. They witnessed the evolution of medicine to a more formal science and the development of laboratory testing and cures through drugs and surgery. Many of today's elderly women view doctors with a certain reverence and may view the medical profession as all knowing (Sidell, 1992). This deference to the medical profession may make it difficult for some older women to make their needs known in hospital. However, this issue has yet to be formally studied.

Many elderly women in hospital will be discharged home, alone. The majority of elderly women are widowed or single. By age seventy-five, sixty-seven percent of women are widowed (Dimond, 1995). In British Columbia five percent of males aged sixty-five to sixty-nine are widowed as compared to twenty-two percent of women of the same age (Northcott and Milliken, 1998). By age ninety, forty-six percent of men are widowed. This figure rises to eighty-six percent for women age ninety and above

(Northcott and Milliken, 1998). The differences in marital status among older men and women are generally explained as follows:

- Women are more likely to marry older men. Men have a shorter life expectancy than women and tend to die before their wives (Gonyea, 1997). The life expectancy for women is currently 81.3 years compared to 75.3 years for men (Senior's Advisory Council, 1998).
- Older men are more likely than older women to remarry. Older men have a wide age range from which to select mates should they become widowed or divorced. As women live longer than men, men are in shorter supply (Crawley, 1994).
- Women who have been married and borne children and who find themselves widowed often do not seek to recreate this experience in later life as they do not desire the caregiving responsibilities remarriage might entail (Crawley, 1994).

Elderly women without a reliable spouse may feel particularly vulnerable in hospital. Women's greater longevity also means that many older women experience bereavement and the subsequent emotional pain and psychological difficulties that can follow a loss (Sidell, 1992). They may need extra support in hospital and may be more anxious about returning home, as they are likely to live alone. However, this is conjecture. To date older women's opinions on these issues have not been reported in any detail in the literature.

In 1994 the U.S. Bureau of Census reported that less than one-quarter of men age eighty-five and above live alone (Gonyea, 1997). Conversely, sixty-four percent

(64%) of women age seventy-five and older are widowed and fifty-two percent (52%) live alone (Gonyea, 1997). In addition, more than one-third of functionally dependent men age eighty-five and older live with and are cared for primarily by their wives whereas only four percent (4%) of functionally dependent females live with their husbands (Gonyea, 1997). In British Columbia forty-three percent (43%) of females age seventy-five and older live alone compared to nineteen percent (19%) of males in that age group (Northcott & Milliken, 1998). Gonyea (1997) sums up these demographics by stating, "Men typically do not bury their spouses, nor are they forced to live alone" (Gonyea, 1997:80). These demographics emphasize that elderly women may have unique needs in hospital which, to be better understood, must be studied separately from men's.

Another factor that may affect elderly women's experience in hospital is that many of these women identify themselves as caregivers. They are used to giving not receiving care. Research examining how elderly women react to receiving care from family members found that elderly women feel ambivalent about accepting help from family and worry about being a burden (Aronson, 1994). To minimize these feelings the women tended to keep their concerns to themselves and limit their requests for help. Research has not examined how elderly women respond to receiving help in hospital. However, many elderly women will need help from the hospital system. To work with these women health care professionals will need to understand what accepting help represents.

Neysmith (1991) points out that women's caring responsibilities have led to a

double bind which may make it particularly difficult for them to receive help:

The commitment women have to caring is often seen as contributing to social problems. The persistence of high poverty rates among widows is often defined as resulting from their interrupted employment patterns. In contradiction to earlier messages, women who have been caring for others all their lives are expected to be independent and self-sufficient and to make few demands on state and familial resources in their old age. (Neysmith, 1991:273).

Similarly, Lewis (1985) asserts that elderly women have received little recognition for the contribution that they have made to society by caring for others. She asserts their work is not considered part of the gross national product (Lewis, 1985). These women have potentially "saved" the community a lot of money by caring for their elderly relatives. An older B.C. woman expresses her frustration that her contribution to society has gone unrecognized:

I looked after two elderly family members for 10 years and saved the government in the region of \$250,000. I, however, because of my inability to work full time and consistently, do not have an adequate pension or savings, or car or my own home. There is an only ever increasing downward spiral into poverty. Do something for the forgotten mothers and grandmothers who suffer in silence. (Woman age 60-64. Seniors' Advisory Council, 1998:11).

Studies have shown that family caregiving is essential to the care of elderly

relatives (Picard, 1999a). However, the role family plays in the care of its hospitalized female members is an area that has received less attention. Concern has been raised that relying on family for support may not be in elderly women's best interests or in the best interests of their caregivers (Aronson, 1994; Evers, 1985; Neysmith, 1991). Elderly women have expressed that they do not want to depend on family for support as it creates problems in their relationships and in certain circumstances can lead to abuse (Aronson, 1991; Evers, 1985; MacLean et. al, 1994). However, government services see family as responsible for the first line of caring (BC Royal Commission on Health Care Costs, 1991).

Elderly women who present to hospital staff may be relying heavily on family and friends for support. Elderly women have expressed that their wish is to remain independent and in their homes (MacLean et.al, 1994). Recently, policy makers have created programs that bring services closer to home (B.C. Royal Commission on Health Care and Costs, 1991). The premise underlying this response is that services can be provided more cost-effectively in the community while still providing the elderly with the support they want (Neysmith, 1991). However, what often goes unspoken is the role family is expected to play in these cost-saving measures (Neysmith, 1991, Northcroft & Millken, 1998). Aronson (1994) criticizes policy makers for forcing elderly women to rely on family for support. She states that social policy makers "have assumed that families are the most appropriate locus for their care and questions of appropriateness for whom are not raised" (Aronson, 1994:18). British Columbia's acute and continuing care program clearly states that an elderly person's family is their

primary source of support. This policy is reflected on their website:

The acute and continuing care program recognizes and respects the role families and communities have in planning and delivering supportive health care services to individuals. The Program's services are designed to supplement rather than replace the efforts of individuals to care for themselves with the assistance of family and friends (www.hlth.gov.bc.ca)

However, families report they are struggling to meet the needs of their aged female members. A recent study by the Heart and Stroke Foundation found that:

Baby boomers are poorly equipped to cope with the growing burden of caring for parents incapacitated by stroke, and presumably by other ailments. Two thirds of survey respondents said they would be unable to adjust their hours of work to provide care; almost the same number said they would find it hard to cope with a person in need of care moving into their home; and as many again said that caregiving would be a financial burden (Picard, 1999:A9).

Older women who do not have family support are particularly concerned about how they will manage in old age (Seniors Advisory Council, 1998). The following quote from an older woman who participated in a British Columbia Ministry of Health study illustrates that access to appropriate health care supports is especially important to elderly women who do not have family:

The greatest concern to me, being single and without any family support will be

adequate health care services - particularly those that will allow me to stay independent as long as possible. The shortage of hospital beds is truly frightening for most seniors as it will inevitably lead to questionable hospital services along the road that will create fear and a loss of dignity and peace of mind (Woman, age 70-74) (Seniors Advisory Council, 1998:12).

Andell and Estes (1991) assert that "the availability of adult daughters to give care for older women is the significant factor in keeping frail and disabled elderly women out of residential care" (Andell & Estes, 1991:211). Interestingly, a recent Canadian study found that forty percent of people who look after elderly relatives are men (Picard, 1999b). This study also found that young people are assuming more caregiving responsibilities. The older woman's perspective on the role their family plays in their care in hospital has received scant attention in the literature.

Elderly Women's Health Care Experience

In the United States older women's health care expenditures constitute sixty-three percent (63%) of the total health care costs of the elderly, although women make up fifty-nine percent (59%) of the population (Andell & Estes, 1991). Elderly women visit physicians more often, and use more days of hospital care and receive more nursing home care than men (Andell & Estes, 1991). Examples of the role ageism and sexism play in the delivery of health care services to women are reported in much of the literature on the health care needs of aged women (Andell & Estes, 1991; Beckett & Schneider, 1992; Doress-Worters & Laskin-Siegal, 1994; Hughes & Mtezuka, 1992;

Sidell, 1992). This section examines how ageist and sexist practices within the health care system have blurred our understanding of elderly women's needs.

Robert Butler, former Director of the National Institute on Aging, coined the term "ageism" in 1968. He describes ageism as:

... a process of systematic stereotyping and discrimination against people because they are old. Ageism attributes certain characteristics to all members of a group because they are old. Stereotyping and myths surrounding old age are the result of a lack of knowledge and insufficient contact with a variety of older people. Ageism also makes it possible to ignore the social and economic plight of some older persons. Discriminatory practices in housing, employment, and health care services foster stereotypes about the aged. Ageism also influences the behaviour of its victims. The elderly tend to adopt negative definitions about themselves and to perpetuate the various stereotypes directed against them, thereby reinforcing societal beliefs (Butler, 1968, found in Maddox, 1985:23).

Sexism is defined as:

Individual attitudes and institutional arrangements that discriminate against people because of sex role stereotypes and generalizations. Sexism values the contributions one sex makes to society over another. Benefits are conferred to the valued sex accordingly. (Barker, 1987:48)

Ageist remarks color media reports of the aged (Gonyea, 1997). Escalating health care costs are reported in grave tones in the media and reference is made to a "graying of the federal budget", "a fiscal black hole" and "apocalyptic demographic forecasts" (Gonyea, 1997). These reports portray the elderly as a burden on the health care system and question society's responsibility to provide for their care. The following example illustrates this point:

...in an article entitled "Bed Blockers Blamed for Emergency Ward Crunch", author D. Grant quotes the executive director of the Hospital Council of Metro Toronto. He describes long-term care patients as: "... imposing on the system. Nobody wants them. The hospital don't. The families don't and certainly the government doesn't" (Aronson, 1994:20).

Comments such as these refer largely to older women as they make up the majority of the aged population. How hospitalized elderly women experience such sentiments requires further study. It is possible elderly women internalize these negative messages and feel they are not entitled to first rate medical care. Such negative thoughts would likely impede recovery.

The ageist practices of staff have been reported in much of the literature on older women's health care (Beckett & Schneider, 1992; Dimond, 1995; Doress-Worters & Laskin-Siegal, 1994; Evers, 1985; Hughes & Mtezuka, 1992). Many doctors are not trained to meet the needs of the elderly and are much less apt to recognize elderly women as having special needs (Sherrid, 1993, CAG, 1999). For instance, only eight

out of one hundred twenty-six medical schools in the United States require separate courses in geriatric medicine (Sherrid, 1993). Ageism can influence how staff deliver services to their aged clients. One woman explained her encounter with the health care system as follows:

We get the feeling from our G.P.s that we have been here too long, that we are too old for treatment. We know we do get aches and pains, but it's not necessarily our age. For anyone of any age something can be done (Sidell, 1992:180).

Evers' (1985) study on nurses' interactions with residents of a nursing home illustrates how some nursing staff "depersonalize and devalue" elderly women by referring to them as "just housewives" in their assessments (1985:104). Lewis (1985) asserts that ageism creates extra challenges for elderly women who rely on home support agencies or live in care. She makes a case that workers in these agencies and homes for the aged are "underpaid and undertrained and seldom have the opportunity to resolve their own personal feelings about working with the sick elderly" (Lewis, 1985:14). She highlights that:

Health care workers of all kinds struggle with anxieties about dependency, suffering and death as they care for the old. In addition, they must provide care in the context of a society filled with negative attitudes toward the elderly (Lewis, 1985:14).

A British study, which examined elderly women's experiences with their doctors, found that ageism and sexism affected the care these women received (Sidell, 1992). The women in this study reported that they felt that the chronic nature of their problems frustrated doctors as "no cure" could be found for their ailments. Interestingly, the women in the study expressed that they were not looking for a cure and were willing to accept their chronic conditions. What they wished for, and felt their doctors did not understand, was some relief from their symptoms. One woman explains:

Nobody says to you, "We can't do anything, we can only relieve it, or there's no way of a cure for it." Well, we don't expect a cure at our age, but at least you want some relief. But you don't seem to get anybody who understands you want relief (Sidell, 1992:185).

This woman's statement that "we don't expect a cure at our age" highlights how some elderly women accept ageist beliefs as fact. There are cures for some of the conditions that elderly people experience. However, based on the rationale of age cures may be overlooked. The women in Sidell's study pointed out that their health problems were often diagnosed as a result of their age. The women felt this diagnosis relieved their doctors from investigating their needs properly. One woman reported as follows:

They're not really very interested when you're in your seventies. You are a little bit, it seemed to me, you are a bit on the shelf. You're past it. You've had your day (Sidell, 1992:185).

The women in the British study described above were found to be less aware than younger women were of sexist attitudes on the part of health care providers (Sidell, 1992). The author of the study speculated that because these women had not been directly involved in the women's movement they would be less likely to identify health care providers' behaviour as sexist. While older women may not recognize it as such, other researchers have provided evidence that sexism plays a role in the delivery of health care services to older women. Lewis noted that major geriatric texts do not adequately address the medical implications of women living longer than men, referring instead to the unisex problems of older adults (Lewis, 1985). Roberts (1985) found that doctors tend to view male and female patients differently. Her research showed that doctors generally assume that female complaints are more psychosomatic than men's. The following quote exemplifies how societal beliefs about the needs of elderly people, especially elderly women, affect the delivery of health care:

Physician and other health care staff share our culture's negative attitudes, myths, and stereotypes toward older people. Medical staff more frequently dismiss older women's complaints and problems as neurotic and/or imaginary than those made by men. As one nurse put it: When a man complains of dizziness, he gets a work-up; an older woman gets Valium (Beckett & Schneider, 1994:345).

Evidence of sexist and ageist practices are further brought to light in studies which have examined the experience of patients in hospital (Coyle, 1999; Fisher &

Peterson, 1993; Irurita, 1996). The current trend towards patient centered care has given rise to a number of studies that seek to better understand the patient experience (Cleary, Edgman-Levitan, Roberts, Moloney, McMullen, Walker, & Delbanco, 1991). The provision of patient-centered care requires that patients' opinions about the services that they receive in hospital be taken into account in the design of programs and services. Two British Columbia Hospitals have incorporated the following patient-centered care principles into their service delivery (Cleary et. al, 1991):

Treat me as an individual

Make sure that someone is coordinating my care and that I know who that person is.

Talk to me in plain English ... and listen to what I have to say.

Keep me informed and educate me about my health and condition.

Help me be comfortable and as free from pain as possible.

Make me feel emotionally cared for and supported.

Involve my family and friends in my care.

Help me make the transition from hospital to home.

Make sure there are no unnecessary barriers to my receiving care.

I was unable to locate a study that looked specifically at the experience of elderly women in hospital. However, an examination of the studies that have examined the patient experience highlighted that we have much to learn about older women's experience in hospital. In this context these studies will now be examined.

