

WOMEN, OLD AND AWARE:
LIVING AS A MINORITY IN EXTENDED CARE INSTITUTIONS

by

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Abstract

Women Old And Aware: Living As A Minority In Extended Care Institutions

The purpose of this phenomenological study was to describe the everyday lived experiences of old, cognitively intact women, residing in an integrated extended care facility among an overwhelming majority of confused elderly people. The research question was "From your perspective, what is the impact of living in an environment where the majority of residents, with whom you reside, are cognitively impaired?". A purposive sample of five older women participated in multiple in-depth interviews about their subjective experiences. All five live at different sites of the Juan de Fuca Hospitals Society, a 512 bed, integrated, extended care facility in Greater Victoria, British Columbia. Data analysis of the essential meaning of participants way of being in the hospital world was guided primarily by van Manen's (1990) work on researching lived experience and Colaizzi's (1978) phenomenological analytical approach. A number of significant statements were extracted and clustered into themes reflective of the participants' perspectives. The findings revealed that the systematic procedures, practices and policies of the institutions where they resided, came before the needs they themselves identified as important. The women in this study did not feel heard by the hospital decision makers. The data suggests that integrating cognitively well residents with people who are confused is not in the best interests of alert residents. The issues raised by

participants suggest that without sufficient staff, more staff training and funding, care geared to specific client needs will not be possible. It is recommended that:

- the understanding given dementia by staff also be given to the cognitively well;
- that the company of people able to communicate in challenging and supportive ways could dramatically increase the quality of life for the cognitively well;
- that structures be created to enable cognitively well residents to have a voice in the organisational goals and objectives;
- and that structures be created to ensure those working in the field the time to listen to clients voices.

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It is to my grandmother Margaret Anne Stevens Otterson (1892-1977) and her son Monseigneur Felix Edward Gerard Otterson that I dedicate this thesis: to Grandma for her enduring love and to Fee for his enabling spirit, generosity and loving support.

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CHAPTER ONE

Introduction

The Face of Old Woman

....I have been searching

lost

alone

I have been searching

for so many years.

I have been searching

Old Woman

and I find her

in

myself

(Cameron, 1981, p. 150)

Introduction and Background

As a woman, growing older, and a practising social worker in an extended care hospital, I have become increasingly aware that old, cognitively intact women living in long term care facilities find themselves in a unique situation. At the extended care level they have become a minority of the long term care population. These women are a minority not only in terms of their status as women in a patriarchal society, or as being old in an ageist one, but as cognitively intact individuals living among a majority of

persons who are suffering from dementing illness.

It is the silences of the women whom I met through my work as well as the silences of my own grandmother, who spent her final months in an extended care facility, that motivated this study. As I grow older I have come to recognise society's fear and ignorance of old age and death that stigmatises persons as they age, and "that the old woman carries the burden of that stigma, and with remarkable, unrecognised, unrecorded courage" (Macdonald & Rich, 1991, p. 12).

The women whose knowledge, perspectives and insights I have sought all reside at Juan de Fuca Hospital, a 512 bed extended care facility with four different locations in greater Victoria. They are women whose minds are alert, as measured by the Folstein Mini Mental State Examination (Folstein, Folstein & McHugh, 1975), but who are coping with functional impairment because of physical frailty and/or disability. Their ages range from 75 to 96 years and they represent a minority of the resident population in this extended care facility. An estimated 72% of the people with whom they live in this extended care facility have a dementing illness (Sewell, 1995; p. 2). The prevalence of dementia in this kind of setting is not unusual. Bland, Newman & Orn (1988) found that cognitive impairment among the elderly in Edmonton was 69% in institutions and only 3.5% in the community. Of those living in institutions, 39% were severely impaired and

no cases of severe cognitive impairment were found in the community. A 1993 study by the National Advisory Committee on Aging (NACA) estimated that the rate of dementia among Canadian Seniors was 5.6% in 1981 (132,000 persons) and 6.0% in 1991 (190,000 persons). The study projected an increase of 71% over 15 years so that by the year 2006 there could be as many as 324,000 seniors with dementia in Canada. The 1994 Canadian Study on Health and Aging concluded that "if the prevalence estimated remain constant, the number of Canadians with dementia will rise to 592,000 by 2021" (Canadian Study of Health and Aging Working Group, p. 899). This study estimated that in 1994, there were just over a quarter of a million elderly people with dementia in Canada, half of whom were living in the community and the other half in institutions and about two times as many women as men. Eighteen percent of the estimated number of cases in the population were 65 to 74 years of age. Forty four percent were between 75 to 84 years of age and 39% were 85 and over. The ratio of women to men was 2.1 overall but 2.9 among the oldest group and two-thirds of that oldest group were living in institutions (p. 905). These demographic studies point to the likelihood that the lives, not only of persons with dementia and their caregivers are impacted but also those of cognitively well, older women who are residing in integrated extended care facilities. As the number of persons with dementia increases the number of persons who are cognitively well

become a marked minority of the resident population.

It is also known that health care organisations are complex systems, designed to serve many functions besides focussing attention on residents. Although those working in the field may not feel the need to be convinced of the importance of what residents think, feel and experience, Gerteis, Edgman-Levitan, Daley & Delbanco (1993) point out that the "intrinsic importance of patient's subjective experience" has not figured prominently in the development of health care services or institutions to date. They suggest the answer lies in part, "with the fundamental tension between the objective analytical tendencies of medicine as science and the subjective and personal nature of medicine as practice" (p. 4). Further studies (Checkland & Siberfield, 1993; Jang, 1992; Knox & Upchurch, 1992) substantiate the contention that health care practitioners' perceptions differ significantly from those of residents. A major concern of this thesis is the inattention paid to older women's perspectives, which as Jane Aronson (1991) argues:

renders them passive participants in care arrangements--as if they were objects rather than the subjects of the circumstances of their aging. Looking at elderly women in particular, the absence of choice in determining the conditions of their aging can be understood as one element of the culture that favours youth, independence, and masculinity (p. 143).

Statement of the Problem

Changing demographics indicate an increasing proportion of chronically mentally impaired older people living in extended care facilities. Appropriately a lot of research has been directed towards understanding dementing illnesses and towards developing better ways to meet the needs of residents with dementia. Less is known about the minority of older cognitively alert residents who require the services of extended care facilities because of functional physical frailty and impairment.

The majority of residents in extended care institutions are older women. According to 1992 Statistics Canada 72% of seniors residing in institutions in 1991, were women. There is however little information about the experience of cognitively intact older women living in integrated facilities where the majority of residents are cognitively impaired. We do not know what their lived experience might be. Their voices have not been heard.

Purpose

The purpose of this study is:

- 1) to give voice to older women who are cognitively intact and who represent a minority population residing in an extended care facility; and
- 2) to increase the awareness of gerontological practitioners and administrators about issues identified as substantive by the women participating in this study.

Lens

The lens through which I view the material in this study is that of a Canadian, middle-class, Caucasian woman who is a feminist, a social worker and one who is growing older though not as old as the women whose wisdom and perspectives I sought. Over time I have come to know that women's experience is different from men's; that male experience is considered normative and as a consequence women's experience has been undervalued. I have come to appreciate how difficult it is for women to voice their thoughts or to articulate the reality of their lived experience. As Carol Gilligan (1993) stated in her research into women's development: "we have listened for centuries to the voices of men...so we have come more recently to notice not only the silence of women but the difficulty of hearing what they say when they speak" (p. 173).

When I think of my grandmother, a woman who developed dementia in her eighties and who died in 1977, I appreciate how difficult it was for her to speak the unadorned truth of her life. Had she thought to write of her life I suspect that she may well have written as she spoke "in the old genre of female autobiography, which tends to find beauty even in pain and to transform rage into spiritual acceptance" (Heilbrun, 1988, p. 12). I know as a mother, a wife, a student, researcher and geriatric social worker, that writing or speaking women's lives is a difficult process.

In approaching the material from a feminist perspective, which appreciates the richness and diversity of older women's lives, I will also endeavour to avoid an ageist approach by recognising the pain that has divided and silenced older women. Elderly women have not often been heard as persons with unique issues. Their silence on the subject of aging has allowed many of us to indulge in the "illusion of the richness of difference without having to confront the reality of difference" (Macdonald & Rich, 1991, p. 9). Indeed it is from our differences that personal power emerges. Audre Lorde (1984) identifies as different or marginal in society, poor women, women of colour, lesbians and older women. She contends that:

those of us who have been forged in the crucibles of difference...know that survival is not an academic skill. It is learning how to take our differences and make them strengths. For the master's tools will never dismantle the master's house....The failure of academic feminists to recognise difference as a crucial strength is a failure to reach beyond the first patriarchal lesson. In our world, divide and conquer must become define and empower (p. 112).

By not recognising differences of age with the simple assertion that "we are all women together" not only robs women of the opportunity "to hear out the pain that has divided us" (Macdonald & Rich, 1991, p. 9) but denies

the wholeness, insight, strength and humanity of women. In recognising the value and the significance of the lived experience of the older women who participated in this study, it is my hope that our interview sessions, conversational in tone, will have helped to “translate their ideas from the darkness of private experience into a shared public language” (Belenky, Clinchy, Goldberg & Tarule, 1986, p. 203).

Throughout the research process I have adopted the notion that “in the contest between experience and theory, experience carries the greater weight” (Nickerson, 1995, p. 30). All of the women involved in this study had to struggle to find their own words to make meaning of their lived experiences. I in turn have struggled to find the words to express what these older women voiced both through their silences and the words they used. To further express the differing experiences of women, I am including a review of the art and literary work of old and aging women. A profound reminder to listen for and to hear the wisdom of old women is expressed by the protagonist in Copper Woman:

...wisdom must always be passed on to women, and reminded her that whatever the colour of the skin, all people come from the same blood and the blood is sacred. She said a time would come when the wisdom would nearly disappear, but it would never perish, and whenever it was needed, a way would be found to present it to the

women, and they could then decide if they wanted to learn it or not (Anne Cameron, 1981, p. 53).

Research Question

The research question guiding this phenomenological study and directed to the elderly women in the research sample was: "From your perspective, what is the impact of living in an environment where the majority of residents, with whom you reside, are cognitively impaired?". This study is based on the assumption that the women who have participated are the knowers and authorities on the experience of living in an integrated extended care facility.

Working Definitions

A phenomenological philosophy seeks to understand each person's view of reality. Therefore, rather than a construction of participants' ways of seeing, the working definitions presented are based on my understanding from study and reading.

Ageism - is a term that was first coined by Robert Butler (1975) to describe the negative views held by society regarding the aged as a homogeneous group of marginally capable, inflexible and helpless people. He saw ageism as a process of:

systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin

colour and gender. Old people are categorised as senile, rigid in thought and manner, old fashioned in morality and skills...Ageism allows the younger generation to see old people as different from themselves, thus they subtly cease to identify with their elders as human beings (cited in Itzin, 1986, p. 124).

Dementia - is a clinical term used to describe a disease process which causes progressive changes to the brain. Persons can lose the ability to recognise familiar visual, auditory and tactile stimuli; to recall the correct words or phrases to identify familiar objects; to make their bodies move the way their minds direct them to; and/or the ability to express themselves through speech or writing. Dementing illnesses eventually affect all body systems, mental and physical, and result in death (Jones & Wright, 1991). Most dementias are either of the Alzheimer type or vascular dementia.

Extended Care - is the term used by the British Columbia Ministry of Health and Ministry Responsible for Seniors Continuing Care Division to describe the level of care required by persons with chronic physical and/or mental disability, requiring 24 hour a day professional nursing services and continuous medical supervision but who do not require all the resources of an acute care hospital. Lesser levels of continuing care services, designated by the Ministry of Health and Ministry Responsible for Seniors Continuing Care Division, include Personal Care and Intermediate Care Levels I, II and

III. As stated in the Ministry Service Provider Handbook, most persons at the Extended Care Level have a limited potential for rehabilitation and generally require institutional care on a permanent basis (BCMOH, 1991).

Frailty - for the purposes of this study, frailty refers to persons over the age of 65 with one or more functional, social or cognitive impairments which necessitate a dependence upon others for the activities of daily living.

Integration - refers to the intermingling of demented and cognitively intact, frail elderly persons within the same long term care facility. Integrated residents share the same physical space, which may include their bedroom in addition to the common areas of bathrooms, dining rooms and the bus when on hospital sponsored trips.

Old - is a term used in our culture to define persons who have reached the age of 65 or over. It is not necessarily a social descriptor of the subjective experience of persons 65 or over. In this study I will be using the terms old, older, aged, senior, and elderly interchangeably.

Old Woman - is a term defined in the feminist dictionary Amazons, Blue Stockings and Crones as:

Wise women, sometimes old in chronological age, always old in spiritual knowledge. Scorned by patriarchs...she is often seen as the symbol of the Goddess, and consequently as a threat to male dominance. (Ann Forfreedom 1983, correspondence)

Many cultures make provisions for the sharing of wisdom and perspective by elders. [Among] The Lakota Indians...it is usually an old woman who admonishes the decision makers to take into account the effects of their actions for seven generations into the future (Michael Avery et al. 1981,49,cited in Kramarae & Treichler, 1985; p. 313).

Patriarchy - is a term which "refers to the social organisation of a culture into systems that are hierarchical and male dominated in terms of power and value" (Cooley, 1990, cited in Otterson, 1991, p. 8). Sexism, classism, racism and ageism are all a consequence of hierarchical structuring.

Resident - is the term used to describe persons living in the extended care facility under study as opposed to the term patient. It is a term that was introduced to help health care professionals recognise that long term care institutions are not acute care hospitals and that people living in them are "not sick in the usual sense of that word" (Mantel, 1992, p. 143).

Sexism - "the belief in the inherent superiority of one sex over the other and thereby the right to dominance" (Lorde in Crowley and Himmelweit, 1992, p.48).

Silence - is to be voiceless, it is "the condition of one who has been dominated, made an object; talk is the mark of freeing, of making one subject" (hooks, 1988, p. 129).

Wisdom - is defined in The Random College House Dictionary (1975) as "the quality or state of being wise; knowledge of what is true or right coupled with good judgment (p. 1511)". In psychology the term wisdom has often been used interchangeably with the concept of crystalline intelligence; the ability to see a problem globally and to find broad solutions. Unlike fluid intelligence or the capacity to learn new things which decreases with advancing age, crystalline intelligence/wisdom is thought to increase as people grow older.

The practical wisdom sought in this phenomenological study of older women has to do with the nature of their lived experience itself. Being experienced is regarded as "a wisdom of the practice of living which results from having lived deeply" (van Manen, 1990, p. 32).

Significance for Social Work

One of the most important functions of social work practice is the empowerment of oppressed persons to participate in the decisions that affect their lives. Empowerment is a term that has been defined as "a process to assist people in stigmatised groups to experience personal influence and perform valued social roles" (Solomon, 1976; cited in Wells, & Taylor, 1991, p. 250). In hearing and consciously attending to older women's perspectives social workers and other health care practitioners will better be able to support residents in the planning of programs and in advocating

intervention strategies. I believe that such support and advocacy must be congruent with older, cognitively intact resident's identified needs, wants and functional abilities. Social workers can help to ensure that older women's voiced opinions and concerns are heard by those in policy development and that as long term residents they are included in the decision making process as principle participants. Professional social work practice is based upon values and beliefs, addressed by the Canadian Association of Social Workers Code of Ethics 1983. Understood is the notion that:

- The individual has the capacity to change and grow in whatever life-stage or health condition.
- Maintenance of supportive family ties and social network is basic to individual well-being.
- Individuals are entitled to have their cultural, ethnic, spiritual differences respected.
- The individual has the right to participate in decisions which affect him/her, such as to choose alternative courses of action.
- Social workers should contribute to creating program and policy options.