Clearly et. al. (1991) conducted a national telephone survey of 6,455 adult patients who had recently been discharged from the medical and surgical wards of sixty-two hospitals in the United States. The purpose of this study was to determine which aspects of in-patient care were most important to patients. This study professed to be the first study which elicited patients' perceptions of their care for the purpose of quality assurance. The results of this study provided the basis for the book *Through the Patient's Eyes: Promoting Patient- Centered Care* (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). The patient centered care principles adopted by the two B.C. hospitals were extracted from Clearly's study. Clearly's respondents were asked a series of yes/no questions which were designed to focus on specific actions taken by hospital staff, i.e., "Were you told about your medications in a way you could understand?" However, this framework did not allow respondents to report on issues outside the scope of the survey nor was the experience that led patients to answer yes or no explored. The result is a somewhat limited picture of respondents experiences in hospital. Thirty-five percent of respondents were over the age of sixty-five. Unfortunately, the study did not report on what percentage of these older adults were women. Older patients were found least likely to report problems with their hospital

stay but a rationale for this finding was not provided. The study noted that women in general tended to report more problems than men (14.4% for women versus 12.9% for men); however no explanation for this discrepancy was offered.

Coyle (1999) conducted a qualitative study which sought to better understand the events that led to an unsatisfactory health care experience. Coyle found that health care users were dissatisfied with their health care experiences if they felt treated in a disempowering, dehumanizing and devaluing way which threatened their personal identity. She discovered that these experiences varied depending on the user's gender, class and race. She found that women over the age of sixty-five and under the age of twenty-four were most likely to be dissatisfied with their health care experience. This study provided insight into the experiences that lead women to feel dissatisfied with the health care system. However, it examined the experience of patients in outpatient clinics and doctors offices and did not specifically explore the experience of older women in hospital. Patients in hospital may be considerably frailer and their experience may be different.

Irurita's (1993) study on the dimensions of quality care in the hospital found that ageism and physical frailty lead to both male and female elderly patients feeling particularly vulnerable in the hospital. Elderly patients were more likely than younger patients to describe instances where their care was compromised. However, a comparison between male and female patients was not made. Consequently, we do not know if elderly women feel more vulnerable than elderly men. This study alerted me to the importance of further examining the experience of older hospitalized patients, in

particular women.

Fisher and Peterson (1993) studied how surgeons and surgical nurses interacted with elderly patients on a surgical ward. Data was gathered through participant observations and in-depth face to face interviews with surgeons and surgical nurses. The study found that the surgeons treated their elderly patients differently from their younger patients. For instance, the surgeons tended to assume their elderly patients wanted to be treated with authority. The nurses who participated in the study concurred that surgeons treated their elderly patients differently. The nurses noted surgeons calling elderly patients "goners" and said they "tend to display a callous, uncaring attitude toward their elderly patients as they are not seen as valuable". The study provided numerous examples of instances in which the quality of care of elderly female patients was compromised. For example, Fisher and Peterson describe how a seventy-year-old woman awaiting arm surgery complained to her nurse about a pain in her leg. The nurse asked the orthopedic surgeon to check the woman's leg. The surgeon responded to this request by marching over to the woman. In full view of the surgical staff, and without acknowledging the woman in any way, he whipped up her gown so that her genital area was exposed and pushed her leg up to her chest. He then stated that her leg would be fine and turned away without addressing the woman. The researchers who observed this interaction reported that the woman looked pained, embarrassed and helpless. This study highlighted a shocking lack of respect for elderly female patients. The study found that none of the surgeons interviewed had received in-depth gerontological training. Given the increasing numbers of elderly women who

will be entering hospitals an examination of older women's perspectives of their experiences in hospital is essential to ensuring that their future care is based on real not assumed need.

Summary

This literature review illustrates that our knowledge of the needs of elderly women in hospital is at a beginning stage. The needs of the elderly in general, and the female elderly, in particular, have not been closely examined or taken into account in the development of hospital programs. An examination of older women's perspectives on their experience in hospital is essential to ensuring that their future care is based on real not assumed need. Elderly women are becoming an increasingly large percentage of our hospital population yet their needs are the least understood. The literature reveals their needs are often lumped together with those of men. Yet, the treatment of these needs may be more casual and less caring than that accorded to men. Their special needs may be overlooked or, worse yet, treated with distaste and disrespect.

This study seeks to enrich our understanding of elderly women's needs by hearing directly from them. It is hoped that making the experience of elderly women in hospital more visible will help to dismantle the myths and misconceptions some health care providers hold about this group. To that end this study proposes to:

1. Hear from elderly women about their experiences in hospital.
2. Raise awareness about issues affecting elderly women in hospital.

3. Provide suggestions for ways hospital services can be improved for this group.
4. Identify ways in which social work can provide leadership in meeting the needs of this group.

CHAPTER 2 METHODOLOGY

This Chapter will discuss the methodology I employed in this study. The design of this exploratory qualitative study draws on feminist research principles, hermeneutic phenomenology and structural social work theory. First, I will provide a rationale for my choice of methods and discuss how these methods informed my research process. I will then review how I recruited participants for this study and how I collected the data. I will conclude with an examination of the analytic process and a discussion of the study's limitations.

RATIONALE

Choosing a Qualitative Study

The research question that guided this study was "How do elderly women experience being in hospital?" A qualitative research design was selected as it provided the best means to understand elderly women's subjective experience in hospital. Qualitative studies seek to better understand participants perspectives of events important in their lives (Maxwell, 1996). This approach was consistent with the goal of this study which was to better understand the experience of elderly women in hospital.

A qualitative research design was also selected because of its flexible and emergent nature (O'Connor, 1996). For example, I wanted to be able to explore new

insights as they emerged during the data collection phase. As Rubin and Rubin (1995) point out:

“Adjusting the design as you go along is a normal, expected part of the qualitative research process. As you learn how the interviewees understand their world, you may want to modify what it is you are studying or rethink the pattern of questioning”.

I required a research design that allowed the participants to guide the data collection. It was important that participants told their story as they saw fit. Participants did not answer a set of predetermined questions but rather responded to the open-ended question “Tell me, what was it like for you to be a patient in the hospital”. A qualitative research design provided the framework from which to develop an in depth understanding of elderly women’s experience in hospital. Maxwell (1996) explains that a qualitative study seeks to understand how participants make sense of events and how their understanding influences their behaviour (Maxwell, 1996:17). A qualitative approach was compatible with this study, as its goal is to better understand how elderly women respond to a hospital stay.

CONCEPTUAL FRAMEWORK

The design of this qualitative study was drawn from three theoretical perspectives: hermeneutics, feminism, and structural social work theory. This section will discuss how these perspectives informed my research process.

Hermeneutics

Hermeneutics is a branch of phenomenology, a tradition of inquiry in qualitative research. Phenomenology aims to describe how actors' experience everyday life. Kvale (1997) defines a phenomenological study as one that strives to:

...understand the social phenomena from the actor's own perspectives, to describe the world as experienced by the subjects, and with the assumption that the important reality is what people perceive it to be. (Kvale, 1996:52)

Hermeneutics takes this process a step further by digging deep within the actors' text to uncover hidden truth and meaning (Kvale, 1996). The purpose of my study was to move beyond a description of participants' experience to a theoretical understanding of their experience. However, these principles offer the qualitative researcher an analytic framework.

A number of hermeneutic principles outlined by Kvale (1996) informed my research process. First, to develop a deeper understanding of the meaning of each transcript I worked in a circular motion between parts of the text and the whole. For instance, I first read each transcript to obtain its general meaning. I then returned to parts of the text that lent insight into participants' experience and tried to develop a deeper understanding of the meaning of this part of the text. I then pulled myself back and examined the deeper meaning of the parts in light of our societal structure and the general meaning of the text. This process continued in a back and forth fashion until a deep understanding of meaning was achieved. Secondly, I was up front with

myself about how my own values and life history influenced my interpretation. While I used my personal experience as a guide for in-depth understanding of the text I was simultaneously mindful of how my belief system might influence the meaning I ascribed to participants' experiences. For instance, I posed questions to myself such as, "Is this an issue for the participant or is this my agenda?" Thirdly, I maintained an on-going dialogue with the text by questioning my interpretations against the parts of the text and the whole. In addition, I sought feedback about my interpretations from participants, colleagues, my research committee, and others familiar with the phenomenon under study. Lastly, I attempted to immerse myself in the world of participants by studying other texts which explore the experience of today's older woman. These texts provided me with an understanding of the role the older woman's life history and our social structure may have played in her experience. This context helped to guide my interpretation.

In summary, hermeneutic phenomenology guided my understanding of the research process by providing me with a rationale for the importance of learning about social phenomenon from those who have experienced it. It also offered a framework for my analytic process.

Structural Social Work Theory

As I mentioned above one of the hermeneutic principles I adopted was to immerse myself in the world of participants by studying texts which explore their experience. These texts helped me develop an understanding of the role our social

structure may have played in the older woman's experience. This context guided my interpretation. It is therefore important that I outline which theoretical perspectives guided my understanding of elderly women's experience in hospital and influenced the study's design.

This section explores how structural social work theory informed the design of this study. Structural social work theory asserts that our social institutions are structured in a fashion that discriminates against people based on their class, gender, race, sexual orientation, health, and age (Mullaly, 1997:104). For instance, the health care system sends the following messages to older adults:

- a) They are a burden on society.
- b) They require costly medical care which increases the cost of health care and, subsequently, taxes.
- c) Older women who have not contributed "visibly" to society are particularly burdensome.

Structural social work aims to change the social structure so that oppressed groups become treated as equal members of society. It is my belief that older women comprise a particularly disadvantaged and vulnerable group in today's society. Older women experience oppression in the form of marginalization and powerlessness. They are vulnerable to violence in the form of elder abuse. Elderly women may respond to oppression by feeling inferior to the dominant group of young white men and women. Their inferiority may show itself in self-deprecation and apathy, i.e., "There is nothing I

can do." Questions I posed to the data included "Is elderly women's inferior status reflected in their experience in hospital?"

A structural analysis links the personal with the political. It enables people to relate their personal experience with oppression to a broader political understanding (Mullaly, 1997). Structural theory maintains that for change to occur it must take place at the structural level. In this way, it avoids "blaming the victim" for structural problems. This theory informed my analysis by helping me link participants' individual experiences with our larger social structure.

A Feminist Approach

A feminist framework also informed my understanding of elderly women's experience in hospital by further framing participants' personal experiences with the political system. There are a number of schools of feminist thought. However, the feminist theory I adhere to most closely is socialist feminism. In brief, socialist feminism:

Views women's oppression as part of structured inequality within a (patriarchal) class-based social system. Women's oppression interacts with other forms of oppression such as race, disability, and age (Payne, 1997).

Socialist feminism would view older women as doubly oppressed, as they are old and women. Older, poor, black women would experience quadruple oppression. Viewed through this lens an older white woman would experience a hospital stay

differently than an older black woman. This theoretical framework informed my analysis by alerting me to the importance of examining how participants' backgrounds impacted their experience in hospital.

Structural social work theory and socialist feminist theory helped me develop a theoretical understanding of participants' experiences. However, feminist research principles allowed me to incorporate the ideas of socialist feminism and structural theory into the research design. I will now outline the feminist research principles this study employed.

Like structural social work theory and socialist feminism, feminist research strives to show how the political stretches into areas often thought personal and vice versa (Reinharz, 1992). The well-known slogan "the personal is political" reflects this method of feminist analysis which "gleans political insights from an analysis of personal experience – in particular female experience" (Mullaly, 1997:165). This premise of feminist research figured prominently in my interpretations of participants' experiences. The other feminist research principle that guided my study is that the experiences of women are important and need to be heard, acknowledged, and validated (Harding, 1992, Riger, 1992).

Feminist researchers work to develop an equitable relationship or partnership with participants (Reinharz, 1992). They strive to develop an equal playing field with their participants in which there is no power imbalance. Developing this type of relationship means that the interviewer must work to establish rapport with her

participants. This is in stark contrast to a more positivist approach in which the interviewer works to maintain an aloof, objective stance. Feminist interview techniques often include sharing personal information with participants. In my case, participants often asked me personal questions such as where I worked and whether I was married. I handled their inquiries by answering them honestly. A more traditional interviewer might respond to personal questions with a laugh and state "It's my job to ask the questions here" (Oakley, 1981). I worked to form a partnership with participants by conducting the interview on the basis that the participant was the expert. To this end, I started each interview by thanking participants for agreeing to participate and explaining how important it was to hear from them about their experiences in hospital. I emphasized that they are the best ones to tell us about what they need in hospital. I tried to conduct the interview as a dialogue between participants and myself. This interactive interviewing style is consistent with feminist research principles (Reinharz, 1992).

I selected an unstructured interview as the data collection method. Interviews are an important component of feminist research. Feminist researchers assert that learning from women is "an antidote to centuries of ignoring women's ideas altogether or having men speak for women" (Reinharz, 1992:19). This principle was especially important in this study because the voices of elderly women themselves have seldom been heard.

Feminist researchers bring to the research process a set of values and beliefs that influence how they conduct a study. A feminist researcher does not attempt to

bracket her experience but rather acknowledges the role it plays in the research process. Through out this study I have attempted to acknowledge how my life experience has influenced my research process and account for it in the data analysis.

Feminist researchers have been “urged to anticipate policy shifts and to conduct studies that policy makers could use” (Reinharz, 1992:251). Policy makers caught up in number crunching and containing cost may forget to put a face on the people for whom they are creating programs. This study strives to put a face on the elderly female patient. It also proposes to make recommendations for change in hospital practices based on participants’ insights.

Feminist research attempts to contribute to social change through consciousness-raising (Reinharz, 1992). This approach is consistent with the goal of this study which is to bring the experiences of older women in hospital out of the margins. This awareness is the first step towards change.

RESEARCH PROCESS

Recruitment of Participants

Permission to conduct this study was obtained from the University of British Columbia’s Human Ethics Board. Once permission was granted a notice advertising the study was placed in the seniors’ section of a local newspaper (see appendix c). This newspaper was chosen as it is widely read by seniors and those who work with

seniors. This paper is circulated to a mostly white middle class readership. I selected this newspaper as I thought it might provide me with a more homogenous socio-economic sample. It is my belief that older women's experience in hospital will differ depending on their class, race and so on. I thought a more homogeneous sample would allow me to explore similar themes among participants with similar backgrounds (Rubin & Rubin 1995; Sandowski, 1996). I hoped this might allow me to reach a saturation point, that is, a point when each additional interview would add little new knowledge to my data (Rubin & Rubin, 1995). Criteria for participation in the study included:

- Female
- Over the age of seventy
- Hospital admission in the last year
- English speaking

Twelve women responded to the ad. Three of these women were referred by a gerontologist who had read the ad. The remaining women contacted me directly after seeing the ad. One caller declined to participate due to travel plans and said she had called me primarily to appease her daughter. Creswell (1998) cautions that participants in a phenomenological study need to be carefully chosen and must be individuals who have experienced the same phenomenon.

Eleven women participated in this study. Ten participants had had an inpatient admission in the last year. One participant was a day patient. They ranged in age from

70 to 93. All were Caucasian. One woman was single, two were divorced, two were married, and six were widowed. All the participants reported good family support and all but one participant had children. Participants represented a somewhat privileged group of older women. They had adequate finances for their needs and all but one participant owned her own home. This study also included the perspectives of a participant's daughter, a participant's husband and a participant's sister. The daughter provided me with a written account of her experience caring for her mother in the hospital. The husband and sister invited themselves into the interview as they wanted to share their experience around the participant's hospitalization.

Participants had been hospitalized for cataract surgery (1), pneumonia (2), heart attack (1), hip replacement (5), cyst removal (1), uncontrolled diabetes (1), stroke (1), and cancer (1). These numbers are greater than eleven as some participants had more than one hospital admission in the last year. Length of stay in the hospital ranged from three days to five weeks. At the time of the interview participants had been home from the hospital from one month to one year. Participants were patients in eight acute care hospitals in the Lower Mainland (Vancouver, Richmond, Burnaby, and New Westminister). A profile of each participant will now be presented.

Participant Profiles¹

In this section, I provide a brief profile of each participant. They are described in the same order in which I conducted the interviews.

Mrs. Ashcroft is an 89 year old widow who has resided in an intermediate care home for the last two months. She is quite frail, suffers from lung cancer, and is a brittle diabetic. She has had a number of surgeries in the last ten years and reported that two doctors who did not think she was a candidate for cancer surgery prematurely told her she was terminal. In both cases she sought a second opinion. She uses a walker and tries to walk ten blocks a day. At the time we met she was recovering from a blood transfusion and was walking about six blocks a day. Mrs. Ashcroft dresses independently, needs minor assistance with a bath, and eats many small meals throughout the day in an effort to control her blood sugar. After being hospitalized for one month for uncontrolled diabetes, she made the decision to move into care. She felt that her frailty made independent living too difficult. She had the option of waiting in the hospital on the long stay unit for a bed in a care home; however, her son visited this unit and determined it unfit for his mother. Consequently, she was discharged to her son's home. She stayed in his living room for two months while awaiting facility placement. She described this period as "kind of hard on the kids" and she was

¹ Names are fictitious and information which would identify hospitals has been changed.

relieved to move into care. While at her son's she suffered a mild stroke for which she was hospitalized for one week. She states she has made a full recovery although she is left with a slight slurring of her speech and tends to "become muddled" and forget things. Mrs. Ashcroft was a school teacher in a small school up North. She moved to Vancouver two years ago to be closer to her son and advanced medical treatment. Her son is her only child and her main source of support. In addition, she is quite close to her daughter-in-law stating, "She's as good as any daughter". She also enjoys spending time with her two grandchildren. Mrs. Ashcroft said she considers herself "lucky to be as able-bodied as I am". On reflection, she said she has had a good life.

Mrs. Herrick is an 83-year-old widow who owns a tidy two level bungalow where she lives with her middle-aged son. She worked as a sale clerk in a department store before she was married. Mrs. Herrick and her husband moved to Vancouver from a small town in Alberta in 1946. Mrs. Herrick did her own housekeeping until she was 78 years old and her doctor told her that her arthritis made it unwise for her to continue scrubbing floors on her hands and knees. She now employs a private cleaning woman and relies on her son for help with shopping and for transportation. Mrs. Herrick was hospitalized for six weeks for an elective left hip replacement. At the time of our meeting, she had been home from hospital for a month and a half. She expressed dismay that she continued to need a walker inside her home. Mrs. Herrick suffers from arthritis and has

pain in her right hip which limits her mobility. She had her surgery in an acute care hospital where she spent a week. She was then transferred to a rehabilitation hospital for intensive physiotherapy. Mrs. Herrick reports she tends to be lonely as she is outliving her friends and it is hard for her to get out. She was an active volunteer until health problems interfered. Mrs. Herrick was the main caregiver for her husband who had Alzheimer's "before they even knew what it was". She reflected that caring for her husband was one of the loneliest experiences of her life. She said her friends drifted and she had no one to talk to about her struggles. She cared for her husband at home for three years until her doctor insisted that she place him in care. Mr. Herrick died when Mrs. Herrick was still in her sixties. She does not have any grandchildren and has another son who is divorced and lives close by. At the time of our first interview, Mrs. Herrick was receiving out patient rehabilitation. She was also receiving temporary help with bathing from the health department as she could not get in or out of her bathtub on her own. At our second meeting, Mrs. Herrick was bathing independently and her outpatient physiotherapy was ending. However, she was feeling discouraged and thought it unlikely she would regain the ability to walk without a walker in her home. She said that given the results of her hip replacement she would be reluctant to undergo surgery on her other hip.

Mrs. Swartz *is in her mid-eighties and owns a large two level home where she lives on her own. The basement is tenanted. Mrs. Swartz and her two young*

sons immigrated to Canada from Hungary in the early fifties. She was divorced at the time. Mrs. Swartz's younger son died in his early twenties. Her relationship with her older son is strained. She said she often feels alone in the world. Mrs. Swartz was in a concentration camp from age twelve to sixteen. She feels she will never fully recover from this experience but has learned to live with it. Mrs. Swartz was a day hospital patient. She provided additional insight into the important role family plays in the hospital which helped me better understand the issues facing participants. Mrs. Swartz had cataract surgery and was upset that her son did not take an active role in her post-surgery care. She said he assured the hospital staff that he would look after her but that in reality he did not plan to help. She was upset that staff did not ask her directly and in private if she needed help. Mrs. Swartz said she has tried to work out her difficulties with her son and recently went with her son and daughter-in-law to see a psychiatrist. She was disappointed with the outcome of the meeting, reporting that the psychiatrist told her she needed therapy and antidepressants. She felt the doctor singled her out as the problem. She chose not to return to this doctor but instead sent the doctor a letter which expressed her disappointment. At present, she sees her son, daughter-in-law and grandchildren sporadically. Mrs. Swartz worked as a secretary and hairdresser in her middle years. She returned to university at the age of sixty, to study creative writing. She receives weekly help with cleaning from the health department and is diabetic and severely asthmatic. She relies on public transit

and cabs for transportation and attends synagogue on a regular basis.

Miss Rawson is in her mid-seventies. She and her sister own a spotless two level bungalow where they live with their two large cats. Miss Rawson taught English and her sister worked as a nurse. Miss Rawson is asthmatic and was hospitalized for pneumonia for three days. Her sister took her to emergency in a panic and was relieved when Miss Rawson was admitted. Miss Rawson prides herself on managing her life independently but relies on her sister for support as needed. She is close to her neighbors and has a number of good friends whom she sees socially. She generally enjoys good health but tends to develop pneumonia each year which she blames on her asthma. Miss Rawson and her sister have "chest conditions". They explained they did not have children because they did not want to pass their condition on. Miss Rawson worries about money, increasing taxes and her health. She strongly advised me to enjoy myself while I am young.

Mrs. Harrington is also in her mid-seventies. She and her husband live in a large stylishly decorated home in an affluent neighbourhood. Mrs. Harrington worked as a teacher. Her husband is a retired professional. The couple moved to Vancouver from England after the birth of their second child. The Harrington's have three children, two daughters and a son, all of whom live in close proximity. Mrs. Harrington suffered a heart attack and was hospitalized for two weeks. At her request, she returned home to await heart surgery. Her surgery took place

three weeks later and she was hospitalized for four days. She has made a good recovery and remains active. She takes exercise classes, tutors her grandchildren and likes to decorate her home. Mrs. Harrington was a clear and articulate participant with strong opinions.

Mrs. Stafford is a ninety-three year old widow who lives with her cat, Cleo, in a one-bedroom government subsidized senior's apartment building. She moved to Vancouver from England twenty-five years ago. Mrs. Stafford receives daily help with bathing and dressing from a homemaker supplied through the continuing care program. She reported she was grateful for this help as it allowed her to live independently in her own home. Her main support is her daughter, who is a retired hospital secretary and lives within walking distance. Her granddaughter, a fulltime speech therapist in a nearby hospital, also lives close by and visits regularly. Mrs. Stafford is incontinent of bowel and bladder and quite deaf. She walks with a walker. Her main pleasure is reading and she does not go out much other than for doctors' appointments. She reported that my visits were "a big deal" in her life. Mrs. Stafford was a secretary. She is well spoken and formerly belonged to Toastmasters. She had two hospitalizations in the previous year, one for pneumonia which lasted three weeks and one for one week which was for the removal of a cancerous growth.

Mrs. Laidlaw is seventy years old and lives with her husband in a bright two-bedroom condominium that they own in a new high-rise apartment building.

Mrs. Laidlaw collects stuffed animals which are displayed prominently around her home. The Laidlaw's recently moved from a house and are enjoying apartment living. Mrs. Laidlaw had a brain tumor twenty years ago which left her with a balance problem. This problem affects her mobility and she was hospitalized after she became tangled in her bedspread and fell out of bed in the early morning. She sustained a hip fracture and had an emergency hip replacement, which led to a three and a half week hospital stay. She is receiving weekly physiotherapy at a clinic near her apartment and does strengthening exercises three times a day at home. Mrs. Laidlaw was unable to stand for any length of time following her surgery and relied on her husband for help with meals, bathing, and shopping. At the time I met her, Mrs. Laidlaw had been home for five months and was able to manage these tasks independently. The Laidlaw's enjoy taking bus trips and meeting friends for coffee at a nearby mall. They have one son who lives a two-hour drive away. Mrs. Laidlaw was a soft-spoken participant who stressed that she was not one to complain.

Mrs. Bradley, age 74, owns an attractive two level bungalow where she lives on the main floor. Her daughter and son-in-law live in her basement suite. She is considering selling her home and moving into an apartment as her daughter and son-in-law are planning to move and she does not want to live in her house alone. Mr. Bradley died a year ago. Mrs. Bradley was severely depressed after his death, becoming frightened to leave the house by herself. Recently, she

started to force herself to go out by bus to visit friends and shop. Mrs. Bradley was very anxious about our interview, reporting that she does not like to be taped and is nervous leaving messages on answering machines. It was challenging for her to meet with me and talk about her experience. She was hospitalized for three days for the removal of a stomach cyst. She did not feel she was given proper instructions on how to care for her stitches and subsequently her wound became infected. Her doctor had to prescribe an antibiotic salve to clear it up. A close friend stayed with her for a week after her hospitalization which was a comfort. Mrs. Bradley had been home for a month at the time of our meeting. Unfortunately, she had developed a hernia and was concerned that she might need to go back into hospital. However, she said she would not feel as nervous the second time around.

Mrs. Edgemont *is a widow in her late seventies. She owns a spacious two bedroom condo in a new high-rise apartment building where she lives alone. She was hospitalized on an emergency basis for a hip fracture after falling when she crossed the road during a fireworks display. At the time of her admission there was a strike at the hospital and she had to wait four days for her surgery. She went into kidney failure two days after her surgery. She believes the kidney failure was a result of taking too much pain medication as a means of coping with the delay. She spent five weeks in the hospital. After being home for a few months she started to experience pain in her new hip and had difficulty*

walking. She consulted with her doctor who could not diagnose the problem and scheduled exploratory surgery. However, one morning, when she was at home waiting for her surgery, she found that she could not get out of bed. She called her son and he took her to emergency where she was admitted on a priority basis for her exploratory surgery. While she was waiting for this surgery she developed severe pains in her stomach and was operated on for a bowel rupture. This hospital stay lasted ten weeks. She now wears a colostomy bag and continues to wait for the exploratory surgery. At the time I met her she was using a wheelchair to get around as the pain in her hip made it impossible to walk. She has a daughter who lives five hours away and a son who lives nearby. She enjoys travelling and has a number of close female friends. Mrs. Edgemont said she did not consider herself old until her recent health problems challenged her view of herself. She presented herself as a strong woman who speaks her mind. She made a point of telling me that she does not believe that doctors are "little gods".

Mrs. Harris is widowed. She lives alone in a new two-bedroom condominium in a high-rise building on the river. She and her husband bought the condominium five years ago when her husband had health problems which made keeping up their house too difficult. Mr. Harris died three years ago. Mrs. Harris said she has learned to adjust to life without her husband but stated that she feels one never really gets over such a loss. She has coped with his death by trying to

keep herself involved with others. She recently became friends with a group of women who live in her area and with whom she takes daily walks along the river. She has three children who live twenty minutes away and her grandchildren frequently spend the weekend with her. A year ago she was hospitalized for eight days for an elective hip replacement. She reports she spent two years trying to fix a back problem which was really a hip problem and wishes the problem had been diagnosed sooner. She reports her health is good and she has not had any difficulties with her hip since the surgery. Mrs. Harris spoke quietly and her speech was interspersed with chuckles. She presented herself as a lively woman who enjoys life.

Mrs. Holland *is divorced and in her early seventies. She lives with two small yellow birds in a suburban bungalow which she owns. Her home is located on a large piece of property which backs on to a forest. Mrs. Holland came to Vancouver from Europe in the early seventies. She speaks with a strong Dutch accent. Mrs. Holland has six children. One daughter lives five minutes away and is her main support. She is on a limited budget and worries about having enough money to pay for her car, property taxes, and house insurance. She was hospitalized for ten days for an elective hip replacement. She was unable to weight bear for four months after her surgery and was house bound. She was aware that it would take her a long time to recover from her surgery and had planned accordingly. Her seventeen-year-old granddaughter stayed with and*

helped her get in and out of bed. Her daughter came over to cook her meals. A home support worker from the continuing care program came weekly to help her with cleaning and bathing. At the time of our interview, she was fully independent although she had some difficulty bending down and found it troublesome that she could not bend down to garden. However, she said she was grateful she could walk and clean her house. Mrs. Holland has had a difficult life and has worked hard for what she has.

Interview Process

Participants were given a choice regarding the location of the interview. All participants requested that the interview take place in their home. The advantage to this setting was that it provided me with a context from which to hear participants' stories. Lincoln and Guba (1985) note the importance of context for giving meaning suggesting that "no phenomenon can be understood out of the relationship to the time and context that spawned, harboured and supported it" (qtd. In O'Connor, 1996). For example, three participants whose homes were spotless, complained that the hospital was unclean. Another advantage of conducting the interviews in participants' homes was that it was more convenient for participants. Four participants could not travel without assistance and would not have participated if they had been required to make travel arrangements. The disadvantage to this setting was that ringing phones, chiming clocks, and pets proved distracting. One tape was hard to understand due to a purring cat who roamed too close to the microphone. In two cases family members

came home and wanted to join the interview. I did not feel it was appropriate to ask them to leave as I sensed it would have damaged any rapport I had established. Their participation highlighted for me the important role family plays in the care of its elderly female members. Family members wanted their stories heard.