These values and beliefs are especially applicable to the social worker in long term care in the following ways:

--Older/disabled people are entitled to services equal in quality to those of other populations. Rights do not diminish with age or incapacity.

--The client and the family have the right to ventilate emotions and express feelings and opinions, positive or negative.

--The individual's and family's unique rate of acceptance of major life changes (e.g. sensory loss, relocation, terminal illness) must be respected.

--The social worker accepts responsibility for an advocacy role.

--The social worker is committed to the enhancement and protection of privacy and confidentiality.

--An interdisciplinary focus to health care is essential (B.C. Association of Social Workers).

Feminist writers have contended that knowing and becoming aware of "women-experienced, women-defined reality" has the potential to change our conceptions of reality and humanity (Collins, 1986, p. 215). Effective advocacy in long term care, is dependent upon an informed understanding of respondent's lived experiences--the challenges individual residents face and their desires for change. Finally it is important for Social Workers to be aware of the impact of ageism, sexism, heterosexism, racism and classism upon older women within our society.

Assumptions

This study is based on the assumption that the women, old and aware, residing in this extended care institution are the knowers and authorities of the experience of living in an integrated facility. No one knows more about being a woman of 75 or 96, residing in a long term care facility than the women themselves.

Limitations

Participants for this study are limited to individuals who are older, Caucasian Canadian women. At the time of this study there were no First Nations, Asian, Black, Hispanic, Jewish or Indian women residing in this Victorian extended care facility, who met the research criteria. The question of sexual orientation was not posed. As a result, the triple impact of ageism, sexism and racism on older women is not addressed.

In addition this study was limited to the individual experiences of five older women. Although we can learn and benefit from their experience, the findings can not be generalised.

Organisation of the Thesis Content

An exhaustive literature review, of empirical research studies, failed to unearth the voices and lived experience of older, frail, cognitively intact women living in long term care facilities. Studies related to older persons have either treated elderly people as one homogeneous group or excluded

women altogether. This does not mean however, that women have not recorded their experiences. I will endeavour therefore, to present some of the artistic expressions of older women's experience found in their poetry, literature and art in conjunction with relevant professional journals and texts.

The first chapter was introduced with the poem The Face Of Old Women, followed by the background to the problem; problem statement; purpose of this study, the lens through which the study was viewed; research question; definition of terms; and the significance for Social Work practice; as well as the assumptions and limitations of this thesis. In Chapter Two a review of literature related to women and aging, institutionalisation and integration is presented. Chapter Three describes the research methodology and Chapter Four presents the findings. Chapter Five presents a discussion of the findings and their relationship to relevant literature. Finally, conclusions, implications for Social Work, and recommendations are presented in Chapter Six.

CHAPTER TWO

Review of Related Literature

Introduction

A review of the literature is presented in this chapter to provide the context and rationale for the research question. Through a review of a number of scientific, sociological, gerontological, social work, and nursing publications I discovered a paucity of information specifically about women's experience of aging and particularly their experience of living in institutional settings. Therefore I am including the literary writings of women who have expressed in fictional and non fictional texts, novels and poetry, women's cultural experience of the aging process. The chapter is organised into three sections: women's experience of aging, institutionalisation, and integration. It concludes with a summary of the related literature.

Women and Aging

Women's experience of aging has not been documented in the literature to the same extent as that of men. Differentiation between the sexes is rare in studies of persons beyond the age of sixty-five. As Dulude (1988) suggests, somehow women lose their gender in old age. "After a lifetime of having a multitude of mythical qualities and failings attributed to them because of their sex, they are suddenly told that after a certain age these differences between the sexes no longer exist" (p. 205). Old women

and old men alike, become senior citizens and are referred to in general terms as the "aged" or the "elderly". Health care research and statistical reports seldom differentiate between the sexes and in so doing mask remarkable differences between men and women and obscure just how much aging is a women's issue (Gilligan, 1993; Sommers in Dulude, 1988). Through a review of the literature I will endeavour to portray a different reality of women's lives in old age within patriarchal structures, not only in terms of demographics but through a variety of descriptions of the aging experience.

Demographics speak to the differences between men and women. It is common knowledge that there is an inordinate proportion of old women; that older women more often than older men live alone; that throughout the world old women are among the poorest of the poor; and that more old women than old men live in private or institutional facilities rather than in their own homes (Dulude, 1988; Faulkner, 1980; Macdonald & Rich, 1991; National Advisory Council on Aging - NACA, 1993). In 1991 there were two women for every man in Canada, in the 85+ age group. Twenty-eight percent of women aged 65 to 69 were widows. Of those over age 90, 82% were widowed. The marriage rate in 1990 was 60 per 1000 for males aged 60+ and only 17 per 1000 for females in the same age group. Among Canadian seniors 74% of men compared to 40% of women were married

(NACA, 1993, p. 1). The discrepancy in marital status between the sexes increases with age. Statistics confirm that a majority of old women live alone while most old men live with their wives. For example in 1991:

73% of men...and 43% of women aged 65+ lived in a private household with their spouse.

14% of men...and 34% of women aged 65+ lived alone

40% of women aged 75+ lived alone (ie., 318,715 women)...

72% of seniors residing in institutions in 1991 were women...

(NACA, 1993, p. 12).

These numbers suggest that the older a woman is, the greater are her chances of living alone. The words voiced by an 80 year old women who participated in this study that "I am still mad at my husband for dying", attests to the reality of life alone, in poor health, that many women of extreme age face. She had been left alone by her husband which had resulted in her eventual admission to an extended care facility.

For many older women greater longevity results in more years of loneliness, ill health and poverty. Citing numbers from Statistics Canada Delude (1988) points to the fact that despite a life expectancy at birth of 7.5 years longer than that of men, women's disability-free life expectancy is only 3.6 years longer. "The truth about old people's health is that it deteriorates with age" (p. 209). In 1991, 72% of seniors living in long term care facilities

in 1991 were women. Delude draws attention to 1982 Statistics Canada figures which verify that with advancing age people that live alone, the majority of whom are women, experience a dramatic increase in poverty. In the same year, 63.5 percent of women over the age of 70 were poor. Delude attributes the cause of the tremendous discrepancy in living standards between older men compared to older women to Canada's pension system--a system designed by men for men: a system based on the traditional belief that there are two categories of people: "full-time participants in the labour market (husbands and fathers), and the people they support (women and children). If you provide adequate pensions to the first group, it was felt, the second group would automatically be taken care of" (p. 212). Although more recent 1993 figures (NACA) indicate that the percentage of unattached women over the age of 65 living below the poverty line dropped from 60 percent to 38 percent between 1980 and 1990, the National Advisory Council on Aging (1993) has stated that "many seniors still hover on the margins of poverty and would join the ranks of the official poor if the LIC [Low-Income Cutoff] were shifted slightly upwards" (p. 4). The same study indicated that in 1986, one third of seniors' incomes came from the Old Age Security and Guaranteed Income Supplement program; and that "in 1990, 39% of women and 33% of men aged 65+ received some GIS, while among women aged 90+, 70% received some GIS" (1993, p. 4). Government

pension programs remain the the primary source of income for women in their old age.

In her research on women's voices and adult development, Carol Gilligan (1993) concluded that "the failure to see the different reality of women's lives stems in part from the assumption that there is a single mode of social experience and interpretation" (p. 173). Historically we have been informed by and have accepted as universal, male definitions of human development. Gilligan argues the need for a new approach to the study of adulthood that reflects of the reality of women's lived experience; by evoking women's voices and depicting in women's own terms the lived experience of their adult lives. She, among other feminist writers (Belenky, Clinchy, Goldberg, & Tarule, 1986; Heilbrun, 1988; hooks, 1988; Lorde, 1984; Morton, 1985; Rich, 1979), refers to the metonym "silence" in her description of women's struggle to convey their experience in a patriarchal society. Silence is regarded as the condition of the disinherited, the oppressed, the exploited, the dominated. Silence is often the plight of old women, who from birth have had to deal with "historically and culturally ingrained definitions of femininity and womanhood - one common theme being that women, like children should be seen and not heard" (Belenky et al., p.5).

Adrienne Rich (1979) implores us to listen to women's voices when she says "listen to the silences, the unasked questions, the blanks. Listen to

the small soft voices, often courageously trying to speak up, voices of women taught early that tones of confidence, challenge, anger or assertiveness, are strident and unfeminine" (p. 243). She maintains that the true knowledge of women will only be found by listening to or watching for the silences, the unspoken and the absences in all the descriptions of our world; be they in conversation, literature, art or the social sciences. "And in breaking those silences, naming ourselves, uncovering the hidden, making ourselves present, we begin to define a reality which resonates to us, which affirms our being" (p. 245).

Nelle Morton (1985) created a magnificent telling of breaking women's silences through the act of "hearing one another to speech", in her book The Journey is Home. Morton, a woman who has long been considered a foremother of Christian feminists, died recently in her late eighties. She has described the astounding experience of Helen Keller who without ever hearing, reached out of the darkness of her life for the woman who heard her to speech--"grateful for the profound gift of herself" (p. 203). According to Morton, women who have been heard to speech know it as a profoundly spiritual and empowering experience. It is a "hearing that is far more than acute listening. A hearing engaged in by the whole body that evokes speech - a new speech - a new creation." (p. 128). To be able to hear the outsider, or the disinherited (in this case old women), break their

silence and name their own oppression and suffering in their own way is an honouring experience. The hearers in turn are empowered in that "we can put ourselves in a position to be heard by the disinherited" (p. 128).

The concept of hearing each other to speech is in keeping with what Gilligan (1993) describes as "the ongoing historical process of changing the voice of the world by bringing women's voices into the open, thus starting a new conversation" (p. xxvii). Finding a voice is essential to the liberation of oppressed persons. Speaking frees women which allows them to come to power and to become subjects rather than objects. "When we end our silence, when we speak in a liberated voice, our words connect us with anyone, anywhere who lives in silence" (hooks, 1988, p. 18), and yet women fear ending their silence. Audre Lorde addresses this fear of speech in her poem Litany for Survival:

and when we speak we are afraid
our words will not be heard
nor welcomed
but when we are silent
we are still afraid

So it is better to speak
remembering
we were never meant to survive (cited in hooks, p.17).

Feminist writers (Gilligan, 1993; Heilbrun, 1988; hooks, 1988; Lorde, 1984; Nickerson, 1995; Rich, 1979) have noted however, that in breaking long established silences women find themselves faced with the secrets they have kept and the lies they have helped to perpetuate through falsehood and silence. In their social-historical struggle for survival women have been forced to tell lies depending on what the patriarchal society of the time wanted to hear. For example, throughout their lives women have been expected to lie with their bodies: "to bleach, redden, unkink or curl our hair, pluck eyebrows...wear padding in various places or lace ourselves, take little steps...wear cloths that emphasised our helplessness" (Rich; 179, p. 188) and in later years they are admonished to deny the aging process.

Denying their old age is common practice among women who have spent a lifetime in an ageist and sexist society. Because of the stigma of old age and their training in ageism, older women often utilise ageist strategies in their struggle to maintain a sense of self, as persons with ongoing lives "with the new, degrading ways in which they find themselves seen (or rendered unseen)" (Rich; 1992, p. 56). One such tactic is the act of "passing" as other than our true age to the outside world. A 95 year old woman participating in this study remarked with pride that "no one can believe my age". Another respondent, also in her nineties delighted in telling about a consultation she had had with her doctor regarding aches in her arms and

legs and was told "you are acting like a 70 year old women" and so they "parted friends". While a third woman spoke with astonishment about a relationship with a young woman who seemed to treat her as a 60 year old: "there I was a 90 year old and she was, oh, I don't know, somewhere in her 20's I suppose, and we used to chatter away, it always amazed me". Rich (1992) contends that the act of passing poses a serious threat to one's personhood because women who find relief in knowing that they are regarded by the outside world as younger than their true age, run the risk of denying themselves. Passing has the potential to divide old women not only from the personal adventure of their own growth but from other women. Regarding other women as stereotypical old (to be feared) and themselves as exceptional (capable, attractive, energetic, intelligent, articulate) can be a dangerous defence, "a single slip can trigger off 'old' " (1992, p. 57).

Contributing to the often devastating and dangerous effects of women denying the aging process, is the common media practise of age role stereotyping and sex role stereotyping. From as early as their twenties women are admonished by advertisers to conceal their advancing age with body altering products, clothing and treatments. We are conditioned to believe that unlike men who become more distinguished with age, women lose their attractiveness as well as their ability to make a valued contribution to society. By their mid-forties most women have fulfilled their sexual and

domestic functions of reproduction and child-rearing. Beresford-Howe's (1994) Eve speaks to the essence of this loss of attraction when she remarks:

attraction...really...ended for me in my fifties, when, to my consternation, a few stiff grey hairs appeared on my chin, and men looked at, but no longer saw, me. Never did get quite used to that--being neutered is pretty dreary (p.85).

Men on the other hand are considered to be in the prime of their lives during their forties and fifties. Meanwhile women begin the second half of their lives "with little status and almost no value. This valuelessness is not inherent, but created; not biologically determined, but socially constructed - with the assistance of the media" (Itzin; 1986, p. 130). As Itzin suggests, it is little wonder that younger women recoil at the sight of older women. "In that revulsion is their fear of what is going to happen to them" (p. 130). The stereotypical ageist and sexist portrayals of women as well as the under representation of older women in the media has served to create a distorted perception of women's reality.

In her literary study of biographies of women's lives Heilbrun (1988) reveals further that however unintentionally, women themselves have throughout history been less than truthful in their portrayal of the female experience. She refers to the dismay that May Sarton, novelist, poet and

memorist felt in reviewing her 1968 account of buying a new home and living alone. Years later when reading her own words in Plant Dreaming Deep, Sarton realised "that none of the anger, passionate struggle, or despair of her life was revealed in the book....[and that] in ignoring her rage and pain, she had unintentionally been less than honest " (cited in Heilbrun; 1988, p. 12). Having been taught the oppressors' language, learning not to listen to the culture is a difficult undertaking. bell hooks (1988) has described language as culture and draws an analogy between women learning to live the oppressors culture with First Nations People "learning the white man's ways" (p. 29). Neither is free to tell the truth of their lives. May Sarton has come to be revered for her honest portrayal of the richness as well as the pain of women's lives. In her eightieth year she honours the "direct speech" of a former student and poet Deborah Pease by including the following poem by Pease in her book Encore: A Journal of the Eightieth Year:

Once, my face protected me: a mask
 Of youth and health and even prettiness.
 The mask protected me.
 It lead me down pathways
 And across valleys
 And into the arms
 Of villains, magically

Eradicating dangers

(one would have thought otherwise).

Now the mask is dented and cracked.

It bears a patina of fatigue

And a moral quality

(In the sterner contours)

It lacked before. It's a mask

No longer: it's me.

Human and open to attack

(Pease; cited in Sarton, 1993, p. 209).

For women to write truthfully about their lives has not always been allowed by the culture. More so, the literary telling about women's lives in old age is seldom heard. According to Heilbrun (1988), it was the women poets of the early 1920's and 30's that transformed the autobiographies of women's lives. These women who were among the first to have expressed themselves, "suffered for expressing, what women had not earlier been allowed to say....They found a way to recognise and express their anger; harder still, they managed to bear, for a time at least, the anger in men that their work aroused"(p. 60). As Heilbrun has noted, women have experienced great difficulty historically in expressing or even discerning anger within themselves and as a consequence have been unable to express and/or

experience power and control. Aware of this reality, Audre Lorde (1992) implores women to "identify and develop new definitions of power and new patterns of relating across difference" (p. 54). She draws attention to the ways that women have been encultured to deal with the human differences among women of class, sexuality, ethnicity, and age. Rather than relating across our differences as equals we tend to react as we have been conditioned - with fear and loathing. As an example, Barbara Macdonald (1991) has described a lifetime of being marginalized; at first because she had been identified as a lesbian and later because she had become an old woman:

Again I was outside, again I was "other". Again I lived with the never-knowing when people would turn away from me, not because they had identified me as a lesbian, since I was no longer thought of as a sexual being, but because they had identified me as old (Macdonald & Rich, p. 5).