Interviews lasted from forty-five minutes to two hours. Informed consent was obtained at the start of the interview (see appendix B). I began each interview with the open ended question "Please tell me about your experience in the hospital. What was it like for you as a patient". I also prepared a list of questions which I asked participants in the event that their story did not spontaneously answer them (see appendix A). The goal of these questions was to further explore participants' thoughts and feelings about her hospital stay. I chose an open-ended interview format as it allowed participants to choose how they wished to tell their story and what they thought was important for me to know about their experience. A number of participants had taken the time to make notes prior to our meeting. Some participants indicated that the unstructured format was difficult to follow. In these cases the women kept asking me "Do you have any other questions?" or "What else?" One woman made it clear that she would have preferred a questionnaire as she thought, "We'd miss something". Participants may have become accustomed to the structured format of questioning found in a medical setting. In a number of cases participants seemed to feel that they did not have much to say on their own accord. These women tended to devalue what they had to say and stated that they thought they "didn't really have much to offer". Another common statement was "I don't think I've been much help". Some participants were not sure

where to begin and in these instances were offered the prompt, "Start with the first thing that comes to your mind about the experience". Once participants started to tell their stories I listened intently and sought clarification on points that were unclear. A number of participants veered off track from the original question and started to talk about other areas in their lives. Participants talked about such matters as caring for their mothers in the hospital, losing a spouse, and their relationships with their children. This led me to think that a hospital stay can bring up old losses. When the participants talked about these subjects, I endeavored to clarify the link between their current story and their hospital experience.

All participants agreed to be taped; however, they did not seem entirely comfortable with the process. I assured them that only myself and the transcriber would hear the tape. However, the tape recorder seemed to make participants somewhat cautious in their speech. One woman who found it particularly challenging to be taped, reported that she finds it hard to leave a message on an answering machine. I question whether taping is the best method for recording information for this group. I took minimal notes during the interview as I wanted to give participants my undivided attention. At the end of each interview I completed a memo in which I jotted down my observations about the interview. This additional information provided me with a context in which to make sense of their story when I analyzed the data.

Data Management

My data consisted of the interview transcripts and my notes and memos.

from the interviews. In addition, I kept a journal at home in which I jotted down thoughts from time to time about my analytic process and methodological decisions (O'Connor, 1999; Maxwell, 1996). All the interviews were taped and transcribed verbatim. I transcribed the first interview and a professional transcriber typed the rest. All identifying information was removed from transcripts and audio-tapes. My transcriber was required to sign a pledge of confidentiality form (see appendix F). The data was stored in a locked filing cabinet. Information which would identify participants was stored in a separate locked cabinet. I created a filing system to help me in the analytic stage. This system consisted of files that I labeled by theme.

Data Analysis

Data analysis started after my first interview. I transcribed the tape and as I transcribed I noted statements and phrases which I thought important to understanding the experience of elderly women in hospital (Coffey & Atkinson, 1996; Rubin & Rubin, 1995). Statements in which the participant spoke louder than usual were considered particularly relevant. I interpreted a raised voice as a sign that the issue under discussion was important to the participant. These statements were tagged as important or, if I noted a theme emerging, they were assigned a more concrete code name (Coffey & Atkinson, 1996). For example, the statement, "So, I told them three times I had to go to the bathroom," was coded as asking for help. When the analysis was complete I wrote a memo which described my understanding of that participant's experience. This information guided my next interview by prompting me to

explore certain issues in more detail if they re-emerged, such as the recurring theme of the role family played in providing care.

Ideally, I would have coded each transcript before I began the next interview (Rubin & Rubin, 1995). However, time constraints made this impossible and interviews often took place before the last transcript was coded. I tried to incorporate my findings from the previous interviews when I conducted new interviews by asking the new participants if my earlier findings reflected their experiences. I introduced the topic of the findings from the previous interviews either while the new participant had told her story i.e., "yes, another participant had a similar experience ..." or after she told her story i.e., "other participants mentioned X. What was your experience with X?" This provided extra insurance that the findings were discussed with all participants and accurately reflected their experience (Creswell, 1998).

To ensure that findings represented participants' experiences all participants were provided with a copy of their typed transcripts and a written summary of the study's preliminary findings. Their feedback was then solicited. The three themes that emerged at the preliminary findings stage were: 1) emotional support was critical, 2) special needs associated with aging were often overlooked and 3) basic services were often found lacking. Due to time constraints I was only able to re-interview five women in person about my preliminary findings. I spoke with five by phone and one of these participants responded by sending me additional written feedback on her transcript and the preliminary findings. One participant could not be reached by phone and I was unable to gather her feedback. Participants agreed that this analysis represented their

experience. However, all participants added one or more points which they felt were not reflected in the summary.

After I had gathered participants' feedback I engaged in a more detailed analytic process as follows.

- First I re-read all the transcripts to get a feel for the data as a whole (Sandelowski, 1995). I then used a cut and paste system to categorize the data (Rubin & Rubin, 1995). I cut out of each transcript quotes which I felt best spoke to participants' experiences. These quotes were labeled according to the theme they represented and placed in the appropriate file. As I moved through the analysis I began to understand where themes overlapped. Consequently, I collapsed files. Each theme was allotted its own folder. Within each folder was an envelope containing sub-theme data. At this point, the main theme that emerged was that a successful hospital stay was a matter of survival.
- Keeping the survival theme in mind I returned to my categorized data and posed the question: Why is a successful hospital stay a matter of survival? (Lofland & Lofland, 1995). Four major themes emerged. The first theme was that the system failed to respond to participants' age specific needs. This failure meant that participants had to learn how to cope with these gaps in their care. I then posed the question to the data "How do participants cope with gaps in care?". Three survival strategies emerged from the data: 1) Participants assumed personal responsibility for their experience in hospital; 2) Participants developed support networks; and 3)

Participants relied heavily on family to provide practical support and advocate on their behalf.

- The above process was circular rather than linear in that I moved back and forth between the process of reading and memoing and the process of describing, classifying, and interpreting (Coffey & Atkinson, 1996).
- Once I had settled on these final themes I sought feedback on my interpretations from my research committee, colleagues, and other familiar with the topic under study. This process is called member checking (Creswell, 1998, Rubin & Rubin, 1995). Time constraints meant that it was not possible to seek participants' feedback on my final findings. However, I presented the study's findings to a group of seniors' peer counselors in New Westminster, British Columbia. Their general response was that the findings accurately reflected their experiences and the experiences of the older women they counsel.

I revised my findings a number of times before I settled on the themes which I felt accurately reflected participants experiences in hospital. Seeking feedback from the participants' and presenting the findings to a group of senior peer counsellors provided me with increased confidence that these findings shed insight into the experience of older women in hospital.

Next Steps

The findings of a study with a sample size of eleven can not be can not be

generalized to the experience of the general population of older women. However, the intent of this study was to develop increased insight into older women's experience in hospital (Sandelowski, 1995) The sample consisted of white middle and upper class elderly women; presumably the least oppressed of this oppressed group. Interviewing women from other backgrounds, i.e. older immigrant, non-English speaking women, would provide additional theoretical insights. Elderly men's perspectives on their experience in hospital would provide interesting comparative data. The participants in this study had good family support. The experience of older women in hospital who do not have family is an area requiring further study. This latter group may comprise a particularly disadvantaged patient population.

I believe a more structured interview format might have made participants feel more at ease and led to the collection of more information rich data. However, to be effective, this approach would require that the researcher work with the target population to develop questions that would accurately capture their experience.

Implications for further research in this area will be woven through my discussion of the study's findings in Chapter Four.

Summary

A qualitative research design provided me with a framework in which to understand elderly women's subjective experience in hospital. Hermeneutic principles helped me develop a deeper understanding of participants' experience. Structural social work theory and socialist feminism guided my reading of participants'

experience. Feminist research principles provided me with hands on tools for conducting the interviews and supported the need to study older women's experience. Gathering participants was not problematic indicating that this topic was important to older women. Participants had the opportunity to provide feedback on the preliminary findings. The final findings were presented to a group of seniors' peer counselors for feedback. This approach allowed me to confirm that the findings accurately represented the experiences of many older women in hospital.

CHAPTER 3 FINDINGS

Data analysis revealed that the system failed to attend to participants' age specific needs. This failure created gaps in care which were particularly troubling for elderly female patients whose frailty made them susceptible to additional health problems. These gaps in care resulted in participants viewing a hospital stay as a matter of survival (see appendix e). Participants developed three major strategies to ensure that their needs were met in hospital. One strategy was to assume personal responsibility for their experience in hospital. This approach showed itself in lowered expectations and a reluctance to complain overtly about their experience in hospital. Another strategy was to develop support networks that included patients and staff. However, participants' most critical survival strategy was to rely on family to provide practical support and advocate on their behalf for better care. In the first section of this chapter I will discuss in some detail how the hospital system failed to meet the age-specific needs of the participants. This section will be followed by a discussion of the three main strategies participants employed to cope with their hospital stay.

FAILURE TO ATTEND TO AGE SPECIFIC NEEDS

"There should be trained staff to do that (bathing). One shouldn't have to rely on a daughter" - Mrs. Stafford

Participants had special needs associated with aging that the system did not meet. Staff shortages combined with ageist practices in the system meant that

participants' special needs often went unrecognized. Participants portrayed the hospital as a hectic place where staff had to literally run to keep up. Phrases such as "rushed off their feet," "bees in a hive," "running like slaves" "working like dogs" and "run ragged" were used by participants to describe the nursing staff. Participants expressed sympathy for the nursing staff who they felt were "doing their darndest" and "trying their best under the conditions." They excused the nursing staff when gaps in services occurred and instead placed the blame on the system:

I found the nurses do not have enough time to look after the patients properly and the nurses were great. I have no complaints about that. There just isn't enough help. ...I don't think it was the nurses' fault. It is the system (Mrs. Holland).

The rushed pace of the hospital made it difficult for staff to meet the needs of a number of participants. Older patients, participants said, need more time, which as their experiences indicate is a sacred hospital resource:

It's not easy when you're old. You have needs that are different from young people's. Well they are, because I was in hospital when I was young too. And with this constant hurry-scurry of overworked nurses you can't expect very much and you don't get very much (Mrs. Stafford).

Participants provided examples throughout the interviews of specific needs that were related to their age that went unaddressed. Lack of help with bathing was seen as

particularly problematic for the participants. Mrs. Stafford's experience illustrates the difficulties that can occur when bathing is inadequate. Mrs. Stafford, age 90, was hospitalized for three weeks with pneumonia. During her admission, her daughter, a retired secretary, came to the hospital to give her a daily bath:

Each morning I would get my mother up, put her into a special wheel chair which goes into the shower and get her showered and dressed in a clean gown. I would change the bed if it needed it and put her back into it. The nursing staff bathe patients weekly. My mother needs and wants a daily bath. So, I did the shower (Mrs. Stafford's daughter).

The daughter's statement, "So, I did the shower," implies that the hospital policy of one bath a week left her no choice but to assume the role of bather. Mrs. Stafford is quite frail. She is incontinent of bowel and bladder and suffers from skin breakdown in the perianal area. As her daughter explains, keeping this area healthy requires a daily bath and special care:

My mother has skin breakdown in the perianal area and I acquired a jar of healing cream (from the nursing staff) which I kept by her bedside and each time I changed her, I was able to wash and apply the cream to the affected area, to heal the breakdown of the skin.

Mrs. Stafford does not rely on her daughter for this support at home. At home, Mrs. Stafford receives daily help with bathing from Continuing Care's Long Term Care

program. This program, run by British Columbia's Ministry of Health, provides subsidized home support to disabled people to help them remain at home. This finding raises questions about the appropriateness of providing patients with Mrs. Stafford's condition with only one bath per week. In Mrs. Stafford's case, the community has deemed a daily bath essential as it helps Mrs. Stafford remain healthy and in her own home. However, in hospital, Mrs. Stafford is expected to cope with a weekly bath despite the fact that her needs have not changed. Her daughter reported it would have been detrimental to her mother's health for her to bath weekly. It is quite possible that without her daughter's attention Mrs. Stafford would have deteriorated and been unable to return home. Mrs. Stafford is ninety, frail and needs special care. However, she saw the hospital as unable to provide for her special needs.

Another special need associated with aging that participants felt was often overlooked was denture care. Four participants spoke about how denture care was an important part of their hospital care. While dentures may seem a relatively minor aspect of an older woman's care the fact that four participants brought their experience to my attention indicates that this is a significant issue.

Mrs. Herrick began our interview by reporting that that one of the first things she remembers about her hospital stay is that she did not receive enough help with her dentures. Her story shows that despite her efforts to make her needs known to staff they were overlooked:

I had dentures and I was very anxious that my mouth not get sore and so

anybody that came around me, I'd say "Oh, I've got dentures" (and they'd say "Oh yeah, well later on." So I had about three days and nights with them never out of my mouth. I had a very sore mouth. It wasn't really looked after (Mrs. Herrick).

Her story illustrates her belief that staff did not understand that she would have a sore mouth if she did not remove her dentures. Her statement that staff responded to her request by saying "*Oh yeah, well later on*" indicates her denture needs were deemed a low priority.

Mrs. Harris had a different experience from Mrs. Herrick in that she felt staff recognized her denture needs. She interpreted their insight as a sign that staff cared about her well-being.

I was getting ready to go into surgery and this intern was standing beside (me). They ask you to take your top plate out when you're in there, and I said, "Oh, do I have to?" and they (nurses in her room) said, "Oh, yes". So I was covering my mouth because it is quite uncomfortable and I said to him (the intern) "Do I have to take out my top plate?" and he said "Oh no you don't really have to" and I said "Well, would you go and get it for me?" and he said "Sure" and down he goes and gets it for me. It is things like that, that shows you they have a heart (Mrs. Harris).

The significance of these stories is that they highlight that it was a common occurrence for participants to encounter difficulty accessing help with dentures. Staff

were often perceived as too busy to help with the task of denture care and were also viewed as lacking understanding of the needs of patients with dentures. Mrs. Harris's story alerts us to the fact that when help with dentures is provided a person tends to feel more positively about her overall hospital experience and better able to cope with her illness. This finding is important as many older women in hospital may have dentures.

A third area that was raised repeatedly as a discounted special need was walking assistance. A number of participants were weak in hospital and needed a helping hand to walk safely. Four participants expressed fear that they would fall when they tried to walk for the first time after surgery. As one said, "*I thought my legs would crumble*". One participant's daughter expressed frustration with the system which she felt expected older patients to walk but then did not provide them with the support they needed to walk safely.

My mother was told to walk. But it was not safe, or possible, for her to get herself out (of bed), the walker positioned, and begin the walk. It was also not safe for her to walk alone. So my daughter and I would take her for her walks up and down the corridor, being there to provide a chair, in case she needed it, or just an arm for support, and also to help her back to her chair or bed when she returned. The lady next door was not so lucky and had at least one fall, luckily with no serious consequences (Mrs. Stafford's daughter).

Mrs. Harrington shared similar sentiments and further highlighted the role family plays

in helping older patients walk:

Family are quite important to the whole (hospital stay). I mean to take one for walks, one is supposed to walk, but nurses wouldn't have time to walk you when you can hardly stagger (Mrs. Harrington).