In defining older woman from young womens' privileged position of youth, older women become "other"--outsiders whose experience is too remote to comprehend. As Lorde suggests, "there is a pretence of experience covered by the word *sisterhood* that does not in fact exist" (p, 48). Macdonald and Rich (1991) concur that to accept the premise that "we are all women together" without recognising the richness and diversity of older women's

experience is ageist and has the potential to divide and silence aged women. That older women experience problems of sexism and ageism differently within patriarchal structures has been acknowledged, and as Crowley and Himmelweit (1992) have stated, no one group will be homogeneous in their experience of oppression.

Aging and Institutionalisation

Bowsher et al. (1993) argue that existing research involving older persons in institutional settings promotes a false assumption of homogeneity--not only that women are like men but that all persons aged 60 to 90 are alike. They suggest that the systematic exclusion or under-representation of women from research protocols in the study of frail elderly people is cause for "ethical concern" because it limits the ability to generalise the findings of such studies to the whole population and potentially prevents one gender group "from receiving the research attention necessary to enhance standards of their care and the quality of their life" (p. 877). Of significance is their finding that frail elderly women are under-represented throughout all research, despite their overwhelmingly higher proportion in institutional settings. When I searched the literature for aging and institutionalisation I found a paucity of studies focusing on the subjective experience of old women which suggests a need for research in this area.

That women themselves are cognizant of their stereotypical imaging

in old age has been captured in the literary work of a number of female writers (Beresford-Howe, 1973; Martz, 1987, 1992, 1994; Miller, 1995; Rule, 1987; Sarton, 1993; The Hen Co-Op, 1993; Weaver, 1987) including Margaret Laurence (1964), whose poignant and uncompromising portrayal of Hagar Shipley in the Stone Angel exemplifies one woman's experience of old age within this patriarchal society:

Now I am rampant with memory. I don't often indulge in this, or not so very often, anyway. Some people will tell you that the old live in the past - that's nonsense. Each day, so worthless really, has a rarity for me lately. I could put it in a vase and admire it, like the first dandelions, and we would forget their weediness and marvel that they were there at all. But one dissembles usually, for the sake of such people as Marvin, who is somehow comforted by the picture of old ladies feeding like docile rabbits on the lettuce leaves of other times, other manners.... To carp like this...it's my only enjoyment, that and the cigarettes... Marvin thinks it disgraceful of me to smoke, at my age, ninety....Now I light one of my cigarettes and stump around my room, remembering furiously, for no other reason except that I am caught up in it. I must be careful not to speak aloud, though, for if I do Marvin will look at Doris and Doris will look meaningfully back at Marvin, and one of them will say, "Mother's having one of her days."

Let them talk. What do I care what people say? I cared too long (p.6).

Hagar's words are in keeping with a cultural/societal view of aging in general, as a time of decline, introspection and the relinquishing of roles rather than a time of growth. This perspective however is challenged by several theorists (Bowsher et al, 1993; Depoy & Archer, 1992; Erikson, Erickson & Kivnick, 1989; Kettell, 1995), who propose that the aging process is one of growth, and that diversity increases with age among older people owing to the effects of varied life events, environments and resources.

Itzin (1986) has suggested that the stereotypical portrayal of old people purposefully choosing to be disengaged from society is in fact "a rationalisation of an ageist society's separation of itself from old people-- their compulsory exclusion from employment, and isolation into residential homes and hospitals" (p. 124). It is important to note however that according to 1991 Statistics Canada figures, the total percentage of persons 65 years and older residing in institutions was as low as 6.4%. But of those 6.4% of the population 72% were women of which 85% were 75 years and older. These figures suggest that Itzin's statement regarding the ghettoizing of old people into long term care facilities may more correctly reflect society's ageist and sexist beliefs with respect to older women.

In Constance Beresford's (1973) novel The Book Of Eve, Eve (a sixty-five year old woman who having made a spontaneous and unplanned

escape from her marriage and husband of forty years awakes one morning alone and in seriously ill health), speaks to society's ageist and sexist attitudes regarding old women and the concern of many regarding the institutional experience when she ponders:

After all, maybe this was the best way. Who needed or cared about me now? What use was I, fat old parasite, member of the third sex now, an irrelevant and uncalled for detail of the human race. And a swift exit had at least some dignity, unlike those horrible lingerings to be seen in nursing homes, where death is the friend who too seldom drops in. No, much better to accept it now, and go (p. 26).

Although there is a dearth in the literature about the residential experience of older women per se, the added concern expressed by Eve that institutional life is undesirable is documented in research studies. Almost twenty years ago Chappell and Penning (1979) reported that individuals living in institutions experience a negative effect in their general well-being because these environments have a tendency to restrict the personal autonomy and independence of the resident population. Several subsequent studies (Callopy, 1988; Clark, 1988; DePoy & Archer, 1992; Jang, 1992; Wells & Taylor, 1991) have come to the same conclusion; not only that institutions restrict autonomy but that they continue to actively encourage dependence.

As a consequence there has been a demand for the reconceptualization of long term care which would address quality of life issues, in spite of chronic conditions and functional limitations associated with old age (Aller & Van Ess Coeling, 1995; Bayer, Bruesloff & Curley, 1986; Clark, 1988; Cox, Kaeser, Montgomery & Marion, 1991; Knox & Upchurch, 1992; Small, 1993). DePoy and Archer (1992) argue, for example, that residential facilities continue to reflect traditional and outdated concepts of aging. They do so by adhering primarily to the efficient (but perhaps not effective) management of the elderly resident's physical care and to medical diagnosis and intervention, rather than the advancement of more holistic models which focus on the positive aspects of aging. As noted, the institutionalisation of the frail elderly can as a result, become a "primary force in extending quantity of life while systematically reducing the quality of life" (Knox & Upchurch, 1992, p. 8).

Depoy & Archer also argue that few studies have used research methodology capable of developing an understanding of the experience of living in a long term care facility from the residents own perspectives. Utilising a qualitative, naturalistic field study design based on ethnographic and grounded theory principles, they studied the meaning of the quality of life to nursing home residents in a small New England community. Their results indicate, as did this phenomenological study, that the facility appears

to be organised as a workplace rather than a home. Providers are required to interact functionally with residents in order to do a job which reduces their capacity to interact in a more personal caring way which the term "home" suggests.

Williams (1994) in turn, has argued that the lives of those in long term care are for living not merely for physical safe-keeping. He found that a degree of normalcy is absent from long term care facilities in general, and that what many residents face is a "life designed, determined and controlled by others--the professional 'experts'" (p.111). In his review of an alternative nursing home model in Sweden and two in the U.S.A. he, as have others (Burbank, 1992; Depoy & Archer, 1992; Wells & Taylor, 1991), identified the need for choice, control, continuity and some sense of community or connectedness in institutional settings.

The importance of community throughout people's lives regardless of individual limitations, has also been captured and described in Starhawk's Dreaming the Dark :

Somewhere, there are people to whom we can speak with passion without having the words catch in our throats. Somewhere a circle of hands will open to receive us, eyes will light up as we enter, voices will celebrate with us whenever we come into our own power.

Community means strength that joins our strength to do the work that

needs to be done. Arms to hold us when we falter. A circle of healing.
A circle of friends. Someplace where we are free (cited in Nickerson,
1995, p. 87).

Theorists have begun to reconceptualise definitions of community and quality of life in long term care facilities. Autonomy for example has traditionally been perceived as the ability to act independently. Collopy (1988) proposes that a more accurate description of autonomy in the aged population is one's capacity to make their intentions known and to utilise the resources in the environment to carry out those intentions. Thus autonomy is regarded as an "interdependent" rather than an "independent" trait (DePoy & Archer, 1992, p. 65). Several studies (Collopy, 1988; Jones & Wright, 1991; Parke, Barnes & Mayhew, 1996) challenge practitioners to create or change programs and environments in long term care facilities by offering purposeful choices and supportive challenges to residents. This could enhance the autonomy experienced by residents, especially women.

A recent focus group study by Parke, Barnes and Mayhew (1996) acknowledges that despite a change in the resident population of frail elderly people living in long term care facilities in British Columbia during the last ten years, from a "relatively stable, to a more complex, population of chronically ill people" (p. 11) quality of life issues continue to be of primary importance to care residents and their families. Rather than specify concerns

related to direct nursing care, the resident focus group involved in this study identified a number of more holistic issues which they viewed as detracting from "normal living in an extended care facility". Of greatest importance to residents was the residential environment, community connections, communication, relationships, independence, autonomy and control (p. 13).

Mantle (1992) has also made a clear differentiation between the appropriateness of maintaining strict biomedical environments in acute care hospitals and endeavouring to provide the same kind of care in long term care facilities which become "home" to older residents. She is a proponent of long term care practice models which support residents in maintaining a degree of normalcy in their lives despite chronic health problems or illness. Mantle makes reference to the ideas of Vera McIvor, a Canadian nurse known for the development of the "Priory Method". It was McIvor's (1978) "intent to liberate older people in her institution from a life in which there had been an exclusive emphasis on custodial, physical care". One strategy was the introduction of the term resident rather than patient, because those living in long term care facilities are "not sick in the usual sense of that word" (cited in Mantle, 1992, p. 143). Mantle maintains that health care needs, although important, represent but one facet of residents' daily lives and for this reason suggests that "nurses perspective on their work [and that of other care givers] must include an emphasis on the psychosocial components of living

in addition to biomedical understandings" (p.143).

Buzzell and Gibbon (1991) argue that "human care" rather than medical care is what is required to address residents' identified issues and concerns. They found that the chronic conditions of the frail elderly patient rather than "personhood", often defines the whole person in long term care. Personhood is acknowledged to be:

at the very root of individual vulnerability. It reflects our values, spirituality, history and strengths, welded together through years of living. Personhood is what makes each of us a unique human being. When our personhood is honoured we feel comfortable; when it is not taken into account by others, we feel depersonalised (p. 32).

By defining individual residents according to their illnesses, the resulting tendency is for health care practitioners to employ the medical model, which although appropriate in acute care, has proven problematic in long term care settings; primarily because chronic conditions cannot be cured. As Buzzell and Gibbon have argued, more important than pathological data are the goals of individual residents. They acknowledge that although it may be appropriate for patients to briefly relinquish their life roles of parent, worker and/or spouse while in acute care, to expect the same in long term care robs individuals of their past and their self esteem and hinders the attempts of health care practitioners to promote wellness.

The notion "that one might fall victim to well-intentioned care providers who could impose their judgments upon a service recipient" is worrisome to many as Checkland and Siberfeld's (1993) study suggests. They argue that greater clarity is needed regarding "the conditions under which beneficently-intended care might be given against (or in lieu of) the preferences of the recipient" (p. 455). Knowing exactly what residents want from their facility however, is not a simple task as Knox and Upchurch (1992) discovered. Utilising a forced-choice values instrument they found that "administrators who believe they understand and communicate effectively with their residents may indeed not perceive the residents correctly as frequently as 70% of the time" (p. 10). Knox et al. suggest that the consequence of such a significant misinterpretation of the values residents consider most important, may well result in the inappropriate distribution of human, physical and fiscal resources. Jang (1992) conducted a similar study in which she endeavoured to discover both residents' and caregivers' perceptions of resident autonomy as determined by institutionalised elderly persons' perceived degree of choice over their individual activities of daily living. She concluded that the staff's perceptions were significantly different from those of residents. It was her suggestion that health practitioners "obtain from residents their own perceptions of importance and choice" so that staff will be "better able to avoid implementing inappropriate...

interventions" (p. 259). In this way they could take into account that elderly residents are not a homogeneous group.

Carboni's (1990) powerful and disturbing investigation of homelessness as a relevant experience in the lives of institutionalised elderly residents gives further credence to their premise and that of others (Chen & Snyder, 1996; Gubrium, 1975; Small, 1993), that institutional environments diminish residents' quality of life. She defines homelessness as:

the experience of the negation of home, where the relationship between the individual and the environment loses its intimacy and becomes severely damaged...homelessness emerges from the many complex and varying interactions between the individual and the environment and evokes such meanings as non-personhood, disconnectedness, no journey, no boundaries, powerlessness/dependence, insecurity/uncertainty, and meaningless space.... [And proposes that the] individual can describe the depth and profundity of these interactions in the statement "I have no home" (p. 33).

Institutions tend to convey a sense of routine and rigid control that undermines the personal autonomy and control of older residents and diminishes their quality of life.

Savishinsky (1991) too found that loss of resident control and a preponderance of institutional routine over individual need is the norm in long term care facilities. He suggests that it is ironic that staff have more responsibilities than they can handle, and residents have so little to do that a sense of uselessness tends to emerge. He makes reference to the book Limbo: A Memoir About Life In A Nursing Home By A Survivor written by American anthropologist Carobeth Laird who at the age of 79 spent several months recuperating in a geriatric facility. Savishinsky maintains that most long term care residents would view this women's experience as common: "loss of control over her daily life, a ubiquitous preoccupation with eating and excretion, financial insecurity, the fragile nature of her sanity and sense of time, and her social isolation" (p. 5). Laird (1979) attributes her "dehumanising" experience to the prevailing focus of caregivers on the trivialities of daily routine and bodily functions. In her residential experience no nurse or attendant ever made the slightest effort to lower their voices. Shift changes were noisy, coffee breaks marked by unmodulated chatter. Perhaps they felt that some of the patients were so noisy and most of them so deaf that it made no difference. More probably this lack of consideration was just a symptom of the conviction--unvoiced and unrecognised--that the old and the mentally incompetent are not entirely human (p.55).

The pervasive assumption guiding the treatment of long term care residents, noted in Timothy Diamond's (1983) ethnographic account of the everyday life of nursing homes, is that mental illness becomes part of all residents' diagnosis. Diamond suggests that the high prevalence of elderly residents with Alzheimer's disease and senile dementia has resulted in the perpetuation of an ideology that regards residents as trouble rather than in trouble. He suggests that this ideology is perpetuated through the documentary reality of institutional systems, including the charting process. Because "charts define residents in terms of their medical and psychiatric troubles [only]....one learns almost nothing about a person's life--the 60 or 70 years that she or he lived prior to admission" (p. 279). Illness therefore, becomes the organising principle of the nursing home culture and medical tasks take predominance over caring work. In concluding that "task-centerdness can hide and prevent the emotional work of caring for human beings"(p. 270), Diamond echoes the documented concerns expressed by several contributors to the literature reviewed in this study.

Institutionalisation and Integration

As the demographics would suggest, not only do women represent the majority of older people living in long term care institutions but a vast and increasing proportion of them have dementing illnesses. A resulting concern raised by Laird (1979) and Diamond (1986, 1983) is that regardless of one's

mental competency, the institutionalised elderly person may well risk being viewed and treated as mentally incapable. Susy May, an aged and cognitively well woman participating in this study, alluded to this concern when she said that she may not have been taken seriously as a mentally stable woman. She remarked:

I think that if the staff would listen to the residents who know what they are talking about...just listen to them...instead of brushing...off [requests, comments or concerns] as a child's nonsense...as long as those of us that are with it, still have our thoughts, our feelings and our aspirations.

Twenty years ago Baum (1977) published a book in which he describes Canadian institutions for the aged as warehouses for death. He theorises that there is not necessarily a correlation between health care dollars spent on institutionalising the elderly and their good health, and that although the institutionalised aged "may survive in body, this does not mean that they survive in mind and spirit" (intro.). Since that time there has been considerable literature addressing institutionalisation and the quality of life experienced by older residents in long term care facilities.

The emphasis, however has generally been on the quality of existence for persons in institutional settings suffering from dementia. As evidenced by the literature, this disease features prominently in

contemporary long term care programming and the development of environmental concepts and designs (Carlson, Fleming, Smith & Evans, 1995; Coulson, 1993; Dupuis, Dobbelsteyn & Ericson, 1996; Jones & Wright, 1991; Kovach & Stearns, 1994; Kramer, 1996; Rantz & McShane, 1995; Stevens, 1987; Sudbury & Mayhew, 1994; Tooth, 1996). And there is generally concurrence that good dementia care calls for homelike care models, the clustering of dementing residents with similar needs into smaller groups, and continuity of care. The growing bodies of knowledge argue that the quality of life for elderly residents diagnosed with progressive dementia can be dramatically improved in dementia specific units which provide homelike environments with regards to scale, security, way-finding, privacy, furnishings, lighting, intimacy and socialisation. Evidence exists within the experience of western institutions that the design and size of specialised dementia care units in conjunction with augmented staff to resident ratios and staff education, results in happier residents and significantly improved quality of residential and work life (Alzheimer's Association, Australia, 1994; Sudbury & Mayhew, 1994).

The Australian Alzheimer's Association (1994) has stated that "if the resident is happier, difficult behaviours diminish. If difficult behaviours diminish, the carer is happier "(p. 5). Kramer (1996) also spoke to the Australian experience of small group dementia care and the development of

enabling institutional environments. Having accepted that dementia is an illness and that there is currently no curative treatment, Kramer argues that the individual resident is the key to effective practice. She proposes a philosophy of care which values the individual regardless of how old, frail, or confused they may be and recognises the resident's right to be esteemed, valued and accepted. This practice model focusses on communication and the individual's successes, memories, experiences and participation in ordinary daily tasks. As such, staff are encouraged to become supporters rather than doers, and to organise their care in order to provide quality of life for the cognitively impaired resident.

Only to a limited degree has the more contemporary, professional literature addressed quality of life issues with regard to cognitively intact elderly persons living in institutions with the demented aged. One example is the work of Teresi, Holmes & Monaco (1993). Having recognised how heavily dementia now features in all long term care programs including the utilisation of special care units for cognitively impaired residents, Teresi et al. utilised measures of depression/demoralisation and life dissatisfaction to analyse the impact of exposure to demented residents on non-cognitively impaired residents in long term care facilities. Based on rater observations, a nursing informant scale and direct resident assessment, they conclude that the practice of integration may be compromising persons who are not

impaired by putting them "at risk in terms of poor quality of life as measured by dissatisfaction with life and the environment and possible 'excess' demoralisation" (p. 358). Factors which they determine to be suggestive of poor quality of life include expressed dissatisfaction with the environment in general, roommates, room noise; and units in which non-cognitively impaired individuals live with or adjacent to demented residents.

Teresi, Holmes & Monaco's study is in part a response to earlier research findings regarding the integration of cognitively and non-cognitively impaired individuals which appear not only inconclusive but conflictive. Bowker (1982), for example, found that the integration of lucid residents with confused residents can have detrimental affects for alert individuals who experience a sense of dehumanisation. Bergman, (1983) on the other hand, argues that when given the opportunity to compensate for demented residents' lack of ability, all residents on integrated units benefit. The confused residents benefit by the mere presence of those able to function at a higher level, and those residents who are less confused benefit by helping the more severely impaired. Gurland, Wilder and Toner (1987) in turn, suggest that the practice of segregation represents a "reaction to the wishes of staff and family who find disruptive behaviour disconcerting" (cited in Teresi et al., 1993 p. 350). Having reviewed some of the literature, it is apparent that earlier research on the segregation/integration issue has

yielded conflicting results.

It would appear that letters to professional journals are also conflictive. For example, in response to an appeal from Wolfson (1983), in the Journal of the American Geriatrics Society for information from the readership regarding the practice of integration, Gang & Ackerman (1983) speculate, on the basis of their work experience at a 200 bed multilevel institution in Yonkers, New York, that integration positively benefits all residents. Their response suggests that the problems associated with the mixing or pairing of rational and demented patients has been effectively dealt with by the admission of the severely demented to special dementia care units. They propose as a consequence that residents who are not demented are spared contact with the most severely demented individuals and the feeling of being "abandoned to the netherworld of the the insane" (Wolfson, 1983, cited in Gang & Ackerman, 1983, p. 628).

Albowitz (1983) in response, in the same professional journal, reiterated the need for conclusive research data on the issue of mixing resident populations on the basis of mental status. Her clinical observation is that most intellectually competent residents have little tolerance for the confused, demented residents with whom they are "forced into close living proximity". Rather than assisting demented residents, cognitively well individuals are "often observed to berate, ridicule, and even physically

assault the confused residents who intrude in their physical space" (p. 627).

Although the conclusions of the literature appear conflictive regarding the controversial integration/segregation issue Brauner (1989) concludes, as has Teresi et al. (1993), that the presence and augmented numbers of disoriented individuals in long term care facilities has contributed considerable dissatisfaction to alert residents. Of significance is that Brauner's study incorporated the perceptions of lucid residents which the other research did not. Of interest as well is that the Montreal "Home" Brauner investigated already has a segregation policy in place, where residents are allocated to different floors in the five-level building based on their mental status. Given changing demographics and the increasing numbers of mentally disoriented admissions, questions have arisen as to the impact this is having on the decreasing proportion of alert residents.

Utilising a descriptive survey, Brauner determined that the vast majority of respondents definitely feel that the presence of confused persons has negatively altered their quality of life. Fifty percent of those who claim to have been directly affected expressed concern that the confused residents lack the ability to integrate into the activities of the home and that the "Home" is becoming a chronic care hospital rather than a home. Nonetheless 38.9% prefer no changes in programming, while 33.3% want additional programs to enhance the quality of life in the Home. Of interest is that the proposals to

integrate activities and to set up a "buddy" system between mentally alert and disoriented residents, were rejected by 78% of the respondents. And although the majority feel they are coping well in terms of the aging process, the study shows that becoming senile is the greatest fear identified by residents. Carobeth Laird (1979) who was assigned a bed nearest the door in a four bed ward, made a statement to the same effect. She wrote: "at the end of the room next to the darkened window I would have felt immured in an autistic world, where the bright spark of intellect I had fought so hard to maintain might finally have flickered out" (p. 55).

Brauner proposes that the high percentage of lucid respondents who suggest that the Home can do little to improve their residential experience is likely less indicative of residents' satisfaction than their fear of complaining. She proposes that residents realise that management likely has no choice but to admit increasing numbers of confused aged; and that residents do have the opportunity in this facility to retreat to the privacy of their own rooms and thereby avoid intermingling with the confused. What seems to have surprised Brauner, is the continuous theme of alert residents' expression of dissatisfaction despite the Home's policy of segregating disoriented and lucid residents to different floors. Her results appear to lend support to the segregation side of the integration/segregation debate.

Having identified Brauner's study as the only client-centered

investigation of non-demented residents' perceptions in her analysis of integration in the professional literature, Paul (1994) designed a quantitative questionnaire to both extend and test Brauner's findings. In keeping with client-centered practice theory, Paul maintains that residents should have input into the "case mix policy" of the institutions where they live. Client-centered practice theory requires health and social services to reflect the expressed needs and wants of the consumer. He therefore chose to investigate how cognitively intact residents experience living with people with dementia, and how integrated they want continuing or long term care facilities to be.

Of the five Vancouver sites Paul investigated, two provide extended care and are fully integrated with most residents in four bed wards. This is reflective of the residential environment for participants in this study. At the two intermediate care facilities he studied all residents have private rooms. At the first site residents are assigned to different floors based on their cognitive level; at the other, residents are semi-integrated, while 20 of the most severely impaired live in a special dementia care unit. The fifth site provides care to both intermediate and extended care residents, is fully integrated, and all rooms are private.

Despite the varying degrees of integration and segregation, and the respondents' access to privacy, the majority of participants reported having

some contact with "the demented". Most experienced only minimal lifestyle impacts. Of significance however are Paul's minority findings:

one in three non-demented residents experienced cohabitation with the demented negatively. Their activities of daily living were regularly disrupted, they substantially modified or curtailed lifestyle in an attempt to minimise interaction, and they did not feel safe. Living with the demented was associated with feelings of unhappiness, unease, and shame and made them pessimistic (p. 6).

Not only did this segment of Paul's research population dislike integration, they recommend some degree of separation. It is interesting to note that the majority who felt they had experienced only minimal life style impacts also recommended a certain measure of segregation.

The need for further consumer-centered research on residents personal assessment of their experience of integration as "opposed to others' analysis of them" was identified by Paul. Both he and Brauner make note of older respondents reluctance to complain about, or report any negative feelings associated with people who are confused. They speculate that the charitable principles, strongly held values, sympathy for, and tolerance of this population group may bias participants toward socially acceptable responses. This perceived bias to the affective/attitudinal questions particularly, was identified by Paul as a possible limitation of his

study. It also lends support for his call for research to “facilitate and document non-demented residents’ explications of their...coping strategies for living with the demented, so that their efforts to successfully cohabitate can be facilitated and the limits of their ability to do so are recognised” (p. 6).

Summary

This review of the literature affirms that the subjective experience of cognitively intact older women residing as a minority population among persons experiencing dementia within extended care level facilities, has not been documented sufficiently in research studies to date. By and large, research studies related to elderly people have tended to treat the oldest segment of the population as one homogeneous group. And often women have been excluded from research altogether. Because of this exclusion of women from research studies, a review of literary writings of women, in conjunction with professional publications with reference to women’s experience of aging, institutionalisation and integration has been presented in this chapter. It is acknowledged that older women experience problems of sexism and ageism differently and risk being viewed as a marginal group. Noted as well is the tendency of long term care institutions to model their health care practices after acute care hospitals. This qualitative study then, will seek a deeper and more intrinsic understanding of older women’s intuitive and empirical knowledge of their personal, everyday, lived

experience of residing in an integrated extended care facility.

CHAPTER THREE

Methodology

Introduction

A hermeneutic (interpretive) phenomenological (descriptive) research method was used in this study. An understanding of the everyday-lives of cognitively intact, older women, living in an extended care facility was sought. Because it is a subjective, reflexive and interpretive method, hermeneutic phenomenological research can be regarded as more consistent with feminist principles than conventional research methodologies. A phenomenological approach is one of discovery. It is a method which allows the researcher "to begin from the world as women actually experience it" and to attend to "women's intuitive and empirical knowledge of their own individual experience" (Levesque-Lopman, 1988, p. xiii). This study sought an understanding of the concrete lived experience of older women through a discovery of the meaning of their experience and how they experience it. The interpretive process of capturing these phenomena in language is what characterises it as a hermeneutic methodology (van Manen, 1990, p. 180). This chapter describes the research design, selection and recruitment criteria, data collection, data analysis and ethical considerations.

Research Design

Because it is in tune with feminist principles, a phenomenological qualitative research design was chosen not only as the method but as a philosophical approach to this study. A phenomenological model of understanding is based on shared meaning. The researcher seeks to explicate the lived experiences, expressions and ways individual participants have of seeing, knowing and understanding their world. Phenomenological researchers look for the fullness and depth of respondents' experience regarding specific phenomenon. Rather than seek out causal explanations phenomenologists endeavour to describe the participants lived experience directly as is, and to "transform the lived experience into a textual expression of its essence" (van Manen, 1990, p.10).

It has in fact, been argued that there is no method for hermeneutic phenomenology (Gadamer, 1975; Rorty, 1979; cited in van Manen, 1990, p. 30), but rather a set of investigative procedures :

- 1) turning to a phenomenon which seriously interests us and commits us to the world;
- 2) investigating experience as we live it rather than as we conceptualise it;
- 3) reflecting on the essential themes which characterise the

phenomenon;

4) describing the phenomenon through the art of writing and rewriting;

5) maintaining a strong oriented pedagogical relation to the phenomenon;

6) balancing the research context by considering parts and whole (1990, p. 31).

Because of the paucity in the literature about the subjective, human and social experience of the minority of older, cognitively intact women living in extended care facilities, this study sought data from the everyday lives of such women. My goal has been to discover, understand, and accurately interpret individual participants' perspectives of their everyday lived experiences. It is acknowledged and honoured in this study that the "dailiness of women's lives structures a different way of knowing and a different way of thinking" and that as women "we have to believe in the value of our own experiences and in the value of our ways of knowing" (Aptheker cited in Reinhartz, 1992, p. 216).

Selection

A purposive sample of five older women was selected for this study. Purposeful sampling for maximum variation helps to ensure that as much information as possible, in all of its various ramifications and constructions,

is obtained from the research participants. The purpose of maximum variation, as Lincon and Guba (1985) suggest:

is best achieved by selecting each unit of the sample only after the previous unit has been tapped and analysed. Each successive unit can be chosen to extend information already obtained, to obtain other information that contrasts with it, or to fill in gaps in the information obtained so far (p. 201).

In this qualitative study it was important that I select persons who could most effectively help me to discover, understand and gain insight into their everyday lived experience. Data collection was conducted over a period of 12 months which helped me to purposively develop the research sample. Each of the participants was knowledgeable and had the ability to provide me with descriptions of their experience of living in an integrated extended care facility. This study was open to individuals who met the following criteria:

- 1) Older woman.
- 2) Cognitively intact, as measured by a Folstein Mini-Mental Status Examination score of 24 or greater.
- 3) Residing at any of the following sites of the Juan de Fuca Hospitals Society, Victoria, British Columbia: Aberdeen, Glengarry, and/or Mt. Tolmie

4) English fluency.

Initially an age specification of 75 years or older was set to ensure that the descriptions obtained would be from an elderly population. However as I became more thoroughly involved in the research process I recognised that setting a specific age could limit my findings. The purpose of this study is to develop awareness about issues identified as substantive by older cognitively intact women living as a minority population, among a majority of cognitively impaired residents. Generally the issue for this population group, in terms of admission to extended care facilities, is physical frailty and disability. These women often run into trouble in their sixties with conditions such as acute arthritis, and in time require 24 hour care. On the other hand, the reason for admission for the majority of the extended care resident population with whom these women live, is mental disability. A primary discriminator for this study therefore, is mental status as measured by the Folstein Mini Mental State Examination (MMSE) score. Nonetheless each of the women who participated are elderly according to the cultural definition of old age. At the time of this study their chronological ages were 75, 81, 91, 93 and 96 years.

Scores on the Folstein MMSE were used as the criteria for selection of potential participants who are cognitively intact. This examination is administered upon admission and is reviewed annually for all residents of

the Juan de Fuca Hospitals Society. It is called mini because it concentrates only on the cognitive aspects of mental functions. With a cut off of 23 out of 30 the Folstein MMSE can be used as a screen for dementia. Residents who scored below 24 were excluded from participation, because a score below 24 indicates probable significant, cognitive impairment and dementia (Sewell, 1995). Three of the women selected for participation scored 29/30; one scored 27/28 and another 28/30. Because of complications related to arthritis, multiple sclerosis and poor eyesight two of the women involved were unable to complete the written segment of the Folstein MMSE. This segment of the examination requires two responses, each valued at one point. As indicated by the 27/28 score, one therapist scored residents unable to engage in the physical act of writing out of 28 rather than 30. A second respondent who was unable to complete the written section scored 28/30. The therapist who administered the MMSE in this case, made note that the two questions the respondent missed were because of her physical limitations. Nonetheless as indicated, all of the scores were high. The scores for selected participants were well above the cut off point of 24 indicating that those selected are cognitively, very capable, competent women. The importance of using mental status tests to determine cognitive ability has been noted in the gerontological literature. Williams, Ward and Campbell (1988) refer to a number of studies indicating that health practitioners "miss

cognitive disorders in a high percentage of patients when relying on their own clinical observations" (p. 25). Suggested reasons for missing the cognitive disorders include the preservation of residents' social attributes and level of education. Because fluency in English is a necessary requirement for successful completion of the Folstein MMSE, the criteria that participants have the ability to understand and converse in English was also met, as indicated by the examination scores.