Participants interpreted the lack of help with walking as a sign that the system did not fully understand their needs and consequently placed unrealistic expectations on their abilities. In particular, they felt their longer recovery needs were not recognized. For example, Mrs. Herrick felt her surgeon discounted her fears whereas her physiotherapist provided acknowledgment:

I was worried about my age. You know I'm 83 and (the doctor) said "Oh well, we're doing (hip surgery) (on) elderly people all the time". Well, even the therapists admit that you take a lot longer when you are older. It's like anything you get when you are older, you don't throw it off as quickly as when you are young. Whether it is the flu or colds or what it might be, you just don't spring back the way you did as a young person (Mrs. Herrick).

Concerns about walking were well grounded in reality. Two participants fell the morning after they returned home which raised questions about how adequately these women were prepared for walking at home:

You see everything is done for you (in hospital) and so it's just kind of a cold awakening when you get home and suddenly you are striving for yourself. (At

the hospital) you do everything in a wheelchair. You go to meals in your wheelchair and you go to the bathroom and then suddenly you are out and you are on a walker. The day I came out of hospital was a wonderful day, I was so glad to get home. The next morning I got up and went to go to the bathroom and fell over backwards with the walker on top of me (Mrs. Herrick).

The morning after I came home I got out of bed and I took the walker and I lost my balance and I fell on the floor. So we had to call an ambulance to take me to the hospital for (x-rays) (Mrs. Holland).

Generally, participants felt that the hospital pushed older patients to get on their feet as soon as possible so that they could regain their strength and return home. However, this approach was problematic as participants were too weak to walk without help and staff were unavailable as walking aids. This experience made participants and their families frustrated and anxious.

A fourth special need associated with aging that often went unchecked was that of hearing impairments. Patients who had hearing problems were doubly challenged to make their needs known to staff. Mrs. Stafford's granddaughter, who is a speech therapist, found it necessary to place a large sign over her grandmother's bed to alert staff on how to communicate with her. Another participant, Mrs. Harrington, described how patients with hearing problems can "fall through the cracks".

We were sent to a room where the physiotherapist would give us instruction. I

discovered that the lady next to me was deaf as a post. Now nobody had told the physio that this poor soul could not hear anything that was being said until I said, "Do you realize that she can't hear anything you're saying?" She didn't seem to be able to or didn't say "I can't hear you." I suppose there are always people who fall through the cracks. No system is perfect (Mrs. Harrington).

These two experiences suggest that hearing problems among the hospitalized elderly require further attention. Mrs. Harrington took charge and informed the physiotherapist that this patient could not hear. She seemed to rationalize this incident as an oversight by stating "*There are always people falling through the cracks. No system is perfect*". However, elderly female patients with hearing problems should not be falling through cracks in the system. Health care organizations that strive to meet the needs of their elderly patients should address hearing problems routinely. This raises questions about staff training needs and resource allocation as it takes time, resources, and skill to communicate with the hearing impaired. Mrs. Harrington remarked that "*No one had told the physio that this poor soul could not hear*". This raises the question "Whose job is this?" It appears that it may not be common practice for all staff to screen for hearing problems in their elderly patients. It is significant that Mrs. Harrington noted, "*She didn't seem to be able to or didn't say, "I can't hear you.."*" Her statement illustrates that staff need to ask their elderly female patients about their hearing needs. Mrs. Stafford's granddaughter had the ingenious idea to post a sign above her grandmother's bed. However, she is a speech therapist in a hospital and it is her job to work with patients on communication problems. The fact that she posted a

sign above her grandmother's bed shows that hearing problems are often overlooked. In addition, Mrs. Stafford mentioned that she left her hearing aid at home because hearing aids are easily lost in hospital. This finding indicates that hearing-impaired elderly face additional challenges in hospital. It also calls to our attention how the system literally silences older women by overlooking their needs if they are hearing-impaired.

Failure to attend to participants' age specific needs created gaps in care which were particularly troubling for elderly female patients as their frailty made them susceptible to additional health problems. This risk showed itself most prominently in the area of food service. All participants who were inpatients made mention of their meals in hospital indicating that this was an important aspect of their care. Participants concentrated on the quality of the food and the way it was served. They blamed fiscal constraints and mass production for poor quality. Food service problems were attributed to staff shortages and a lack of recognition of the needs of the frail elderly.

The most common problem with food service was that participants could not access their meals without help. Participants were often too weak to lift the cover off their meal trays or open their cartons of milk. A number of participants indicated that they needed their tray set up but that staff were hard pressed to provide this help. Polly, the daughter of one participant, described difficulties participants encountered in this area:

The food arrives and the patients were expected to cope from there. Quite

impossible! It arrives in the ward carried by a kitchen aide who puts each covered tray on each bedside table and leaves. Sometimes the patients are seated and cannot reach. Sometimes they are in bed and cannot reach. Most times they haven't the strength to remove the cover or the place to put it. I found myself running around the ward attending to all four ladies, unless the lady had her own visitor and she did not need me. The milk, juice, butter and jam were sealed with little tab-pull tops (which) none of the ladies had the strength to remove. The lady next to my mother stabbed ineffectually at her's with a fork! I set-up each ladies's tray opening the milk, juice, spreading the butter on the bread/toast/muffin. Occasionally a staff member would (appear) - often 20 minutes or so after the food had arrived, to inquire whether help was needed. In reverse, the problem was the same. The finished meals were not cleared for a very long time (Polly Stafford).

Polly's tale illustrates that many older female patients had needs at meal times that were not met by the system. Mrs. Harris, whose needs for assistance at meal times were met, highlights the difference this help makes:

When a meal came around they'd come in and help me out of bed, and move me to the chair and bring the tray for you to eat on and it would be a nice change to eat in a chair. You know it was a little thing but it made a difference between feeling good about it and feeling resentful as some people who come out of hospital do (Mrs. Harris).

Generally, participants' appetites were poor. Unappetizing food that they could not access did not help matters. Mrs. Stafford lost weight during her stay and had "to be coaxed to eat". She described her meals as inedible and inaccessible. Her daughter described an additional problem:

My daughter or I would try to be present at each meal. We would either try to coax my mother to eat the very unappetizing meals provided, or go and cook things in the microwave, for example little meat pies and quiche. I had various items in the freezer in the patient area. Unfortunately over the course of three weeks these items, especially the Eggo waffles, were stolen although they were plainly marked with her name.

The fact that Mrs. Stafford's waffles were stolen highlights yet another problem encountered by participants in this area. Mrs. Stafford continued to lose weight despite her daughter's efforts. An attentive nurse solved the problem:

As I wasn't eating I lost a lot of weight, and they wondered what on earth to do to get me out of the place. There was this one nurse ... and she was human. She said to me, "Why don't you try Ensure?" and I said "Ugh". So, she opened a tin and stuck in a straw and said, "Well, you can taste it anyway". She'd always been pleasant and chatting and nice so I tasted this Ensure and I said, "Oh, that's not so bad, I can eat that". And because of that I was able to get out of that awful hospital. They were anxious to know I could eat. She took trouble you see. Nobody else had time to (Mrs. Stafford).

This nurse took the time to form a relationship with Mrs. Stafford and provided her with the individual attention she needed. As a result, this nurse was remembered as someone special. This finding emphasizes how important it is for staff to provide patients with individual attention. This is especially crucial for older patients at meal times:

I think there is a problem with older people who can't feed themselves well. The staff doesn't have time to really come and feed them. There's too many people in that boat to be looked after properly if their family isn't coming. I mean they don't care if they eat or not, and it's too much trouble to try to feed themselves, so they just don't. I saw lots of that. A lot of those trays just get carted away again (Mrs. Edgemont).

These participant's experiences support the notion that meeting the nutritional needs of the elderly in hospital is an important challenge (Kaufman, 1999; Picard, 1999).

Participants indicated that older patients rarely ate their meals. Mrs. Stafford commented that, "Everyone complained (about the food) but there was nothing to be done about it." This demonstrates that the system may be well aware that the food served to patients is barely edible. It appears that health care dollars are not being used wisely and as a result may be contributing to nutritional problems. Leaving a tray of unappetizing food before a frail elderly woman and providing her with no assistance with the meal conveys a lack of caring and respect. This finding points to the need for increased resources so that staff have time to help older patients at meals. Frail elderly

women are apt to need more individual attention at meal times than younger patients. However, participants' experiences show that only bare bones care is available during meals.

In summary, participants needed more individual attention than the system could provide. Their experiences showed that they have special needs related to their age that require extra resources to address. Ageist practices meant that these needs were ignored. Discrepancies in care were particularly evident in the areas of bathing, walking assistance and meals. In addition, the system did not recognize and individualize the needs of its hearing impaired or denture wearing patients. These gaps in care were especially problematic for older female patients as they are not as resilient as younger patients.

The participants' three major strategies for coping with gaps in care will now be discussed.

ASSUMING PERSONAL RESPONSIBILITY: LOWERED EXPECTATIONS

Perhaps one of the clearest views expressed by participants was that their hospital experience was influenced by their attitude:

I was being observant with other patients and seeing what a difference it makes. If your attitude is a good attitude and you're helping yourself, and not complaining about every little thing (it) makes a difference (Mrs. Ashcroft).

This sense of personal responsibility for their experience led participants to discount

their concerns about their care. Participants went to great lengths to assure me that "*the important medical care was there*" but the "extras" were missing. Extras included such matters as staff asking patients how they were feeling to helping patients set up their meal trays. Participants defined "extras" as "*luxuries*" and "*little things*" that "*one can live without.*"

I don't remember anyone coming around to ask how one was feeling. But I think that's a luxury we can't afford these days (Mrs. Harrington).

Participants recognized fiscal constraints in the system and accepted current ageist propaganda about the elderly "burdening" the health care system as fact (Goynea, 1998). This acceptance led participants to take the stance that "extra" care was not important "*in the whole scheme of things.*" However, the majority of participants frequently mentioned gaps in their care which indicated that the lack of care was more important to them than they let on. For example, Mrs. Harrington mentioned on three separate occasions that she was upset by how staff delivered her meals. However, she qualified her concerns as low on the totem pole and at one point stated in an embarrassed tone, "*Well, I mean, if one is saying what is the ideal*". In this way she dismissed her concerns as somewhat far reaching and indicated that they were not to be taken too seriously.

One of the things that really bothered me, and it is only a little thing, but an attitudinal thing, it seemed to be males who brought the meals around and they would sort of throw them down. Maybe they had to hurry or something, but it

was a very unpleasant way of doing things. I really object(ed) to that. I thought they were awful. I felt nobody had ever said to them, "It would be nice if you could just put it down and say hello". One feels as if there (should be) somebody who could give them a bit of guidance. But in the whole scheme of things, I guess that isn't important. The waiting lists are what is important and the big stuff (Mrs. Harrington).

Mrs. Harrington further distanced herself from this issue and disowned her feelings by depersonalizing them as belonging to a non-specific one, "*One feels as if there (should be) somebody who could give them a bit of guidance*". Although participants had concerns about their care they seemed uncomfortable making blatant complaints and downplayed their concerns.

In addition to minimizing the importance of their concerns another way participants coped with gaps in care was by blaming themselves for expecting too much. They then viewed their problems as stemming from their expectations rather than shortcomings in the system. This coping mechanism allowed participants to feel in control of a situation often beyond their control. Mrs. Herrick reflected that she had learned from her mother that, "*If one does not expect too much then one won't be disappointed*". She indicated this motto had served her well in the face of adversity. Similarly, Mrs. Laidlaw believed that the reason some patients have problems in hospital is because their expectations are too high:

Some people just expect too much. They think the nurse is there for them alone

(Mrs. Laidlaw).

Mrs. Laidlaw's sentiments were echoed by a number of participants:

You can't expect restaurant meals when you go into the hospital. Hospital is there to get you out as soon as possible (Miss Rawson).

With this constant hurry-scurry of overworked nurses you can't expect very much and you don't get very much. (Mrs. Stafford)

What can you expect from an institution like that where they are serving thousands of meals? (laughs) I guess you could expect a bit better (Mrs. Edgemont).

The above comments imply an acceptance of one's circumstances in hospital. Participants spoke about their concerns in a complacent and defeatist manner. When problems occurred they adopted a shrugged shoulders approach as if to say, Well, so be it. What can one expect? For example, Mrs. Edgemont laughed when telling me about the meals she was served as opposed to being upset about the quality of the food. Participants seemed to feel they were not entitled to complain. One reason they did not feel entitled to complain was because the system was in chaos due to a nurses' strike. In other words, given the circumstances, it was unreasonable to complain:

"You really couldn't criticize them because it was just when the nurses were going on strike, in fact the next day they had pickets outside the hospital" (Mrs.

Herrick).

Participants also felt they were not entitled to complain as there were patients who were "worse off." Consequently, they felt guilty complaining about "little things" in the face of gravely ill patients.

"I can't complain. There are lots of people worse off than I am". (Mrs. Holland)

Another explanation for participants' complacency may be their perception that their care was "free." One participant recounted that the quality of her meals was poor. However, she recounted her complaints on the basis that her hospital stay "...didn't cost me one dime". Another participant said that I wouldn't "get any complaints from (her)" because as she said, "I don't pay for medicare". The implication of receiving a "free service" is that one often takes what one gets and does not have the right to complain. Others appear to have given up trying:

"And the food, everyone complained, but there was nothing to be done about it (Mrs. Stafford).

Another reason participants lowered their expectations is that they did not wish to be viewed as demanding. They equated asking for help with being demanding. In other words, to be assertive was to be demanding. Participants defined other patients as demanding if they did not take some responsibility for providing for their own needs. Participants expressed annoyance at patients who complained a lot or called for help frequently. They described the staff as overworked and thought patients should have

the sense to request help sparingly:

I think patients to a point should, when they go in there, help themselves as well as help the nurses. Do what you can. Some people just sit there and expect the nurses to do everything ... I don't want to make more work for people who are already over-worked (Mrs. Laidlaw).

Patients who did not adhere to the participants non-complaining ideal were spoken about disparagingly. Participants placed a high value on taking care of oneself:

She was a loud person (roommate) that made the rest of us kind of upset with her. She was very demanding and we felt she was unnecessarily so. She was always calling the nurses whether she needed them or not. (Mrs. Edgemont).

I never called anybody unless I absolutely had to have some help. There were some people in there .. there was one woman (another patient) and she just bugged the nurse all the time. Calling for little things that she could look after herself. I didn't think that was right. (Mrs. Ashcroft).

Participants defined a "good patient" as someone who tended to her own needs and did not make demands. Participants identified with good patients:

Well, things got on their (nurses) nerves, you know. I was a good patient. I didn't ask for anything I didn't need, I know that. I didn't have to call them much. (Mrs. Edgemont).