Finally, all of the participants reside at different hospital sites or units/floors of the Juan de Fuca Hospitals Society. This long term, extended care institution has four separate locations: Aberdeen, Glengarry, Mount Tolmie and the Priory hospital site, with a total of 512 beds in greater Victoria. The majority of rooms are four bed wards. An internal wait list is maintained for the lesser number of semi-private and private rooms. A 1993 resident profile survey indicated that 82% of the residents in this hospital society were women (Clinical Nurse Specialist Program). A later survey estimated that 72% of the resident population had dementia (Sewell, 1995). By and large this is a fully integrated hospital system with the exception of one 19 bed dementia care unit. This unit was opened in April, 1994 as a study project to develop, implement and evaluate care programs for residents with dementia. The vast majority of the resident population, regardless of cognitive status, share the same physical space which may

include bedrooms, common areas, bathrooms and dining rooms. It has been my experience, as a practising social worker within this hospital system that, as much as possible, staff try to facilitate the placement of residents in bedrooms and at dining room tables with persons with similar and/or complementary cognitive levels, sleep patterns, social skills and personalities. Nonetheless at the time of this study no formal segregation and/or streaming policy or practice guidelines were in place.

Recruitment

Having been granted approval for this study by the University of British Columbia, Behavioural Sciences Screening Committee for Research Involving Human Subjects (Appendix A) as well as the Juan de Fuca Hospital Society Research and Ethics Committees (Appendix B), a letter was mailed to each of the social workers, physiotherapists, occupational therapists, recreation therapists, and directors of nursing, practising in this hospital society. The letter outlined the purpose and objectives of this study; the research question; a description of the research population; and the criteria for participation; and asked for their help in identifying and approaching residents who met the selection criteria. To ensure informed and voluntary consent:

- 1) No residents living at the Priory site where I was the practising social worker were contacted.

- 2) A second letter outlining this study was attached for presentation to interested, qualified residents (Appendix C).
- 3) I did not not approach any respondent without an invitation from the individual resident herself.

Each of the potential participants identified was approached by a staff member she knew to determine her interest in this study. Of the 17 older women who agreed to be contacted, one asked that her name be withdrawn. This request was made prior to my initial contact with any of the potential participants. One resident called me directly to set up an appointment time to further clarify the study and to answer her questions. The balance of interested respondents gave permission to individual social workers, therapists or nurses, to contact me on their behalf. To ensure confidentiality staff were given no information as to which residents were purposefully chosen to participate in this study. I purposely chose women with diverse backgrounds, and residential experiences. One resident whom I had planned to interview became bedridden. Despite three attempted interview sessions she was unable to leave her bed as hoped. Because this woman shares a four bed ward there was no opportunity to talk in private or tape record an interview session. My initial contact with interested residents was made either by telephone or in person. Further explanation of this study was provided in person, either in residents' rooms or the social work office at the

respective hospital site. Each of the five women purposefully chosen agreed to participate in this study. Prior to the first interview each signed and dated a consent form which outlined the voluntary nature of this study and addressed the issues of privacy, confidentiality, anonymity and risk (Appendix D). Copies of the signed consent forms were offered to each participant. Sample size was not predetermined. Rather, data collection continued until the interview data repeated itself and no new themes emerged.

Data Collection

Fundamental to this phenomenological study and to qualitative research in general is the assumption that the “participant’s perspective on the phenomenon of interest should unfold as the participant views it, not as the researcher views it” (Marshall & Rossman, 1995; 80). The respondents’ subjective view (how they feel their residential experience has affected them), is what matters. The behaviours, expressions and perceptions of the women participating are accepted as significant descriptors of the essential nature of their lived experience in an integrated extended care hospital. A phenomenological study asks what a specific experience is like:

It differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it...

[Phenomenology] offers us the possibility of plausible insights that bring us in more direct contact with the world (van Manen, 1990, p. 9).

This study is based on the assumption that people make sense out of their everyday world and in so doing create their own meaning of "lived life"; and that through conversation, inspiration and reflection, the essential nature of respondents' lived experiences will gather hermeneutic significance (p.37).

A significant concern for phenomenological researchers is perhaps knowing too much about the experience under study prior to data collection. Because of my own experiential and theoretical knowledge in the field of gerontological social work, for example, the potential of interpreting the nature of participants' lived experience pre-reflectively; before truly listening to and hearing the essential meanings of respondents' communications, is very real. To more accurately perceive the experiences described by participants, phenomenological researchers (Beck, 1995; Husserl, 1970, cited in van Manen, 1990; Knaack, 1984; Omery, 1983; Schutz, 1964, cited in Holstein & Gubrium, 1994), often adopt the technique of "bracketing" their preconceptions, knowledge and beliefs about the topic under study. Bracketing, according to Schutz, calls for the setting aside of one's taken-for-granted orientation of participants' life world. "All ontological judgments about the nature and essence of things and events are suspended" (cited in Holstein & Gubrium, 1994, p. 263).

In order to capture data on the essence of participants' lived experiences and common sense knowledge and perceptions, I endeavoured to approach each interview with an open mind; without preconceived expectations, categories, or operational definitions. As Schutz (1964) has argued, the safeguarding of participants' "subjective point of view is the only but sufficient guarantee that the world of social reality will not be replaced by a fictional non-existing world constructed by the scientific observer" (cited in Holstein & Gubrium, 1994, p. 262). At the same time however, I also appreciate the notion of the researcher as "instrument" and remain cognizant of the fact that inevitably, the world I enter as a researcher is impacted by me. Therefore I question whether or not bracketing is entirely possible. Dorothy Smith (1987) contends that entering the knowers' world allows the researcher the opportunity to learn about the world from their position in it, from their experienced knowledge, from their embodied knowledge. The difficulty of trying to put aside everything one knows about about the phenomenon that one has chosen for study, is that we may find as van Manen (1990) suggests, that our "presuppositions persistently creep back into our reflections". I accept his proposal, that it is better to "try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character" (p. 47).

To understand the experience of the women who participated from their own point of view, as shaped by the social context, fits with my feminist principles. Aware that many women value equality, an interactive, collaborative approach to the interview situation was sought; in contrast to a more traditional hierarchical interview structure. I chose to use open-ended questions in informal, unstructured, conversations as a means of collecting data reflective of the everyday world of womens' lives. Some feminist researchers have found that self disclosure helps to both initiate true dialogue and allow participants to become co-researchers. Minister (1992) for example, regards self-disclosure as a "feminist ethic of commitment and egalitarianism in contrast to the scientific ethic of detachment and role differentiation between researcher and subject" (p. 27). It was made clear from the beginning that I viewed the interview process as an exchange of information. I actively responded to participants' reactions in the research experience, by answering whatever questions the women had about myself or this research study. As did Minister (1992), I found that receiving feedback from participants enables the "disclosing researcher" continual opportunities to correct the interview process.

Multiple in-depth interviews also accord opportunities to clarify earlier narratives or statements and are a means of securing a level of comfort and trust between the researcher and the participants. Feminist researchers

have argued for models of interviewing that promote intimacy, acceptance and trust. Reinharz (1992) makes reference to the work of feminist sociologist Denise Connors who utilised multiple interviews in her study of Irish-American working class women in their nineties. She found that later interviews not only allowed women the time to clarify their statements but their deepening relationship resulted in richer content. "As we became more comfortable with one another, we shared more of ourselves in the process. The desire to please and to give socially acceptable answers changed over time" (1992, p. 36). Multiple interviews were similarly helpful in this study, as was the simple gesture of taking the time to share a cup of tea "in a proper tea cup", as one woman stated, before getting down to the business of the research questions. A china tea pot, china tea cups, and a selection of teas was brought to each interview. I think allowing each woman the time she required to feel comfortable and safe contributed to the maintenance of sensitive, respectful, interactive relationships and the collection of rich, meaningful data.

One woman chose to meet with me in her private room. All of the others resided in four bed wards and agreed to meet with me in the respective social work offices. Because the respondents were older, physically frail women who risk experiencing problems with fatigue, concentration and/or personal care, it was necessary to remain at the

hospital sites. Both the participant's room and the social work offices are natural settings in this hospital environment. The social work offices are located on the same floor as respondents rooms. Appointments were made at the convenience of individual participants. By choice all of the interviews took place on weekends or evenings. This proved to be a quieter time and allowed for greater privacy. It also meant that that the social work offices were free. I was able to arrange a comfortable, welcoming space prior to each interview and to assure respondents that time was not a factor.

Sessions began with informal conversation and the pouring of tea. In time the women were invited to respond to the following statement:

"What I want to do is get a better understanding of what it is like for you to live at Juan de Fuca with people who have difficulty with their memory".

It was made clear that the focus of this study was primarily on *women's* experience as cognitively well persons. Participants' responses guided successive questions. On occasion for example, respondents were asked to describe or elaborate upon their descriptions of a typical day: what things give quality to daily life; what things create a quality living environment; what things detract quality from their environment; and what their views were on living with confused individuals (Appendix E). No constraints were put on the number of responses. The length of interviews ranged from 45 minutes to 90

minutes.

Each of the five initial interviews was tape recorded and transcribed verbatim. To verify the data all respondents participated in a second interview. Follow-up sessions were taped and transcribed for three of the five respondents. Because of a technical problem with the tape recorder the fourth respondent's second interview was not captured on tape. Nonetheless comprehensive notes of the issues discussed were made later the same day. Because of the emotional energy required by the fifth respondent to complete the initial interview, a second taped interview was not scheduled. I did however speak with her casually, on two occasions, to verify data and my analysis. Sporadic, informal conversations continued with participants throughout the data collection and analysis process.

Data Analysis

In qualitative studies data collection and analysis is a simultaneous, recursive and dynamic process. Analysis is not complete however after all the data has been gathered: it simply becomes more intensive (Merriam, 1988). Throughout the data collection and analysis process of this feminist, phenomenological-hermeneutic study I tried to discover and understand the fullness of living experienced by participants; what it means to live in an integrated extended care facility; and how life in such an environment is experienced. Data were accepted as given, in the language of the women,

without any overlying, organising structures.

Phenomenological research approaches do not specify a specific, well-defined method or process of data analysis. van Manen (1990) suggests that the meaning of phenomenological description as a method lies in the reflective interpretation and articulation through writing of the meanings expressed by participants as they emerge from the phenomenon. He argues that it is the responsibility of a phenomenological study to ensure that "recollective thinking...be brought to speech, rather like what happens in the poetising writing of the poet who gives form to an authentic speaking" (p. 133). Some feminist researchers (Siefer & Sexton, 1982, cited in Reinhartz, 1992) reason that transcripts should not be analysed, as a means of preventing the researcher "from speaking for, speaking better than, or transforming" participants' accounts. It is believed that if respondents are given the opportunity to be heard directly, "without...interference, the reader will be able to identify with them. It is this identification that will produce social change, not the oral historian's analysis of women's lives" (p. 137). Given the depth and profundity of data collected in this study I was initially hesitant about conducting a formal analysis and considered allowing the womens' voices to stand on their own. However in the process of reflecting and deliberating on participants' words, I came to appreciate the importance of researchers using "our authority to help bring other voices into print and to

use our voices to comment on what we have learned" (Hampsten, 1989, cited in Reinhartz, 1992).

The ongoing and more intensive final analysis of the essential meaning of participants' way of being in the world was guided primarily by van Manen's (1990) work on researching lived experience and Colaizzi's (1978) phenomenological analytical approach. The following procedural steps were employed:

- 1) Six of the audiotapes were transcribed verbatim by a transcriber and two by me (including the five initial interviews and three follow-up sessions).
- 2) To ensure the completeness and accuracy of transcripts, each audiotape was listened to and corrections were made.
- 3) Each transcript was reflectively read, and each tape reflectively listened to, a number of times in order to acquire as much interpretive insight as possible.
- 4) Significant statements/thematic descriptions that directly pertained to the phenomenon under study were highlighted and numbered on each transcript.
- 5) Meanings/themes were identified as they emerged from the data. Thematic descriptions/significant statements were organised around the formulated themes.

- 6) The above process was repeated for each participant. Individual respondent's thematic descriptions were compared and contrasted with previous and subsequent participant's descriptions.
- 7) The formulated meanings/themes common to all respondents' (identified as essential themes), were then referred back to the participants' original statements in order to validate them.
- 8) For final validation I returned to the participants with the exhaustive descriptions. Any new data was then incorporated into the research findings. Colaizzi (1979) suggests that as a result of this step "The already known becomes seen in a new light, allowing hidden meanings of the familiar to emerge" (p. 65).
- 9) The results of this analysis, were integrated into a reflective description of the meaning of participants' experience of living in an integrated extended care facility.

Analysis involved a process of deep thoughtfulness, questioning, clarifying, writing and rewriting. It was not a linear process as these steps might indicate. I found myself returning to the original transcripts on numerous occasions and in so doing, came to appreciate van Manen's (1990) contention that:

the methodology of phenomenology is a more cultivated thoughtfulness than a technique....The methodology of

phenomenology requires a dialectical going back and forth among...various levels of questioning. To be able to do justice to the fullness and ambiguity of the experience of the lifeworld, writing may [as it did in this study] turn into a complex process of rewriting (re-thinking, re-reflecting, reorganising)....To write/theorise is to bring signifying relations to language, into text. (p. 132).

Rather than a supplementary activity, reflective, reflexive writing has been the essence and ongoing work of this study. As van Manen has stated "writing is the very activity of doing phenomenology" (p. 132). The research and analysis process became one of discovery. It has involved the incorporation of individual meanings, experiences, perspectives and truths of participants.

In the final analysis credibility or the truth of the data has to do with the believability of the data obtained. It has been argued that a qualitative study is credible when: 1) "it presents such faithful descriptions or interpretations of a human experience that the people having the experience would immediately recognise it from those descriptions or interpretations as their own" and 2) "when other people (other researchers or readers) can recognise the experience when confronted with it after having only read about it in a study" (Sandelowski, 1986, p. 30). Such credibility is accomplished, as van Manen (1990) suggests, by the "validating circle of

inquiry". He argues that "*a good phenomenological description is collected by lived experience and recollects lived experience--is validated by lived experience and it validates lived experience*" (p. 27). Interpretation, the end result of qualitative analysis, is the knowledge produced. Through the ongoing analysis of the women's descriptions (their words and their silences), I hope to discover something new in the data which will allow me and the reader to see the phenomena in a new way.

Ethical Considerations

This study is concerned with presenting credible knowledge about how respondents view themselves and their experience in an ethical manner. As indicated under Recruitment a sincere effort was made to ensure participation was informed and voluntary. Permission to conduct this study was obtained from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects (Appendix A) and the Juan de Fuca Hospitals Society Research Committee (Appendix B) prior to recruitment. As a registered social worker I was also guided by and remain bound by the Canadian Association of Social Workers Code of Ethics.

Anonymity was maintained throughout this study through the use of pseudonyms (which were chosen by the individual respondents), on transcripts and in the thesis. These names were Florence, Annette, Susy

May, Amanda and Ish. The audio taped data were available only to the researcher, transcriber and thesis committee. All recorded information on the tapes was destroyed upon completion of this study. And, finally, a brief summary of the research findings was made available to participants at their request.

Summary

A phenomenological research design was chosen as the method, and philosophical approach of this study. I believe that the subjective, reflexive and interpretive nature of phenomenology is favourably suited to a feminist study of womens' lives. It is an approach which values "enlargement rather than reduction, generosity rather than economy, complexity rather than simplicity, the lens rather than the hammer" (Psathas, 1973, cited in Oiler, 1981). Phenomenology does not present a specific methodology or set of procedures but rather a philosophy which values experience. A description of the process I engaged in for the selection and recruitment of participants, data collection and analysis has therefore been presented, in this chapter; and ethical considerations addressed.