If you are a nurse and you know exactly what problems they (patients) are facing and they are making more of it than necessary you'd get sick of it. They (nurses) are only human. No, I would say you've got to be good. (Mrs. Herrick).

Participants expressed the need to be liked by staff. The system responded favorably to good patients and participants were well aware of this. They observed that patients who were demanding were difficult for the staff to care for and presumably were not particularly well liked. For instance, Mrs. Ashcroft mentioned earlier that she limited her calls for help. When she left the hospital after a six week stay the staff gave her a warm goodbye:

The nurses, when I left, gave me big hugs and said I was the best patient that ever happened.

Similarly, Mrs. Bradley felt praised by her surgeon who called her a "tough one" as she did not call for help a lot:

I didn't push the button (bell to call nurse) unless I absolutely had to. When my surgeon came in he said, "Boy, you're sure a tough one."

Participants believed one way to earn the respect of staff was to put their needs second. However, this behaviour almost cost Mrs. Edgemont her life.

Mrs. Edgemont was admitted to hospital for a hip replacement. However, she developed severe stomach pain while waiting for her surgery. Eventually, she told her daughter how she was feeling:

When (my daughter) came in one day I said, "Oh, geeze, I feel so damn sick, I don't feel like eating anything, I wish I was dead, honestly. This pain is so awful". And so, she went to the nursing station and she said, "Get my mother off that Tylenol. Pay attention to her stomach. There's something happening and she needs a doctor, a stomach doctor." So they got me one and within an hour I was operated on for a bowel rupture. I don't think that would have happened if I hadn't had (my daughter) there. I'm sure it wouldn't have. I would have just got sicker and maybe would have died. Because it was touch and go as it was (Mrs. Edgemont).

Mrs. Edgemont was not able to bring her concerns to her doctor as forcefully as her daughter was. She had mentioned her stomach pain to her doctor and nurses but it was dismissed as a result of too much pain medication or a cracked rib. On the other hand her daughter demanded a thorough investigation. Mrs. Edgemont said she would not have spoken to her doctor as bluntly as she had to her daughter. She saw him only sporadically and did not feel they had a relationship of trust. Interestingly, Mrs. Edgemont describes herself as someone who is not intimidated by the medical profession, *"I'm not one of those people who think doctors are little gods."* However, despite these views she was reluctant to speak to her doctor about her pain as she equated it with complaining. She would handle the situation differently now:

I guess I had to learn to be aware that when there was something to complain about I better let somebody know. Maybe not complaining, but at least let them

know that this is bothering me. I kind of changed my attitude. My doctor told me, "Don't make a hero of yourself when things are going wrong. Nobody knows unless somebody will let somebody know" (Mrs. Edgemont).

Mrs. Edgemont's need to be a good patient placed her in a precarious position. She summed up her experience by assuming responsibility for not bringing her concerns to her doctor's attention:

But, I can't really complain. They were busy concentrating on the leg and maybe it was partly my fault, because I wasn't saying enough. That's what my doctor said (Mrs. Edgemont).

Mrs. Edgemont's story illustrates how the system positions older women to feel bad about making demands and leaves them caught in a double bind. They are rewarded if they do not make demands but are chastised if they do not speak up when problems occur. If a patient is loud and seen as the complaining type her concerns may not be fully heard. However, if she does not speak up her needs will not be known and ultimately she will be blamed if anything goes wrong. This finding teaches us that we should not assume that "everything is alright" if an older female patient does not complain. Another reason participants may have been hesitant to ask for help is that the care receiving role is a foreign one to them. Neysmith (1991) asserts that women who have been caring for others all their lives are expected to be independent and self-sufficient and make few demands on state and familial resources in their old age (Neysmith, 1991). Participants seemed to have internalized this message.

THE DEVELOPMENT OF SUPPORT NETWORKS

Participants reported that emotional support was especially crucial for them in hospital because they were at a stage in life where they were facing death. As Mrs. Bradley put it, "*You know going in at 74 (you're), afraid you'll be a goner almost*". This sentiment was echoed by Mrs. Stafford, age ninety, who said, "*If you go to hospital, you never know if you're coming out again. Or whether it's feet first.*" Participants pronounced it important that staff appear empathetic to their fears. However, two participants observed that staff did not have time to ask patients "*How are you feeling?*"

Participants noted that staff offered patients some comfort when they were at their sickest but that this attention diminished when the crisis passed. They interpreted this as a sign that staff needed to prioritize care:

I have nothing but praise for the nurses because it was quite frightening. I can remember how terribly cold I felt and I really thought that maybe this was it. They were very caring in that they would hold my hand, and rush around for warm blankets and do all the ordinary things that maybe one wouldn't have – and yet which are terribly important when you think you're breathing your last and everything is all in a panic. So, they were all very caring at that time (Mrs. Harrington).

Mrs. Harrington's statement that they would "*do all the ordinary things that maybe one wouldn't have – and yet are terribly important*" refers to her experience while she was in

intensive care. Once she was stabilized she was moved onto a family practice ward where she no longer received individualized attention. She describes that experience as follows:

Once one was out of intensive care their (staff) main role seemed to be (taking blood pressure, administering medications). They didn't seem to say, you know "How are you?" or "Do you have any pain? I mean one always had to tell them (Mrs. Harrington).

Miss Rawson recounts a similar experience:

It's all right when you're sick and throwing up and doing this and that. They call you sweetie and all that, but (once you start to get better) they don't even know you. They're too busy with the sick ones (Miss Rawson).

Mrs. Harrington's and Miss Rawson's experiences highlight that it is important to patients to be provided with emotional support throughout their stay. Otherwise, participants seemed to feel forgotten, unsupported and resentful.

Studies have shown that being admitted to hospital creates anxiety and fear (Gerteis, et. al, 1993). Many older women may be coping with the experience alone as they have lost spouses and other family and friends and may feel quite isolated. Statistics show that sixty-four percent (64%) of women age seventy five and older are widowed and live alone (Northcott and Milliken, 1998). This statistic suggests that the majority of elderly women in hospital will be discharged home, alone, an experience

that they may find disconcerting. One participant, Mrs. Bradley recently lost her husband and was particularly anxious about being in hospital without his support. For women such as Mrs. Bradley, support from staff takes on a new importance:

When you are nervous they were nice, you know, you go in and you are nervous. I was nervous. I don't have my husband to lean on. That's who I miss most of all (Mrs. Bradley)

All participants in this study had family upon whom they could rely to “fill the gaps emotionally.” However, I found it significant that all the participants expressed concern for patients in hospital who did not have family or friends. Their concern highlighted the important role family plays in meeting the emotional support needs of older female patients. Participants' hearts went out to those patients whom they described as being all alone:

I don't know whether it's because the nurses are short of time but they never seemed to have time to ask anybody how they were or what sort of day they were having. (They'd say) “I'm your nurse for today” and they were off. I used to think of some of the people I would see walking up and down who didn't have anybody to visit them and nobody seemed to have time just for those fairly ordinary – not really nursing – but just for the human side of things (Mrs. Harrington).

Mrs. Harrington experience begs the question: Whose job is it to take care of the

human side of things? This question led me to wonder about participants' experience with the hospital social worker. Traditionally, one of the jobs of the hospital social worker is to provide patients with counseling services. Three of the ten women I interviewed reported that they had direct contact with a hospital social worker. However, Mrs. Harrington was the only participant who reported receiving emotional support from a social worker. Mrs. Harrington said that the social worker who helped plan her discharge provided comfort by recognizing and acknowledging her fears about going home:

It was a male social worker, very pleasant, and I think we called him once about help because you know when you have just had surgery you really can't do that much and it is a bit scary going home. The social worker was very helpful in that he said "It will be fine. You know it seems a bit scary." And he talked to us. So I think the social workers play a very important role (Mrs. Harrington).

Interestingly, when asked what she saw as the social worker's role, she said she saw their main role as organizing concrete support services rather than providing emotional support:

There are so many people on their own, living on their own, who don't have family around and (who) don't know where to turn, where to go for help. They probably haven't a great deal of means to pay and so the social worker is very important. I know from other people how helpful they are. Very helpful with geriatric patients (Mrs. Harrington).

A number of other participants viewed the social worker's role in the same light. The social worker was not viewed as a provider of counseling services.

A clear message conveyed by participants was that staff could provide emotional support and form relationships with them by treating them with respect. Participants' felt treated with respect if staff honoured their individuality. However, the structure of the system was such that some participants felt that their individuality went unrecognized

"Some hospitals are too big, that's the whole problem. You get lost in the general whirl and you're simply whatever ails you. You're not a person anymore" (Mrs. Stafford).

When participants' individuality was honoured they seemed to have more confidence in the staff and a better sense that their care would be handled competently:

*They (Hospital A) were short-staffed and **nobody had time to be kind** (emphasis original). Now I happen to be very incontinent and had to be changed at night and the staff who came on then were most unfriendly. They never talked to me. They would simply say, "Turnover" and they had such hard hands digging in to me. I thought "Oh, can't you be kind?" But I was just a lump in the bed to them. They were terrible. I dreaded their attentions. But when I was at (Hospital B) you feel as though they really care about you. You're not just a floating kidney or a broken femur. You're you and you have a name and they*

treat you like a person and they are so kind (Mrs. Stafford).

At Hospital B Mrs. Stafford felt staff treated her as an individual in her own right as they called her by her name and acted in a caring manner. However, at Hospital A she felt staff viewed her not as a person but as a "lump in the bed". Their actions conveyed that she was a non-person "they would simply say turn over". Mrs. Stafford's experience with the nurses (at Hospital A) at night caused her distress and made for an unpleasant experience in hospital. It was hard enough for her to be ill and unable to manage her personal care independently let alone have to deal with unkind staff. What Mrs. Stafford required was compassionate care. Staff who barked "Turn over" as opposed to asking if she could please turn over communicated disrespect for her age and stage. However, she indicated that the staff at a different hospital called her by name. She interpreted this as kindness and later described these staff members as "like friends."

Participants interpreted the language staff used when talking to them as a sign of respect or disrespect. Participants were particularly upset if staff spoke to them in a patronizing way. This was hard to cope with and created feelings of anger and resentment:

They didn't just casually call me by my first name. At 90 years of age, I felt that Mrs. Stafford was a more suitable form of address...it's the feeling that you're respected. This modern idea, the doctor comes along and says "Hello E" and he expects me to call him "Dr. K", now I mean, what's the sense in that? I was old

enough to be his grandmother half the time (Mrs. Stafford).

You look a bit stupid when you're sick. So they treat you like you're an idiot. A bed pan, you want a bed pan? They talk about it being a pee pee pan. I'm not an infant! (Miss Rawson).

These findings raise questions about staff training needs. The Dr. K whom Mrs. Stafford spoke of showed a lack of regard for Mrs. Stafford's elder status. This example shows how important it is for staff to develop a relationship of respect with patients. To establish respect one must first establish rapport. The use of language is especially important to the establishment of rapport with this population. Mrs. Stafford's experience with Dr. K. illustrates that calling an older woman by her surname until you are told otherwise is a good rule of thumb. Similarly, Miss Rawson alerts us to the fact that talking to an older woman as if she is a child, i.e., using phrases such as "pee-pee pan", is insulting and disrespectful. As Miss Rawson points out such language ignores the fact she has lived a full life, "*I'm not an infant*".

Participants emphasized the need for staff to understand that they were not just a "*lump in the bed*" but had lived full lives and had a life outside the hospital. Their experiences highlight the prevalence of ageist beliefs and practices within the system. One participant lamented that staff tended to devalue her life experience:

All the nurses see in me is an old shriveled up lady who is crabby. A lot of women who have held jobs aren't realized for that. They're only seen in their

present state of pain, not seen as the person they once were. They could use a little more understanding (Mrs. Herrick).

These women's experiences show that their treatment is often sadly lacking in respect.

Participants recognized systemic difficulties and developed effective ways of coping that drew on their relational skills. They indicated that they had a more pleasant hospital stay if they could connect with their roommates. Five participants became friends with other patients and kept in contact with them after discharge. Being in hospital together was a bonding experience:

There were four of us and it was a really pleasant room. All four of us were around the same age bracket and seemed to really like one another. I thought that (it) was a wonderful experience because it really can be the other way, it only takes one ... The lady right next to me, she and I really helped one another out because sometimes the press button would be down on the floor and she couldn't get it and I'd ring for her (Mrs. Herrick).

I was never lonely. I talked to other people that were in the ward. There was always four unless I had a private ward. I wouldn't want a private ward, I don't think. I like to talk to people. I have friends I met on the surgery ward that I write to. One girl we phone and she's been to my place and I've been to her place (Mrs. Ashcroft).

The majority of participants said they did not mind sharing a room with other patients as

they liked the companionship. However, the two married participants expressed a preference for a private room citing the need for personal privacy. In general, participants' enjoyment of their roommates varied with the ability of their roommates to provide companionship. A number of participants were stirred up by patients with more severe health problems. Mrs. Herrick shared a room with three women with dementia, which revived painful memories of her husband who had died of Alzheimer's:

I was put in a room with three elderly women, who were all demented and so it was not a pleasant week. Having had a husband with Alzheimer's for ten and a half years made me aware. I wasn't in the room ten minutes till I knew the situation. I couldn't talk to them. I talked to their visitors. They used to come over and have a good talk but you couldn't talk to the others (Mrs. Herrick).

In summary, participants used their relational skills to compensate for gaps in service by reaching out to other female patients for support. Participants indicated they felt connected to staff at times of crisis. However, they were left to their own devices when the crisis passed. This finding teaches us that it is important to facilitate older women's social connections. It suggests that feeling connected to others in hospital is crucial to a sense of well-being and provides patients with a coat of armour.

RELIANCE ON FAMILY

"I survived. Thanks to my daughter" – Mrs. Stafford

Participants highlighted that family are filling in gaps in the system and play an integral role in the care of their hospitalized elderly female members. However, their role is a challenging one. The system sends a message to patients that their families are obligated to tend to their needs. As one participant put it, "*You better have family to help you*". Elderly patients without family are at a disadvantage. Participants consistently used the word "*lucky*" to describe the fact that they had family support and expressed relief at their good fortune. It was Mrs. Harrington's experience that her family's support gave her an advantage over those patients without family. As she put it, "*I just think I was very lucky (that I had) people to go to bat for me. I was very privileged.*" Participants felt family cared about their needs and they trusted them to look out for their welfare. They relied heavily on family support to get them through their hospital stay. Participants interpreted liberal visiting policies and staff shortages as signs that family was expected to pick up the slack:

Gosh in the old days visiting would be from 2-4 Tuesday, Thursday and Sunday, which was awful. They didn't want you around. All the beds had to be made and everything before the visitors were allowed in. I think this is much nicer for the patients, much nicer. Of course the visitors fulfil a useful role too. They take one along to various groups or on walks. I'm sure that's probably why they allow visitors to be there all day because they do a lot of things that aides used to do.