CHAPTER FOUR

Presentation of the Findings

Introduction

A brief historical description of the women who participated in this study and a compilation of their descriptions of the meaning of their lived experience in an integrated extended care facility are presented in this chapter. Relevant variables from participants' personal stories are introduced as a backdrop to the findings. Also introduced are participants' explications of the factors that necessitated their admission to an extended care hospital including their descriptions of how these moves altered the quality of their lives. The major findings are presented as five inter-related themes; precedence of routine over person, alone among many, penalties of difference, no escape and "it's not a rose garden." These themes emerged from my analysis of participants' words.

Participants' Past Histories

With careful thought and apparent purpose, each woman chose her own pseudonym for this study. One woman decided to use her mother's name. Other participants did not indicate why they chose the names they did. Their personal stories are presented below:

Susy May is 75 years old. She was the only child born to parents in their later years, and spent a rather isolated childhood on their small mixed

farm outside of Victoria. Her very social and friendly nature emerged when Susy May started school. In 1939 she joined the paid work force. It was through her work in the secretarial field that she met her husband. He was with the Armed Forces. During the war years Susy May moved the family from coast to coast. She had given birth to two children and adopted a third. Susy May enjoyed married life. Her husband's death eight years ago was a profound loss. Despite having to cope with a progressive and chronic disease of her central nervous system, Susy May managed to live on her own for a number of months following his death. She nonetheless recognised her increasing need for help in managing her personal care needs and the household work. Susy May made the decision to move into an intermediate, long term care facility. Five years later it became apparent that she required an extended level of care. It was then she chose one of the Juan de Fuca Hospitals Society facilities. When we met, Susy May had been living at one of the sites of this integrated, extended care hospital for two years.

Annette was admitted into the same hospital system almost four years ago. She had suffered a stroke in 1990 which caused paralysis on her left side. Although Annette regained some of her former strength through intense rehabilitation, she was no longer able to live alone. Annette's husband had died twenty years earlier. At that time they were working a

small farm which she kept going on her own for another fifteen years before building her retirement house on Vancouver Island. After her stroke Annette hired someone to help with her personal care and continued to participate in community activities and to travel. Unfortunately her pain was unremitting. Four years later she reluctantly accepted an extended care bed with the Juan de Fuca Hospitals Society. For a fiercely independent woman, it was a difficult decision to make. Annette had a long history in the paid work force having held jobs in construction, labour and the retail industry. As part of the war effort she helped to build planes. When Annette retired at 65, she held a managerial position with one of Canada's largest retail firms. At the time of this study Annette was 81 years old. Annette continues to read and to study, and to a more limited degree has remained involved in community activities.

Like Annette, Amanda was born on the prairies and was the oldest daughter of a large family. She attended high school and then found work in the garment industry. She continues to have a great appreciation for and knowledge of fine fabrics. Amanda had married in her late twenties and was widowed 23 years ago. During her retirement years she became actively involved in the volunteer sector. Eight years ago, at the age of 81 she suffered a stroke and was hospitalised. Unable to return home, Amanda transferred to one of the extended care sites involved in this study. Amanda is totally dependent upon her wheel chair for mobility. Her visual problems

have limited her ability to read and she is hearing impaired. At the time of this study she was 96 years old.

Florence is 91. She has profound visual problems and is confined to a wheel chair because of arthritis. Although born in Ontario, she completed her primary, elementary, high school, college and normal school education in Victoria. She taught school in a number of small B.C. communities.

Unable to secure a permanent teaching position in Victoria, Florence turned to the retail industry where she found work in both the private and public sector. She eventually opened and operated her own clothing store.

Florence married a few times; was widowed and divorced. For the past twenty years she has been on her own. Her only son, who is very dear to her, lives out of town. Over the years Florence has also volunteered her time and skill to a womens' service group. Nine years ago she moved from her apartment to a private retirement residence. Three years ago because of her deteriorating health status Florence had no option but to move into an extended care facility and chose the Juan de Fuca Hospitals Society.

Ish also lives at one of the sites of this integrated extended care hospital society. She is 93 years old and was born on an island off the east coast. Following high school Ish accepted a teaching position in the community school. A few years later she and a girl friend ventured to Ontario, where together they found work as hostesses at a large post-

secondary institution. Ish continued to travel across North America. In her mid-forties she arrived in Victoria and shortly thereafter was offered an office position with the Provincial Government; a position which she accepted and held until her retirement at age 65. Ish who describes herself as an independent soul, never married. In 1990 she moved from her apartment to a retirement residence. Five years later she was faced with the amputation of her leg because of gangrene. At the same time she began losing her vision. These dramatic changes in Ish's physical health status necessitated a move to an extended care facility. Ish has been a resident of the Juan de Fuca Hospitals Society for over two years.

The length of time each woman has spent in this integrated extended care residence, ranged from two years to eight years. One woman came into this hospital system from intermediate care; two had been living in private retirement residences and two came from their private homes. At the time of this study, only one respondent had a private room; one shared a semi-private room and the others were in four-bed wards. The womens' ages at the time of this study were 75, 81, 91, 93 and 96 years. Their stories attest to the fact that this is a group of autonomous women who have made a substantial contribution, in both the public and private spheres. It was only because these women found themselves alone and with profound physical frailty and functional impairment that they began living as a minority

population among a majority of elderly, cognitively impaired residents in extended care.

Participants' Descriptions Of Their Lived Experience

Each of the women who participated in this study, made a statement as to why or how she found herself living in such an environment. Almost from nowhere Ish commented "I don't know if I told you but I had my right leg amputated" and later explained that she was also going blind as a result of a disease process "which is evidently incurable." Speaking of her health status Annette offered, "I don't think I lost too much, but--it's just my left side is all gone. But that will never come back so I'm not going to worry about it. It's improving slowly. And then of course you get that improved and something else goes. I'm afraid everybody uses old age as an excuse. I guess it's a good one though." Florence explained: "what has curtailed me is my health--my hip and arthritis, that is what is beating me, because I can't do what I used to do" Her next statement "I should never have been in this kind of a place," captured the astonishment and surprise felt by all of the participants. None foresaw having to spend the last few years of their lives in an extended care hospital. Unforeseen as well was the widespread confusion of the resident population. Susy May remarked that "I've never been in a place like this--this demented they call it. It's kinda hard, even at my age to accept this....It gets very, very frustrating at times." Presented

below are the participants' descriptions of their lived experience in different sites of an integrated extended care facility. The formulated meanings that arose from those descriptions are categorised as five essential themes. Incorporated into four of the five themes are two defining elements. Where respondents referred to other residents by name, pseudonyms have been used.

I Precedence Of Routine Over Person

Precedence of routine over person is the first theme which emerged from this study. It describes how the demanding nature of the hospital routine, with its' emphasis on physical well being, significantly impacts the quality of the lives of those in extended care. Elements of this theme are presented in two sections: "my bladder is not on a schedule" and "nobody hears me".

My Bladder Is Not On A Schedule. What emerged from my discussions with participants was the pervasive impact of the institutional routine. In their experience the hospital staff and administration assumed direct control of their day to day lives. Respondents were well aware of the organisational issues. They spoke of staffing concerns regarding schedules, union demands, budget restrictions and workload issues. One woman explained "I do not wish to cause more work" but went on, as did all of the other respondents, to express her frustration with the demonstrable notion

that "nobody ever seems to have time for the important things--at least what the residents see as important." Respondents suggested that staffs' organisationally defined roles, responsibilities and routines, seemed to take precedence over the identified needs of themselves and other residents. For example, during morning care staff tended to rush about trying to complete their assignments yet that same morning care seemed to take forever for the resident:

Well all right, I get up say about 7:30 and wait patiently in bed, in a four bed ward. Two people doing that side [helping the two residents on the opposite side of the room,] and then they'll be in the business of doing you. Somebody comes dashing in "I need help with somebody down the hall." Away they go. You're still partly in bed, half undressed, waiting to get the rest of you undressed, and they're off down the hall doing something else. I've never known a minute to last so long. Because "they will be back in a minute." A minute sure stretches in a place like this. It can go on and on while you're still waiting. They do come back. They finish you and you've got a hundred questions. "Oh, I gotta go. Someone else has got to be done." There always seems to somebody ahead of you...that needs their immediate attention....You can only ask one question at a time because they are too busy....You get one answered and by the end of

the day you're maybe half way through...by the end of the week all your questions are answered, if you remember them all.

The rush to get "patients" up and beds made at the expense of taking a few minutes to talk with residents does not always make sense to the women I spoke with. As one participant remarked "I can sleep in an unmade bed".

The notion that beds have to be made on schedule is in keeping with common hospital practice and routine. As Susy May explained:

They work on a time schedule and the time schedule doesn't have any space for anything out of the ordinary to happen--anything extra you might want. Unless you can get what you can in the time frame, you might as well forget it because they'll either be going to a meeting or going for a coffee break, or if somebody needs to go to the toilet or if somebody needs to come off the toilet, and they [the residents] all have to go at a certain time [set by the staff].

She went on to clarify her concern about routine care schedules, citing the hospital practice of set toileting times, as her "main contention":

I can't understand why the hospitals, the government or whoever is in charge, have a right to dictate what time we do this, what time we do that, what time we go to the bathroom. Believe me I can understand that there has to be rules and regulations...but as far as telling us "you're going to have to wait another 10 minutes" when you're just

busting to go. I mean I'm trying to tell my bowels WAIT, but apparently my bowels don't always hear....It's frustrating for everybody....I do everything I can not to give more work but there are times you just can't help it....The thing is, beds have got to be made. People have got to be fed....I'm sure they wouldn't starve in five minutes if the caregiver put somebody on the toilet. They could go feed half a dozen people while I'm on the toilet....But why beds have to be first and people have to be (silence).

Four of five respondents identified rigidly set toileting schedules as an enormous concern which put them at risk of becoming incontinent. The following situation too highlights this point:

Well I have to be toileted right away because I can't wait for hours. They have a schedule for me which they don't follow. So I go out [into the hallway] and find my nurse and she says "wait 20 minutes I am going for my break". I told them that my bladder was not on a schedule. When it is ready, it's ready. And if you do have an accident they think you did it on purpose. Who would do anything like that on purpose? Tell me. I know better.

Annette explained that resident care schedules are set:

By who knows who. Who doesn't know a damn thing about it. She's never on the floor. She's sitting behind the desk in the RN Station and

she doesn't know what's going on except she gets the words from the girls that look after you sort of, and of course they all have their own ideas. Some of them even change the schedule to suit them because they have to have their coffee.

Overall from Florence's perspective, the staff are "good", but she too worried about becoming incontinent. In her opinion "the worse thing they do is make you wait to answer the bell, until they're ready." And although she had a "lovely working crew" Florence did go on to explain, that "sometimes at five or six o'clock, that's when they get busy, well I have had to let it go [my bladder] because I couldn't hold any longer...now I use one of those nightall paddy things."

The difficulties that arose for these women as a result of not having the opportunity to direct their own care, with respect to toileting and other personal care issues, were often compounded by staffing shortages or changes. At the best of times, according to Florence, "the nurses all claim that they are shorthanded. [But] if one person stays away sick that's a killer." She added that "I've had some girls tell me that, oh sure, if they don't feel like going to work they just phone in and say they're not coming to work. You see they've got the union to back them."

Alterations in staffing, including irregular personnel changes and staff shortages, have impacted participants lived experience in this facility, as the

following examples illustrate:

1) Now sometimes they won't bring the seven o'clock nourishment or else they miss me, and I've asked them...why didn't I get my cocoa and they say "well we were shorthanded".

2) They've come into me [and said] "can you be ready by nine o'clock to be put into bed because my coffee break is nine o'clock or ten after nine" and that's more important to them than it is to spend an extra ten minutes or so to put a person to bed. Whether I'm too strict or what, I don't know but I don't like it .

3) Some nights they'll come up and say "there is no bath"...I said you [attendants] don't even go two days. You can wash and bath everyday, but we (silence)....I don't think they ought to get away with it because you can't imagine going without when you've been used to one every day, and in fact some days I have gone home in hot weather and had a noon bath. I didn't live too far from the office.

4) I don't know how, but they need more staff to take the pressure off the ones they have. Otherwise the ones they have are going to break But they have so many part-timers....You just get to know them. They know your needs and you know what they let you do. There are so many people [staff] in here I know I have seen before but that was three weeks ago....There is a new stranger on today. I've never seen

her before in my life, apparently she's one of these call-ins, casuals, part timers or whatever. But then I guess the work is so stressful that they can't do it eight hours a day, everyday of the week.

5) And yesterday I was going into my room, and he [a confused resident] was going to go in front of me. Good thing the nurse was with me. She just grabbed his chair and turned it around and said "go to your own room" I said more of that should be done. "Oh just ring for help." I said look, you ring for help and you sit an hour and wait for it to come through, so what's the use of saying ring for help.

And finally as one woman suggested:

6) The biggest thing to learn in here is patience....They seem to get the work done but they can't jump at every ones' beck and call. You've got to wait. You've got to have patience. Some don't learn it at all. They're the ones that do the calling out and the (silence). Yeah, well they don't realise. They're angry. They [staff] sometimes go by [without stopping to help]. Anybody will do [for the confused residents]. They don't realise that certain residents have certain people to help them and some of the residents will ask anybody for help.

Nobody Hears Me. The experience of not feeling listened to, or heard, was mentioned by all of the women in this study. One participant mused that

the quality of her life and that of her contemporaries would be improved "if the staff would listen to the residents who are with it, who know what they are talking about, would listen to their requests instead of saying 'I'll be back in a minute' and make it an hour before they come back." She appreciated that staff were asked "a lot of silly questions" but suggested that some of those questions were "practical....I know a lot of the residents don't make sense, but for the ones that they know are free thinking--just listen....Maybe the residents can't be dealt with [but] they should be listened to anyhow."

One respondent associated not being listened to with the hospital practice of set routines. Beside each resident's bedside is a written care plan that the staff are instructed to follow. According to this woman however, "most of the time you have to tell everybody what to do. Some of them get mad at you: 'We know what to...we're reading the schedule of the thing.' I said well you don't read very well. I can be so damned sarcastic it's disgusting." This woman went on to explain her need to express herself and to be heard. Her request was simple: "Listen to me, I know what I want and what I need. You don't have to read somebody else's [instructions]."

Amanda in an earlier conversation mentioned that she had "put her voice toward" concerns she had about the bathing program. I asked her whether or not she had gotten a response to the issues she raised. She responded to my question with tears, and indicated that she did not feel she

had been heard:

I don't like being bathed (teary silence). I don't like it when a man has to bathe you. Not too long ago I asked not to have a man, a man nurse, in to help me because ah (tears) but I guess they can't, they can't do that. I don't know. I think they should put more thought into it.

Florence proposed that other female residents may be reluctant to speak their minds, particularly women who did not have "the ability to speak out in private life. Consequently in a place like this they are worse than ever. They don't speak up."

Annette commented on the same phenomenon, using meal times as her example:

Well, the men are sort of--they accept everything they're given to eat. They don't complain. Women do. They might not complain constantly, but they'll say while they're eating it, "it's very good." But after that they get together--then they say how awful it was. There's a couple of women who say that constantly. How did you like the dinner, I say. "I didn't eat. I didn't like it very much." I say...why don't you tell that at the right place, when we go to the [Resident Council] meetings....I say you never complain then. They don't....I have no idea why they do that, but the men--it doesn't matter what men you ask, "Oh yes, it was good."