Participants reported that family support helped them leave hospital sooner. Earlier in this chapter I discussed how family provided participants with practical

support by assisting with bathing, meals and walking. Another way family provided support was by acting as advocates for their hospitalized member. Participants were often too ill to make their needs known. They felt vulnerable and had difficulty asserting themselves. Consequently, they needed an advocate who understood their needs and could act on their behalf. While participants were concerned about asserting themselves they expressed relief that family advocated for them, *"I don't know what I would have done if (daughter) hadn't been there"*. Participants indicated the hospital placed unrealistic expectations on family and made assumptions about what their family could do. They felt the system did not fully understand the pressure these expectations put on participants and their families. One participant stated that, *"Family get a bit worn out and it doesn't always help relations."*

Two participants, Mrs. Edgemont and Mrs. Stafford, stated that they thought they would have died if their daughters had not looked out for their welfare in hospital. Earlier in this Chapter I discussed how Mrs. Edgemont's daughter lobbied staff to *"pay attention to (my mother's) stomach"*. The result of her daughter's action was that Mrs. Edgemont was operated on within an hour for a bowel rupture. Reflecting on her experience Mrs. Edgemont stated:

I was helpless and if I hadn't had an advocate (in) my family or someone to look after me, things would have turned out differently in the hospital. She (daughter) wouldn't let anything go by (Mrs. Edgemont).

Mrs. Edgemont's experience highlights how important it is for elderly female patients to

have someone to act on their behalf. Mrs. Edgemont needed someone to monitor her care as she was not in a position to do this herself. Her statement "*things would have turned out differently*" implies a lack of faith in the system. She later commented, "*I think I would have died without (my daughter)*". Mrs. Edgemont's story highlights that elderly patients often have complex medical needs. Older women are likely to suffer from a number of chronic health problems (Goynea, 1998). Consequently, an advocate who is aware of the needs of the whole person is particularly important. For instance, Mrs. Stafford's mother was hospitalized for pneumonia. However, her daughter knew that if her mother did not have a daily bath her skin breakdown would get worse. It was not enough to just treat her pneumonia. Mrs. Stafford expressed a sentiment similar to Mrs. Edgemont's, "*I don't think I would have gotten out of there alive if it hadn't been for (my daughter)*." These experiences illustrate that elderly patients are often too sick to advocate for themselves. The structure of the system is such that patients require an advocate. Family filled this gap by staying close to the bedside and watching out for their loved one's care.

Participants' experiences suggest that the chance of a frail elderly woman surviving a hospital stay may increase if she has an advocate. However, the effectiveness of the advocate depended on how they presented their case. As Mrs. Edgemont stated, her daughter was someone people would listen to:

She's got a personality where people will talk to her. She is intelligent and doesn't just rattle on (Mrs. Edgemont).

To be successful advocates families need to know how to navigate the system. Participants experiences show that it is hard for the system, patients and families to work together. For example, in an effort to plan her mother's discharge Mrs. Stafford's daughter kept tabs on her mother's social worker to ensure that plans were in place. As a result, she describes herself as viewed by staff as "a big pain in the ass." Family who advocate for their loved ones' needs can be perceived by staff as "demanding". The medical system gives mixed messages about family involvement. It courts family help but discourages too active an involvement if it threatens hospital routines. The majority of participants indicated that they did not feel they were working in partnership with staff. Rather, they felt they had to fight and struggle to have their needs met.

Advocates were also important for information gathering. Participants were often frightened of the unknown and felt that the staff did not have time to explain things to them. Advocates helped to allay their fears. Mrs. Harrington's daughter explains:

It can be quite scary. The nurses don't really have time to talk to you. I was lucky because my daughter would make sure she knew exactly what was going on and that I knew what was going on. I think it must be hard for older people who don't have an advocate (Mrs. Harrington).

This group of participants were raised in a time when medical professionals were treated with a certain reverence. Consequently many of them may have been reluctant to make demands or question authority. This value, combined with a high

pressure hospital environment, makes the role of the family advocate all the more important.

Participants felt that the system placed unrealistic expectations on family. Although the purpose of this study was to interview older women about their experience in hospital two daughters talked to me about their experience caring for their mothers in hospital. Their comments supported participants' perspectives on the importance of family. One daughter spoke about how difficult it was to cope with her mother's hospitalization while at the same time manage tasks related to her mother's personal care. She said she felt compelled to bathe her mother in hospital because, "*There was no one to do it*". Consequently, she was positioned in a no-win situation. She worried about robbing her mother of her dignity as she felt her role as bather was an invasion of her mother's privacy. She expressed anger and resentment at her position and stated "*I would do anything for my mom but I didn't want to have to wipe her bum.*" She felt the system did not understand the difficulty managing these tasks represented. She stated that family are grieving and need time to cope with their loss. However, it is hard for them to work through their losses when their energy is taken up with basic tasks. The system may be asking family to take on roles that may not be in patients or their family members' best interests. For instance, Mrs. Stafford expressed ambivalence about accepting help with her personal care from her daughter and stated she would have preferred the help of a nurse. It must be stressed that these two daughters were providing nursing care within a health care setting. These daughters did not have a nursing background but were entrusted with nursing tasks within the hospital setting.

This finding highlights that family members feel pressure to assume basic nursing tasks in order to ensure that the needs of their hospitalized elderly female members are met. While it is important to involve family in the care of its hospitalized members how involved is too involved? For example, two participants expressed great fear that they would not have survived their hospital stay without their daughters' support.

A number of participants felt the hospital overrelied on family to fill in gaps in care and made assumptions about the help that family would provide at discharge. As a result they felt their needs were not investigated fully. Mrs. Swartz described the problems with this approach:

"They (staff) never once asked me if I needed help (at home). They asked my son in the hall. But noone ever came to ask me" (Mrs. Swartz).

Mrs. Swartz has a strained relationship with her son. However, she felt staff assumed they were a loving family. She said her son told staff he would look after her at discharge as he was "too embarrassed" to admit otherwise. In reality, when she got home there was no help forthcoming. She felt ignored and was upset staff had not made the effort to ask her about her needs privately. It is important to ask patients directly about their care needs, particularly given the incidence of elder abuse.

A number of participants felt that the system assumed family had an abundance of time to look after their aged members. However, participants worried about being a burden on their families while they were hospitalized. In this study most of the family members who helped participants in hospital were daughters and daughters-in-law.

Two of the eleven participants had husbands who assisted with their care. One had a sister. However, it was hard for family to arrange to be at the hospital:

It was not particularly easy for her (daughter) to come here. She's her own boss but her work suffers when she comes over here. I had a son here, right in town but he's working and he's got a wife and three kids. A boy doesn't look after his mother the same as a girl (laughs) (Mrs. Edgemont).

Staff often lack the resources to meet all the needs of their elderly female patients. This study has shown that there are many facets to an older women's care in hospital. Fiscal constraints have led to family assuming more responsibility for the care of their aged female members. Families are learning how to bathe, feed, and walk their aged members. Managing these tasks has the potential to strain family relationships and may place unrealistic expectations on what the family can do.

Summary

This study highlighted elderly women's vulnerability in hospital. Their experiences show that a hospital stay can be a frightening time in an elderly woman's life and require increased support. Participants found it difficult to make their needs known and coped with their patient status by downplaying their concerns and making the best of them. Their reports suggest that the system is hard pressed to provide more than minimal care and fails to recognize age specific needs. Participants handled these gaps in care by drawing on support from other patients and relying heavily on

family for practical and emotional support. This reliance had the potential to strain family relationships and participants worried about burdening family. However, gaps in care left participants little choice but to rely on families support. Without it they may not have survived.

CHAPTER 4 MEETING THE NEEDS OF HOSPITALIZED ELDERLY WOMEN

The primary insight that emerged from this study is that a successful hospital stay is viewed as a matter of survival. Participants' experiences alert us to the fact that the system is failing to respond to their age specific needs. To cope with gaps in care participants developed three survival strategies. Their first survival strategy was to assume personal responsibility for their experience in hospital by lowering their expectations and keeping their concerns hidden. Their second strategy was to develop support networks which included other patients and staff. Their third and most critical strategy was to rely on family to provide practical support and advocate on their behalf for better care. This chapter discusses how these findings complement and add to our understanding of older women's needs in hospital. Practical ways to provide support to this group are suggested.

SEEN BUT NOT HEARD

Participants did not have a strong voice in their care. Theorists have asserted that elderly women's experience in later life is reflective of a life history of gender and socio-economic stratification which has relegated them to the margins of society (Chafetz, 1988; Mullaly, 1996). Their experience in hospital illustrates how they may have internalized their marginal social status. This section examines how this dynamic

surfaced in their experience in hospital. Implications for social work practice are discussed.

The participants' methods for coping with their patient status mirror coping mechanisms used by oppressed groups to deal with their marginal status. Mullaly (1996) asserts that the oppressed cope with their marginal social status by a process of inferiorization in which they accommodate and comply with the dominant groups' views. It is as if the oppressor gets in the head of the oppressed (Mullaly, 1996). While these behaviours function to maintain the status quo they also provide the oppressed with coping mechanisms to deal with the oppression. Participants lowered their expectations about the type of care that they could expect in hospital and in this way accommodated inferior treatment. This perspective allowed them to maintain a sense of control over their circumstances, "*If you don't expect too much you won't be disappointed*". They also accommodated inferior treatment by assuming personal responsibility for their experience in hospital, "*Some people just expect too much. They think the nurse is there for them alone.*" Participants did not feel entitled to better care and this showed itself in a reluctance to complain overtly. They discounted their concerns as "*little things*" that "*weren't important in the whole scheme of things.*" Their reluctance to complain overtly might be influenced by a life history of unpaid labour in the home which has gone unrecognized by society. The majority of participants were homemakers or worked in low status jobs. Participants may have internalized the prevailing belief that they have not contributed to society (Chafetz, 1998; Lewis, 1985). Consequently, they do not believe they have the right to make demands on the system

that an employed tax paying citizen would. These women may have become accustomed to accepting second best. Aronson (1994) found similar feelings of disenfranchisement to government services among a group of elderly women in need of community care.

Another way oppressed groups respond to oppression is by mimicking the behaviours and attitudes the dominant group displays towards the oppressed group. This response is an attempt to gain a slightly more privileged status (Mullaly, 1996). Participants employed this coping mechanism by being critical of female patients who were demanding. Participants worked hard to maintain a low profile. Patients who made visible demands for help were spoken about disparagingly, *"She was a loud person (roommate) that made the rest of us kind of upset with her. She was very demanding and we felt she was unnecessarily so."* They saw themselves as superior to these demanding patients, *"I was a good patient. I didn't ask for anything I didn't need. I know that"*.

The media portrays elderly women as a burden on society (Goynea, 1997). Elderly women have been bombarded with this message and participants internalized this view. Mullaly (1996) points out that internalized oppression can cause members of oppressed groups to act in ways that affirm the dominant group's view of them as inferior. This leads to a process whereby inferiorized persons reproduce their own oppression (Mullaly, 1996). Participants kept their concerns to themselves which contributed to their invisibility. For example, one participant mentioned several times that her meals were served rudely. She relayed that staff would throw her food down

and walk away without acknowledging her presence. In essence, staff treated her as invisible. However, she qualified her concerns by stating "*But in the scheme of things, I guess that isn't important. The waiting lists are what is important and the big stuff.*" She did not voice her complaints to staff but rather accepted her inferior treatment. Other participants minimized their inferior treatment by blaming themselves for expecting too much, "*You can't expect restaurant meals when you go into hospital. Hospital is there to get you out as soon as possible.*" Mrs. Edgemont's story about how her stomach pain was overlooked until her daughter demanded an investigation highlights how an elderly woman's reluctance to be a burden places her in a precarious position. Mrs. Edgemont blamed herself for not communicating her needs to her doctor earlier. Her story demonstrates the complexity of this situation. Older women are positioned in a no-win situation. They are rewarded if they do not make demands but are chastised if they do not speak up and problems occur. Mullaly (1996) points out that when people internalize their oppression by blaming themselves for their troubled circumstances they often contribute to their own oppression by considering it as unique, unchangeable, deserved or temporary. This double bind effectively silences older women.

FINDING A VOICE

These findings point to the need to help elderly women develop a voice in their care. Aronson (1999) asserts that images of elderly people "making demands" are few and far between. She stresses the need to develop the image of older adults who

advocate for resources and the means to “overcome collectively experienced obstacles” (Aronson, 1999). What role does social work play in helping older women in hospital have a stronger voice? As a first step, Aronson suggests that social workers examine their views of older adults. She asserts that the dominant image of older adults is “as passive bearers of an assortment of problems which require standardized management” (Aronson, 1999). Mrs. Stafford resisted this view of older adults by stating emphatically that she wanted to be viewed as a person, not a broken femur. In addition, she was critical of her doctor who called her by her first name but expected her to call him Dr. K. Mrs. Stafford had very clear ideas about her needs and wants. It is important that social workers do not fall into the trap of viewing older adults as stereotypically passive and dependent. Social workers need to re-evaluate their practice and see older women as effective change agents in their own right. Social workers can also play an active role in bringing this perspective to other health care professionals.

Empowerment-oriented and anti-oppressive approaches to social work practice have been suggested as helpful methods for working on empowerment issues with older women (Browne & Colette, 1995, Cox & Parsons, 1994). Empowerment-oriented approaches would focus on raising the older woman’s awareness of issues which are having a negative impact on her life and help her strategize ways to address these issues. To date, research has not examined the effectiveness of these approaches and future research in this area would be helpful. However, research has examined women’s perspective on the meaning of empowerment in their lives (Sheilds, 1995). This research found that women experience empowerment as a “multifaceted

expansive process with three central themes: the development of an internal sense of self, the ability to take action based on their internal sense of self, and a salient theme of connectedness" (Sheilds, 1995:15). Compatibly, Evers (1985) found that women who had tended to work in the home and had not developed interests separate from their families relied on others to make their decisions and took a more passive approach to life. These women were likely to find attempts by hospital staff to empower them to take a more active role in their health care particularly upsetting. Social workers will need to be sensitive to the life history of their elderly female patients to successfully work with them. My study indicated that participants were often unaware of how their experience was reflective of the dominant social structure. Empowerment oriented approaches would help these women place their concerns outside of themselves rather than view them as personal shortcomings. Primary interventions might focus on consciousness raising at an individual and group level.

Participants seemed open to group level interventions as they drew on their relational skills to cope with their patient status. Their experiences alert us to the fact that elderly women tend to reach out to each other for support. A number of participants made friends in hospital which led me to believe that they would be receptive to empowerment oriented approaches in which they shared their problems and worked towards mutual solutions. However, the logistics of bringing elderly women with chronic health problems together is a hurdle that would require careful planning and creative thinking. A telephone network would be an option. Currently, elderly women's silence is often maintained by their distance from each other. However, their

experiences in hospital tell us that they are open to social connections.

From a practical approach hospital social workers may wish to think about organizing a support group of older women. The social worker's role would be to facilitate the group until the members could take over. The emphasis of the group would be on women sharing their experience in hospital. The social worker would assist members in learning to think critically and see problems with their care as outside themselves. The goal would be for the group to develop action strategies aimed at improving services to older women in hospital. As mentioned earlier, I spoke about this study to a group of seniors' peer counsellors. One of the recommendations that came out of that talk was the need to develop tools older women could use to help them navigate the health care system. The counselors raised the issue that the current trend to patient centered care in which the patient assumes responsibility for bringing her concerns to the team is challenging for many older women. They discussed how these women were raised not to question doctors and that unlearning this philosophy is quite challenging. An understanding of this difficulty alerts the social worker to the need to help older women strategize ways in which they can bring their concerns forward. For instance, helping the older woman define and prioritize her concerns prior to a meeting with her doctor may help. Another challenge older women face is that the medical system is in a state of flux and not all health care professionals have bought into the patient centered care perspective. Older women may need help strategizing how to deal with resistance in the system so that they do not become discouraged.

A HOLISTIC PATIENT-CENTERED APPROACH TO CARE

The system failed to meet participants' age specific needs. The current trend in the health care system is to provide patient-centered care. In the traditional hospital structure, the patient is divided into parts and connected to staff according to her ailments i.e., physiotherapy for mobility, social work for psycho-social issues and the lab for blood work (Globerman, 1999). However, compartmentalizing patient needs means that the needs of the whole person may be overlooked. Participants' experiences teach us compartmentalizing patients' needs can lead to serious gaps in care. Hospitals are now adopting a patient-centered care approach that postulates the importance of considering the needs of the whole person when planning health care interventions. However, participants' experiences illustrate that this approach is in its beginning stages and remnants of the old system remain. In addition, some older women may have a hard time adjusting to this new approach to care. The findings of this study support the need for a patient-centered approach to care.

Participants lamented the lack of care which honoured their individuality. As Mrs. Stafford expressed earlier, "*You get lost in the general whirl and you are just whatever ails you. You're not a person anymore.*" Geriatricians in the United States coined the term "whole body medicine" to describe the care elderly patients require (Levin, 1999). These doctors stress the importance of bearing witness to their elderly patients' pain and taking the time to talk about things that are important to them (Levin, 1999). They point to the need to establish rapport with their elderly clients. This approach requires

listening to elderly patients with a careful ear and not interrupting them during an exam (Levin, 1999). Participants in this study expressed a desire for this type of care but said that staff were so pressed for time that they were unable to ask patients how they were feeling. One study found that doctors commonly cut patients off after 18 seconds, a point at which some elderly men and women have barely collected their thoughts (Levin, 1999). Mrs. Stafford highlighted how important it is for staff to form relationships with patients. In her case an attentive nurse, by virtue of establishing a relationship, convinced her to try a high calorie drink and solved her weight loss problem, "*She took the time you see. Nobody else had time to.*"

Participants' experiences show that failure to look at the needs of the whole person may lead to more problems for elderly patients. Mrs. Edgemont provided a striking example of the importance of examining the needs of the whole person. As we saw, Mrs. Edgemont was admitted to hospital for a hip replacement but suffered a bowel rupture while awaiting surgery. However, her stomach pain was overlooked because "*they (staff) were concentrating on the hip.*" It has been said that staff require the detective skills of Sherlock Holmes to determine their elderly patients' care needs (Levin, 1999). However, participants pointed out that even if staff have the skills they often lack the time to complete an indepth assessment. This time shortage is particularly problematic for older women as they often have complex medical needs that take time to understand. For instance, among women age eighty and older, seventy percent have two or more of the following conditions: arthritis, hypertension, cataracts, heart disease, varicose veins, diabetes, cancer, osteoporosis or hip fracture

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and stroke (Gonyea, 1998). One study found that older women were especially prone to care gaps (CAG, 1999). Care gaps are missed clinical benefits for patients and unnecessary costs for payers (CAG, 1999). Mrs. Edgemont's experience is indicative of a care gap. This finding supports the assertion that illness in older people is often "misdiagnosed, overlooked or dismissed as the normal process of aging, simply because health care professionals are not trained to recognize how diseases and drugs affect older people" (Levin, 1999). These ageist practices put elderly women at grave risk.

Health care professionals who are inadequately trained to identify the needs of elderly women, combined with elderly women's desire not to burden staff with their needs, has created a situation fraught with communication problems. Much is missed and misunderstood. The significance of some of these gaps is becoming well supported by other research. For example there is growing concern regarding the nutritional needs of hospitalized seniors. This gap is significant as proper nutrition is key to helping elderly women maintain good health (Dimond, 1995). Participants' experiences illustrate that the system is struggling to meet the nutritional needs of its older patients. Proper nutrition is an essential part of the recovery process. For instance, older women suffer from skin breakdown and a proper diet will help heal the skin. A younger person can cope with hospital meals better than an elderly patient who is more prone to develop health problems secondary to a poor diet. Recent studies found that if an elderly person becomes malnourished his or her risk of subsequent illness and death increases dramatically (Kaufman, 1999, Picard, 1999). These findings

highlight the shortsightedness of providing hospitalized elderly patients with substandard meals. My findings support recently published studies which found that the elderly are often malnourished in hospital and their chance of recovering from illnesses decline as a result (Kaufman, 1999, Picard, 1999). One of these recent studies found that patients who were admitted in good health for elective surgery were most at risk. This recent study also found that hospital staff were unaware of the seriousness to an elderly patient of developing nutrient deficits. Participants' stories support these findings, as their diets were not closely watched, "*No one besides my daughter ever came to see whether I ate what was on the tray*". The recent studies found that patients were not getting enough food due to nausea, lack of appetite and dislike of the food (Kaufman, 1999). My study however, found that patients had trouble eating because they were too weak to feed themselves and staff did not have time to help. As one participant observed, "*I mean they (elderly patients) don't care if they eat or not, and it's too much trouble to try to feed themselves, so they just don't. I saw lots of that. A lot of those trays just get carted away again.*" Recent studies indicate that part of the problem is a lack of clear guidelines and assessment tools (Picard, 1999). They point to the need to find innovative ways to improve care and get people fed (Kaufman, 1999). My study suggests that in some hospital settings staffing levels make it impossible for staff to help patients with meals. It points to the fact that elderly patients require more resources at meals than the system has allocated.

Another gap in care identified by participants was the need for emotional support while in hospital. While participants bonded with other patients they often described

staff as emotionally distant. Participants developed support networks with other patients to cope with this gap. However, they found staff were unable to address their emotional support needs unless a crisis occurred. Lack of support in this area is problematic for elderly women. For many who lack family support, support from outside sources takes on a new importance. Though participants in this study had good family support they all expressed concern for patients whom they observed to be alone. Statistically speaking, in British Columbia forty-three percent of females age seventy-five and older live alone compared to nineteen percent of males in that age group (Northcott and Milliken, 1998). Studies have found that maintaining social connections is key to helping older women maintain their health in old age (MacLean et. al, 1994). Hence, it is important for older women to feel connected to others.

Participants made it clear they considered emotional support an important part of their care. However, they felt these needs were more likely to be met when they were seriously ill. Studies have shown that health care professionals tend to rank patients' physical needs first and their psychological needs second (Gerteis, 1993, Irurita, 1996). Many hospitalized elderly women suffer from chronic diseases that require management not cure. These women are not the sickest of the sick and may require rehabilitation and convalescent care before discharge. Consequently, they may need emotional support to adjust to their disability. However, this is problematic if staff attention is directed primarily towards crisis intervention. In a 1995 study conducted by Herbert and Levin, a group of social work administrators in Canadian hospitals (n=42) were asked to document what they felt were the current issues facing hospital social

workers. They found that in times of constraint funders and administrators tend to revert to "the basics" and deem the non-physical aspect of health expendable (Herbert and Levin, 1995:90). In such climates, there is an increased emphasis on early discharge and a decreased emphasis on the process of discharge planning. As a result, there is less opportunity for social workers to establish a therapeutic relationship with their elderly patients (Herbert and Levin, 1995). This finding suggests that emotional support may be considered an expendable hospital resource.

Undoubtedly staffing shortages make it hard for staff to make time to spend with patients. However, there may be other factors at play. The majority of front-line hospital staff are women. Younger female staff are forced to confront their own aging issues and the aging issues of their family when they work with elderly women. Their elderly patient could be their mother or their grandmother. Staff may tend to distance themselves from their elderly female patients as a means of coping with what their patients represent. Their need to distance may rear its head in disrespectful speech or infantile treatment (Genevay and Katz, 1990).

Another factor is that many of today's elderly women were raised with the philosophy that one does not air their business in public. Thus they might not be forthcoming with requests for emotional support and may even portray themselves as not needing it.

It is clear more resources are needed to meet the needs of elderly women in hospital. However, increased resources must go hand in hand with staff training. In

addition, staff require training to dismantle ageist and sexist practices and dispel myths about older persons. Dr. Dalziel, President, Canadian Society of Geriatric Medicine stressed the need to fill this gap:

"Skilled and committed geriatric health care professionals represent the absolute necessary foundation for the appropriate assessment, treatment and care for Canada's growing elderly population. To invest in future care for Canadian Seniors, Canada must now ensure adequate generalist training in care of the elderly for all health care professionals and an appropriate number of geriatric specialists in all disciplines" (CAG, 1999).

ADVOCATES FOR CHANGE

Participants' stories suggest that the system relies heavily on family to fill in gaps in care, *"There are too many people in that boat (needing help eating) to be looked after properly if their family isn't coming in"*. The alternative to family providing care themselves was for them to stand helplessly by watching their loved one suffer, *"There was no one else to do it"*. This situation created additional stress. Participants described an environment in which patients were left to their own devices and relied on family members for practical support. However, if families continue to fill in these gaps in care and do not advocate for change the system will have little incentive to increase its resources. I commend family for helping their family members get well. However, in the long run their good intentions mask the serious gaps in care.

It appears that the rationale behind community care policies is filtering into the hospital setting. The goal of community care is to provide families with home support help to enable their aged members to remain at home. Community care services are "intended to enhance not replace the role of the family" (Ministry of Health, 1999) The policy underlying community care is that the family is the most appropriate locus of care for its elderly female members (Aronson, 1994). However, as Aronson (1994) points out, "appropriateness for whom" is seldom considered. She asserts that there are some obvious economies behind these policies. Such economies became clear when I examined participants' experiences in hospital. For instance, participants provided numerous examples of how their family provided hands on care. The cost of their caregiving if translated into dollars would be substantial. However, participants have shown us that they needed this care to get well. They raised the serious question of what happens to elderly women who not have family. Research that examines the experience of elderly women who do not have family is needed. Two participants went so far as to state that they survived their hospital stay because of their family. It is important that we understand how patients without family cope.

Asking families to advocate for change in the system may be unrealistic. The majority of elderly women are cared for by their daughters (Aronson, 1991, Neysmith, 1991). Many of these daughters are juggling work, family, and the care of aged parents. They have little time for themselves much less advocacy work. Their caregiving responsibility may place their health at risk. One study found that these daughters were at particular risk for heart disease and high blood pressure (Picard,

1999a). The degree of stress and burnout among caregivers is high (Pearlin, L., Mullan, J., Semple, S., & Skaff, M., 1990). This study has shown that a hospital admission does not provide the caregiver with respite. In fact, their services may be needed more. Today's elderly women are susceptible to a number of chronic health problems. If the younger generation does not reduce their caregiving responsibilities they may be following in their footsteps.

Participants' families, anxious to see that their aged members receive the care they needed, stepped in to fill in gaps. Their individual efforts were viewed as private matters. In some ways they contributed to maintaining the status quo. For change to occur, families will need to see their problems as reflective of the larger social structure's treatment of the elderly. There is a need for social workers to educate families on how to advocate for better care by making their private issues public. Social workers may also need to assume a more active advocacy role. The challenge to this suggestion is that some social workers in the hospital setting are stretched to the limit and feel they have little time to do anything more than discharge planning (Globerman, 1999). Caregivers are struggling to keep their heads above water. In short, no one seems to have the time or energy for advocacy work. However, the British Columbia Ministry of Health recently created a task force to study issues important in older women's lives. Educating the task force on the issues older women are facing in hospital might be a good place to start.

Summary

Elderly women's needs are often out of place in a system that values cure over maintenance and intervention over comfort (Levine, 1999). Participants' strategies for coping with their hospital stay helped them survive on an individual level. However, their strategies will not facilitate long term change in the system. Participants did not have a strong voice in their care and might be reinforcing their own oppression by excusing gaps in service. Their family provided them with much of the care they needed in hospital. However, their families support serves to cover up gaps in care. Elderly women who are ill can not be expected to advocate on their own behalf. The structure of the system places elderly women in a no-win situation in which they are chastised if they speak up and blamed if they do not speak up and problems occur. This dynamic places hospitalized elderly women in a precarious position in which their needs are often misunderstood or ignored. Participants were receptive to social connections with other women and may respond well to consciousness raising techniques. At present, older women may view problems with their health care as private matters as opposed to political issues. Social workers could assume a leadership role in this area by developing opportunities for older women to link their personal health care issues with the political.

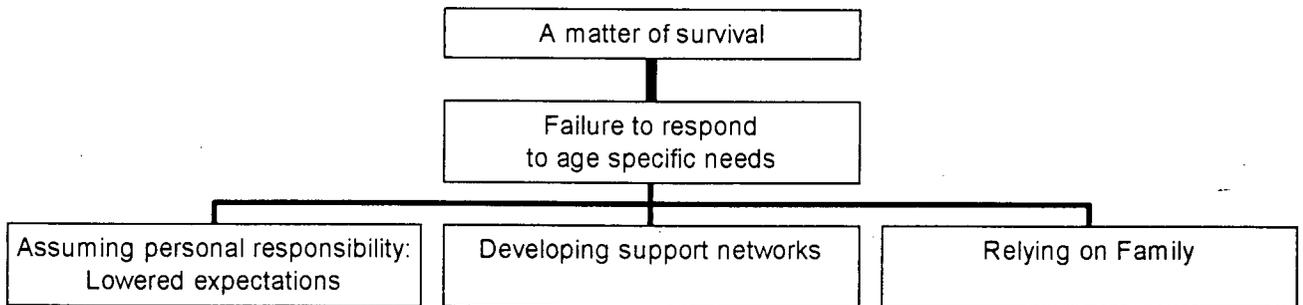
APPENDIXES

APPENDIX A: SAMPLE INTERVIEW QUESTIONS

1. Can you tell me about your experience in hospital?
2. Can you give me an example where you had to make your needs known to hospital staff? What was that like for you?
3. Did anything happen in the hospital that was particularly helpful?
4. Did anything happen in the hospital that was particularly unhelpful?
5. Is there anything you would do differently if you were admitted to hospital now?
6. Is there anything in particular that you think health care professionals need to understand to be of assistance to you?

APPENDIX E

How do elderly women experience being in hospital?



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