Despite the suggestion that some women may not be inclined to

speaking up each of the women in this study expressed deep appreciation for the opportunity of being heard, as the following comments to me indicate:

- You know, you are a nice person to have on the job, because you have heard things from an actual resident and I guess you don't get that opportunity very much in your daily work.
- Well, I think it is very important because I haven't taken you as an employee of Juan de Fuca Society. I haven't taken you as that. I have taken you as a person that I could talk my heart out to, and tell you the truth; which is fortunate....you can repeat to superiors above you, of anything I have said, if you wish....
- I don't mind talking to you, if I am of any help. I can't say that I am but if it helps you in your studies, and it helps you to understand somebody else, well then I am very happy to do it.
- Thank you for listening to me and all my breaking down.

Participants' concerns about being heard were reiterated by Susy May.

What she expected of staff was to:

just listen...instead of brushing it [her words] off as a child's talking, as nonsense, as long as those of us that are with it still have our thoughts, our feelings and our aspirations. To have [your words] brushed off day after day, you sort of lose your ability to even think for yourself. If something is going to get brushed off why even bother to

think.

In a follow-up visit the same participant began with her usual question "Are you finished yet," then went on to say: "We need our ideas expressed. We can't do it effectively ourselves."

II All Alone And Nothing To Do

Participants associated not being listened to and the experience of a rigidly organised and controlled hospital environment with a real sense of aloneness and long meaningless days. The second theme "all alone and nothing to do" emanated from respondents' expressed frustration. This sense of aloneness is expressed poetically by Joanne Seltzer (1987) in her poem A Place for Mother: The Orphan

There's no umbrella now
to separate you
from eternity.

Meanwhile an army
marches behind you
in the rain.

Your friends are dead
or dying.

You're a survivor
with all the loneliness
of survivorship
(p.36).

Nothing To Do. Despite an expressed appreciation for the medical care received, simply having their physical needs met was not sufficient for the respondents in this study. They wanted a role beyond that of patient in the facilities which had become their permanent homes but were unable to expand their roles without staff support. Florence explained:

as soon as you go in...you have given up your home. You have sold your furniture. You own nothing but the clothes that you have brought with you....Generally speaking...without any argument you have given up your independence.... You are depending on the hospital. If you are in the extended care you are 100% depending on the staff to look after you and this is going to be your place until you get your call. So it is your home.

Upon her arrival at the private retirement residence, where she lived prior to coming into this extended care facility, Florence had been told "this is your home, treat it like your home.....In other words do what you want....Fix up your room the way you want, just start acting natural, acting yourself." She and the other women I spoke with, however, did not feel that the extended care environment had allowed them to be fully themselves because there was almost no opportunity to become meaningfully and/or purposefully involved in the day to day life of the facilities in which they were living. While respondents appreciated that the hospital was not only their residence but a

work place for others, management of the organisation and hospital routine seemed to take precedence over their personally identified needs. As one woman put it "I've never known so many meetings being held, everyday, in any institution....Don't the residents' needs come into it at all?"

Susy May offered the following example of how the business of operating a hospital created long meaningless days for residents like herself. What she identified as problematic was that, while the staff were

all at these meetings, we're sitting around criticising each other, getting bored of each other. I waste more [time] in...the halls of this place, by going up and down trying to find something to do. Perhaps I'm too with it. A lot of people can sit for hours and do nothing. I want to be effective....I just can't sit and twiddle my thumbs and watch because the more I do that, the more frustrated I get. The more I realise what I am missing in life.

Florence reiterated this concern with the statement "I want to be active. I can't stand this sitting around doing nothing...the main thing for me is to keep occupied". I understood her to mean she wanted the opportunity to be involved in more productive or engaging activities. She had previously explained, "well it is awfully hard here [to keep occupied,] because they do not have a good activity program."

When I asked a second woman what she did to fill her days, she too

spoke of the hospital activity program. She began with:

Ten o'clock in the morning--I am free to go anywhere I can find to go. Nothing to do. Well all right now, I shouldn't say that. They wanted me to play this Toss Across. It has little holes in it and you are supposed to throw a ball into the holes. That's all. That's it for the day. They go around three times and that's it. The rest of the time you--personally I--sit and ride up and down the halls, watching people, getting into a quiet corner and just sitting watching everybody else go by.

During a second session she described a similar activity:

Three tosses of the bean bag where you have to get it in a certain hole. It's not very mentally stimulating. It is just something to do. It is just a gathering of everybody together tossing a bean bag around but there is no mental stimulation to it, no learning process...nothing in the way of my thinking....We play horse racing where we draw balls out of the bag. Whatever number we draw that is how many steps the horse takes forward. Well a child could do it....I feel some of these activities are reducing us to a childhood state because there is no forwarding in it. It is all just stagnant....It is all just keeping us occupied.

This respondent made it clear that profoundly confused residents seldom attended activities but that most of the people in attendance were nonetheless "confused":

The staff... say "throw the bean bag" and they throw it. But what are they playing for? What are they supposed to be aiming at? If it hits fine and if it doesn't, so what? [In her own case, if she played and].... actually got it in the hole. So what? What have I done? I don't feel that I've advanced at all. I'm still the way I was when I went down [the hall].

What most respondents would come down the hall for, according to Susy May, was the weekly out of hospital luncheon that was planned for each site. "But only four go at a time. They mainly pick out of a hat so your chances of going out might only be one in, oh four or five months. Well that is not much." From Amanda's perspective "they are trying to get people to go out to luncheons and things like that, but they have the same people too often." When meeting with Annette, she mentioned that "this afternoon at 2:30 they have bingo so they are trying to get most residents up for bingo...but bingo is not my cup of tea. I'd rather have tea." From her perspective the activity program would be more appealing if they offered such things as a "reading session":

....a few minutes [with] either the newspaper or just a book or something. And if the people don't participate that's fine. You just read a little bit. It gives you a chance to expand...reading and writing, that's two things that you should have in your life.

Although Annette found the regularly scheduled activities of little interest,

preferring to have the opportunity for conversation over a cup of tea, she did miss not having the option to attend:

You know, we have nothing to do here on a Saturday or Sunday....

That's a little annoying. And then the girls [reactivation assistants] have their extra days off, like their flex day, so they are usually off on Friday, Saturday, Sunday and then the other girl takes the Monday. So we never have anyone in the reactivation room....We find it very boring.

The Monday to Friday activity program did not help Ish to pass the time either. As she explained, she seldom attended scheduled activities:

I don't see well enough to recognise features--faces I don't see. I try and write a letter to my family, to my brother, or to my niece....I used to read an awful lot but that's all lost to me now, I am afraid. [At other times] someone comes and talks to me or I get a phone call from home....I have a couple of nephews and nieces and between them they phone me and that helps fill the time....The day seems to go.

The days did go by for the woman in this study but for the most part, ever so slowly. Most respondents had endeavoured to search out opportunities or roles beyond that of patient or care recipient. As one woman said

I try to help where I can but then again we are not supposed to help in

here....[For example] those that can walk aren't supposed to push somebody else around, just in case something goes wrong....There is no incentive to do anything, if you can, for anybody else....But I can actually talk to people, laugh with people. It is possible but then how many in here really could laugh [or] have a good conversation.

What Florence said she most needed, was to "just exercise [her] independence." Determined and independent were the adjectives she used to describe herself; adjectives that could be aptly applied to each of the women participating in this study. Participants' descriptions of day to day life, at the different integrated extended care facility sites suggest, however, that prescribed hospital routines take precedence over resident identified needs. One result of this "care" practice, noted by all respondents, is that while staff keep themselves exceedingly busy they have nothing to do. Days are long, meaningless and boring.

Alone Among Many. It was in her search to find a way to fill her days, that one woman came to more fully appreciate that although alive among many, she was alone.

I ventured downstairs the other day just to see what it was like down there. You know because I just wanted to know, how will I put this, if the people down there are at a different stage in life than we are up here, or whether there was a certain type down there. In other words segregated (...silence...). But everyone down there seems to be the

same wandering around, sad looking, sitting around doing nothing as they are up here.

This respondent's journey to another floor reaffirmed that she, a cognitively intact older woman, was living in a non-segregated institution among a majority of confused elderly people. Her expressed sense of being different than most of the resident population was reiterated by all who participated in this study. The women in this study recognised their minority status.

In an effort to deal with her minority status, Ish endeavoured to give very little thought to the large number of confused people with whom she lived; "except for sympathy". As she stated:

I have sympathy for them, as much as I can, but I can't say I enjoy them 'cause I don't, not actually. They don't talk to me or at least they don't express any views or anything. Sometimes it is a bit difficult.

Sometimes it is really very difficult. I don't mind living with them but at the same time I would much rather if they could express a few views here and there....I get so lonely sometimes.

The term loneliness was often used by participants, at the different extended care hospital sites, to express how very alone they felt. According to the women in this study, few opportunities existed for conversation or companionship among the resident population; the great majority of whom were unable to communicate verbally because of dementia type illnesses.

To illustrate how lonely and alone she has sometimes felt, Susy May spoke of a resident she had known, years before the woman developed Alzheimer disease:

She's a beautiful woman. I'd love to have a conversation with her. I talk to her and...she'd pat my knee and what not and smile at me. But what kind of a conversation is that? You know...or they'll just look at you. They'll stare at you in absence, totally completely different.

Such experiences were not unfamiliar to Florence. She noted, there are "very few residents that you are actually able to talk with". Like every other woman in this study, she commented on how difficult it was to learn who among the resident population had the intellectual capacity to carry on a conversation. Because of their individual physical limitations, respondents were for the most part unable to initiate contact with other residents without support. As Florence indicated, there were a good number of residents she had

never spoken to...never had a conversation with...there's still quite a few. I don't even know their names and since I've lost the sight of this eye completely, things are worse. Things are very, very much worse.

Did you know I went blind?

Annette whose vision was not impaired had found "a couple of nice friends" but nonetheless commented:

Well there are more that are confused than not....I think there is sort of a happy medium. Not really, there's very few that could express themselves completely, very, very few. There's a couple up on [the second floor]. There is Jane. She could express herself and also Margaret. I know most of them [cognitively well residents] are lonely.

I asked Annette if feeling lonely had been her experience as well.

She responded: "not really. I think it is because I go out quite a bit so I don't have to get that down in the dumps." Of all the women I spoke with, only Annette had the financial resources and physical stamina to more regularly leave the hospital premises. She employed a companion, who accompanied her to weekly service club meetings, the occasional dinner out, and on other community excursions.

For the most part however, the women in this study described the experience of being very much alone. All had made efforts to seek out companionship beyond the resident population. Several months earlier for example, Ish like Annette, employed a companion:

She was a very nice girl. She used to come in an hour a day and take me out for fresh air or something but suddenly she stopped coming (pause) which was very upsetting. A loss for me yes and at the same time it is a loss for her and I don't particularly want to put somebody else in her place.

When we spoke Ish mentioned, that generally she did not "talk too much....There are some residents that are really quite interesting...but others I can't get anywhere with them." She described her life in extended care as:

very lonely because of course you see, my family are not here. I have no family here at all but they phone me every once in awhile and that gives me a lift, a great lift. I like people coming in to see me, some people don't but I do....I have friends that come in to see me, some friends come (pause). I used to have a lot, because as I told you, I worked in [a provincial government office] and I had quite a good connection and we were together and stayed together for quite a long time. But now they, of course, they are slowly dying off and I don't have as many [visitors] as I'd like.

Amanda an eight year resident, lost the one close friend she met in hospital:

When I first came here I got to know one lady very well and we were friends. We wouldn't even go down to dinner without each other....We used to talk. Of course she was from Regina too and I knew the family and it was really nice. I looked forward to it. But now there are days you don't look forward to at all.

Florence's companions among the resident population were limited to "Alice and the lady on my right at the tea table. They're about the only two that I

converse with." She had, had a relationship with one of the hospital volunteers which had recently broken down:

The volunteer lady has been very good to me but unfortunately she moved and she couldn't take me anywhere for two weeks because she was busy with moving....And then she moved a chair that was too heavy and she strained a muscle in her shoulder. So that took another three weeks....

When she finished her story I asked Florence what she did for company or to be active and independent when she did not have her volunteer. She responded "You do without." Susy May stated simply "I get more conversation with some of the staff, if they're not too busy " and went on to ponder:

but as far as the residents are concerned, of course if they were with it. I guess there wouldn't be many of us though. Really there's not many people that you can carry on a real conversation with. I like talking as you know but how many people can you talk to and get a knowing and intelligent, understanding conversation with?

In saying good bye after discussing many issues, Ish again referred to her aloneness: "I liked you coming in and visiting me. I feel so lonely sometimes, 'cause I am from so far. I would give anything to have my family come in and visit me, and sometimes they do visit on the phone;" but not as

often as she would like because the telephone is "so blessed expensive."

It was interesting that the women all chose to meet on weekend days when the hospital was less busy and the full staff component was not on duty. Most of our conversational sessions, which included the sharing of tea from a china pot and biscuits, ran longer than I had anticipated. It appeared that participants purposefully extended the time we spent together, as the following attempted closures indicate:

- 1) Are you feeling like you have had enough for today Ish? "Oh no. I don't mind as long as I am not tiring you out."
- 2) You're in pain. Would you rather get back to your room? "No it's okay dear. I'll have tea with you first."
- 3) It's getting close to your lunch time [my second attempt to close].
"It's 12 o'clock?" It's 12 o'clock. "Oh this went by so quick. Ask me if you have any more questions. Take out the the ad lib [in your write-up], and the chit chat and the tea drinking (laughter)."
- 4) Listen I have taken a lot of your time today. "What time is it?" It's almost 20 minutes to 12:00. It will soon be lunch. "Just the right time!"

I understood this last woman to mean that she had hoped to have paced our conversation, to ensure the time spent, extended into the lunch hour. As such she would continue to have something to fill the time, which offered the possibility of conversation and companionship.

I learned that similar opportunities were few for the minority of cognitively intact residents. The following respondent's statement appears to support this contention: "Well in the first place, like I say, we should be better paired, you know at the dining table and that, with people that can speak with you." The words and actions of the women I spoke with reinforced the notion that participants lacked opportunities for meaningful conversation. They were often isolated, alone and very aware of their minority position, albeit living among a large number of elderly people. As one woman said "if I could find anyone [resident or staff,] I'd talk to them."

III Penalties Of Difference

Being different than the majority of residents created all sorts of trouble for the women in this study. In their experience there was a penalty to be paid for being cognitively intact. Participants' very awareness, (of the intellectual differences among residents; the quality of the meals presented; the limitations of scheduled activities, bathing and toileting programs; and staffing issues), forced them into uncomfortable relationships with the staff assigned to their care. It was suggested that the more demanding presence of cognitively intact residents created problems for some staff. These women found it unsettling, to feel regarded by staff as "trouble" rather than "in trouble"; or to be treated as though they were homogeneous members of the larger, confused resident population. To this end, Ish felt it important to note

“everybody is different. You will talk to somebody else and they will present an entirely different idea.”

The women in this study found it exceedingly stressful when their different needs or capabilities as intellectually competent persons were not recognised or accommodated:

You know it's just like when you're a child, you have to report where you are going, what time you will be back. Your life isn't your own in here....I mean I can understand their reasoning. If there is a fire they've got to know how many people that they've got to account for. That I agree with. I can understand that. But some of it's a little belittling....You know when you've raised a family and you've had them report to you, it's just like the circles reversed. I just wish some of the government officials would have to come in and spend their whole day; doing everything you do in a day; having to ask permission to go to the bathroom and this stuff....If they experienced this themselves, maybe they'd realise that these places are not a bed of roses, even though they think they are.

Florence proposed that it may be troublesome for caregivers to have to deal with the different demands of alert residents. “I am a difficult person, I think, to handle. I am very independent and I like things nice. I was brought up that way.” Annette stated that for her, being among the small minority of

cognitively well people, had "been terrible." She cautioned: "I am a bad person to talk to." In her experience certain staff enjoyed looking after alert individuals and "others don't. They'd rather be with somebody that doesn't understand a darn thing. They wouldn't want everybody like me."

It was from such references, to the quality of participants' everyday institutional lives, that the third theme "penalties of difference" arose. The notion that cognitively well residents are "trouble" and their expressed fear of retaliation are two elements of this theme.

I'm Trouble. Wanting "things nice" and asking for staff support to make it so, was not always well received. Respondents presented numerous dining room scenarios to illustrate this point:

The first [confused] one I tried to make friends with...came at me with a fork and they [the staff] didn't believe me. She punched me in my arm so bad that I could have passed out....Then just lately there's another one....She says to me "you keep away I'm an old lady." I said, well congratulations, I am too. "No you're not. You're a young person." She can't see me for looking you know. She doesn't know what I am like. She doesn't know a thing about me. But you've got to keep out of everybody's way because you have a little brain so you're the one at fault no matter what's happening. It's up to you to move away.

The problem according to Amanda, is that staff

...can't put themselves in your place. The same with the food--why last week the food was so awful, I went and tipped my plate....And I said [to a staff member] would you eat this? And she said something about the loss, and I said but I can't eat it (tearful laugh). Do you think it's awful of me?

How the dining rooms were managed and the meals presented, was mentioned by most of the women I spoke with:

Well you see, an awful lot comes from my bringing up and I have to say again, this is another thing my mother taught me, that presentation of your dinner plate means a lot. We get the dinner plate, there's your mashed potatoes, there's your vegetables, here's your meat (gesturing). Not quite a lump but linked together.

It was disconcerting for these cognitively intact women (some of whom viewed the extended care hospital as home and others who saw themselves as paying guests in a residential facility) to have to sit and wait for meals served late, without the simple courtesy of an explanation or a cup of coffee.

In a restaurant...after a waitress has seated her guests, the first thing she does is either bring them coffee or say would you like a cup of coffee. I worked in a restaurant when I was going to Normal School. ...I was a greenhorn [and told] "as soon as the guests come in and are seated, serve them a cup of hot coffee....That keeps them

quiet in case there is any delay in bringing their dinner or confusion or something." I have never forgotten it.....If you have a cup of coffee or a cup of tea and you are drinking that and you are talking--you forget the time. I don't know, sometimes I wonder. I think I am too much of a perfectionist. I like things to be nice.

Annette too wanted her dining experiences to be a little nicer. She described a scenario in which her meals were continually being sampled or "completely" eaten by a confused resident who shared her table. Her concern was that staff did not appear to recognise, appreciate and/or acknowledge her stress as a cognitively intact resident in such situations:

This morning I had no toast, no egg and she had an egg [my egg] on her plate and she puts it up and says "here is an egg." I said for goodness sake Goldie I am not that stupid. You have been handling that egg all morning. Really. "Oh" someone says, "she is so sweet." I am a bitch you see. They all make excuses: "Oh but she is so sweet." I don't give a damn if she is sweet or not, let her eat her own stuff. I buy my stuff. I am paying for it. I don't need to feed her.

Finally, the same woman captured the lived experience of feeling like an outsider with these words:

I'll tell you one thing, it's not a nice place to live--I feel like I am in a crazy house....Why can't they put some of these people who keep

yelling and shouting somewhere, instead of piling them right in here (gesturing to the room next door)? I asked them if they did that on purpose so I'd get out of here. "Oh...we wouldn't do that." I thought oh yeah, wouldn't you. Who are you kidding?

I'm Afraid. The fact that this woman questioned the motivation of the hospital staff shed light on participants' descriptions of feeling vulnerable; and afraid of retaliation. Respondents were very aware that, as another woman I quoted earlier stated, "in extended care you are 100% depending on the staff to look after you." During a previous conversation she had mentioned:

I won't report anybody unless it is real serious. I haven't reported anybody yet and I don't want to because no matter how wrong that person is, she can get back at you and you know it. If I was to report on something that she did to me and she still had to service me she could be pretty mean. It's only human nature, it's not the person, it's human nature and that's done.

A third respondent described a situation in which she had reported being physically injured: "Here pull up my sleeve will you, way up, I want to show you something [a large bruise]." She went on to explain that she had been hurt by an attendant trying to raise her up with a mechanical lift. "They hurt me terrible.... and I don't bruise. I am a toughie (tearful laugh)....

somebody saw it and we reported it." It was this woman's experience that a number of the

nurses are very nice. If I say, oh love you are hurting me, they stop and correct what they are doing but some people don't....They don't take it easy (long silence). So I feel sorry for some of these that can't speak out for themselves....others so often can't say anything. That hurts (sobbing)."

To speak and not be heard, or to speak and not be acknowledged or responded to as competent persons, allowed respondents little opportunity to direct their own personal care. Aware of their profound dependence upon caregivers, the seemingly normal ambivalence in these situations left some women feeling concerned that there might be retaliation should they report poor care. Others found comfort in the fact that they could generally count on staff support. Ish described the care she received in this extended care setting as

very good on the whole. I feel that they are very kind here. As a matter of fact I spent Christmas in [an acute care hospital] and was so happy to come back. To hear the morning noises...was just what I needed.... Somehow it seemed to help me and I loved hearing it. I recognised that the getting up in the morning, washing your face, listening to the sounds in the hall, listening to the different things that went on in the

morning, I realised that that was good and it was just what I needed....I don't mean that they [staff] are perfect, they are not, but at the same time they do give you a lift.

IV No Escape?

I understood from participants' descriptions of day to day life that there was little opportunity for an interval of relief or respite, from the stressors associated with living among people who are cognitively impaired. It was from their expressed concerns about becoming confused for example, that the final theme "no escape?" presented itself:

- You are not only in the minority, one of these days you are going to be in their category. I'm sure. I'm quite sure, if they [cognitively intact residents] are left alone long enough. It's not affecting me that way yet because I can still screech and holler and speak my mind. [But] It could.
- I don't know whether maybe I would as time goes on, get a little bit like that [confused]. I don't know. Right now I wouldn't because I realise what's what. But having that eye go [loosing her vision,] I sometimes worry about becoming confused. What would I do? I'm afraid to think of what I'd do.
- Well my memory is not as good as it used to be; but it used to be reasonably clear but now it is beginning to get hazy, so I don't know .

- You get confused with them. I think that's the idea. We're all nutty.

Crazy feeling you get (pause). You're lucky she's not yelling next door. Here, that's enough to drive you up the wall. She stops yelling and the other one starts.

Most respondents associated their lack of respite with being in residence with so many people that are confused: Respite is described in the Random House College Dictionary as "a delay or cessation for a time, esp. of anything distressing or trying; an interval of relief" (1974, p. 1124). It is a commodity which the women in this study had difficulty securing, in so far as they, like the majority of persons in extended care, required 24 hour a day medical supervision. Unlike the majority of residents in integrated extended care facilities however, their institutional care needs were based solely on functional impairment and physical frailty rather than mental disability. As the women spoke of their lived experiences two elements of the theme "no escape?" emerged: the fact that respondents could not get away and that their privacy was repeatedly invaded.

I Can't Get Away. As Susy May pointed out, staff are only on site "eight hours of the day. We're here 24 hours, seven days of the week." There was no escape. At all times participants shared living space with the larger number of confused elderly people. The women in this study, described the difficulty they had in maintaining a continuing level of tolerance, compassion

and understanding for the cognitively impaired residents with whom they lived:

You know I feel sorry for a lot of the [confused residents]. (silence) A lot are also very frustrated....There was one lady down at the other end--I don't know where she gets the voice from or the breath from....All day long she is talking to herself, or somebody. On and on about water, about her mother, and water and on, and after a few hours a day, everyday of the week, the same time, as kind as you try and be....when you hear those [words/people] it's just like a broken record. It gets driven into your head until you are doing the same thing. And rather than letting myself fall into that trap, I try and get away from it as best I can.

What she did, to try and get away, was explained in a second conversation:

Well what I do now is--in the summer it is fine. What I do is go downstairs and out the back door to the garden and it is quiet down there. Now that it is colder I don't know where I will go but I will find some place if I have to.

Not all respondents had the physical stamina to independently leave the floor or unit where they lived and therefore generally spent 24 hours a day in the company of persons with dementing illness. That continual integration can strain a person's ability to remain patient and empathic was

made clear by the following respondent's description of day to day life:

I had to go to one of the ladies the other day...she is always singing you know. She doesn't know the words to the song she is singing. She starts off with a very religious piece and then she ends up with "I want to go to the toilet." I went to her and I said Lara please shut up. She says "Are you telling me to shut up?" Yes, I said. It would be nice if you kept quiet over dinner instead of listening to you wanting to go to the toilet. "Oh she says, "I don't say that." I said you say that every minute. So she stopped for a while and I wasn't nasty about it. I was very nice about it. I could have been nasty about it, if I wanted to but I wasn't. I just thought well what's the use, she's not understanding and of course that's the excuse everybody uses in here: "she doesn't understand what she is doing." I said I am sure she does and it's just like Luke coming into my room to use the toilet. I says, you've got your own room, get out! "Oh, you're a miserable bitch."

As participants noted, the stress associated with 24 hour integration continue into the night. This was true whether respondents had private or semi-private rooms, or shared four bed wards:

I'm in a four bed. The lady in the next bed to me is 91. She's a Christian. Everyone else is going to the devil. This goes on at two or three o'clock in the morning. I'm a Christian. We're all going to the

devil and you're all pigs. Now this is just one small incident but what happens is that at two o'clock in the morning she starts yelling out. A bit difficult to be tolerant and understand.

It was difficult for Annette as well:

And there you are waiting patiently [in bed] for somebody to shut up. And then of course they put so many in that call out and everything, and we could hear it all the way down the aisle. The other day I said why don't you put her in her own room? "Well she keeps the patients awake." I said what about us, aren't we patients? I mean aren't we residents too? We pay just as well as the other person and that doesn't seem to count.

This woman was paying for a private room which was situated along a corridor of rooms occupied by persons who, for the most part, were cognitively impaired. We met in the privacy of her room and I remember listening very carefully to her while she spoke. It was only upon reviewing the transcripts of our conversation while listening to the audio tape, that I heard something in the background. For the full 40 minutes we were together, the distant sounds of a woman's moaning filled the room and I had not heard it at the time.

This experience was a reminder that 24 hour integration was profoundly different than spending moments or hours as a guest or on shift

as a member of the hospital staff. One woman explained "I'm here all the time unfortunately" As she said:

It is my experience...that these people, they're always yelling the same thing over and over again. They must have something in their back life that causes it....Or like Deborrah... swearing today. She's got holy shit on her mind again. And I thought I was imagining it, and the nurse that was with me said that was exactly what she was saying.

Invasion of Privacy. In addressing the difficulty of spending 24 hours a day in an integrated extended care facility, participants also expressed their want of privacy. Even having a private room, as only one woman did, was no guarantee that participants' personal space would not be invaded:

I have a private room and somebody is always coming in here, especially at night. There is one man who goes to every room he can get in. I said that one of these days I am going to throw something at him and he may never get up again and I'll be up for murder, but I will so help me.

What this woman expressly desired was a door that she "could lock and keep any stray out." In terms of privacy she suggested "our cows at home get better treatment than I get."

Having to share bedroom space, as well as the the hospital common areas, was unavoidable for the other respondents. The following examples

are indicative of the stressors associated with, living hour upon hour, day after day, year after year, among persons with dementia:

I came home from supper, walked into my room and lo and behold, somebody was in my bed....So I rang the bell for a nurse and the nurse came in and she said "Oh, that's Kathleen so and so. She is very confused. She doesn't know top from bottom." But being in my bed--a few days previous she was right in my bed, in the sheets. Two or three weeks before then she was in my bed again. The girl that has charge of the activities, she knew all about it and she said "you should put a rope across your door...." Now if there's a rope across my door that means that I [and the other three women in the room] have to unhook it if I want to go in or [out]. And it's supposed to stop them from coming in. But if they want to come in they'll undo that rope. So I don't know when it's going to be that she'll do it again and I don't like it.

Nor did the following participant, who also shares a four bed ward, appreciate having her small segment of private space invaded:

I want to say something else about this lady. She's in our room of course. When she's in not very good humour, she takes her chair and goes in the hall and sits there so you can't go out, even into the hall or into your room. And she questions you whether you live there or

not....Sometimes I have to wait for half an hour. Sometimes I go into the bathroom and put the light on as I can't get past her to go into my bed to get my own buzzer. So I have to wait for the nurse to come. I'm sure they know she does do it on purpose....

Having their personal space repeatedly invaded was a frustrating, often confusing and disappointing experience for participants. It was nearly impossible to secure privacy in the integrated facilities where respondents lived, as story upon story suggested:

You know yesterday when we had that snack. Well, just shortly afterwards they came up and told me it was time for supper. So I put them both [biscuits and dip] in a plastic bag and handed them to the nurse. And she said "where will I put them?" and I said oh, just shove them under my pillow. So she did and I went down to the dining room for my dinner and when I came back...I walked right up to my bed and here my afghan was turned down and my bag was gone. That was within an hour from the time I put it there until I came back. Right away a nurse came in with my biscuits. She said "I found them in Isabelle's room....I was absolutely disgusted because that cost me seven dollars and I hadn't really tasted them. I was furious. I am on the role call to go to...[another long term care facility]. I am just sitting waiting for somebody to die so there will be an empty bed for me....Up until

yesterday I didn't really want to [move] because I like it here. But in the last several months I have had so many disappointments--things stolen. I have put different food and candies, hid them, but they find them and they steal them.

Yet another woman who shares a four bed ward lamented that what she misses are the small pleasures associated with privacy:

I'd like to have a TV and some nice little personal chairs, like when company comes. Somewhere for them to sit you know, and a bit of privacy so you can talk. Cause we have to come down here [to the end of the corridor] and find a little nook and cranny, where there is nobody, and sneak in....I know it's hard to get privacy. I realise that.

Although it was possible to have a TV in the room she shared, this woman was acutely aware that any time a set was on, the auditory and visual space of every person in the room would be impacted. Neither would this woman be able to count on watching the occasional program in solitude. Clearly for her and the other participants, there were times when the lack of privacy in the integrated facilities in which they lived was experienced as a profound loss. As Susy May explained, it is very hard when "you've lost your ability to just do the ordinary everyday things, and the ability to have privacy when you need it."

For participants to have to continually share living space, without

respite, was not easy: "but anyway" as one woman stated, "I am adapting myself and it is hard. Three televisions in my room and I don't know whether they are paying attention to them or not." That respondents' privacy could be compromised at any time during a 24 hour day was indicative of the incessant, environmental stresses the women in this study experienced.

V "It's Not A Rose Garden"

In addition to sharing bedroom space, respondents generally took their meals, attended activities and even shared the hairdressing space with persons who were cognitively impaired. Participants' expressed need for reprieve from room mates and table mates, as well as room noises in adjacent or shared bedrooms, and the noise, confusion or deathlike silences of the communal living spaces, pointed to the concluding theme: "it's not a rose garden."

Speaking to the experience of sharing living space Amanda remarked: "oh, I wouldn't mix them. I'd separate them but I'd see [to] those that need help of course." She went back and forth about this notion, acknowledging being placed with one or two residents with whom she could communicate, as well as her frustration with and compassion for cognitively impaired residents:

They shouldn't mix them all up because most of them (silence)....We had one man, I don't know how ill he is but he spends most of his time

with his head on the table, pushing all the food away. And that is disturbing you know because three people are eating and he's (pause). They should put him in the room where they feed them I feel. Make him feel better too. I think he doesn't like it [the food] and that's what he does to draw attention....His head is so close to your plate and everything and it is not nice. Although he looks nice and clean.

Referring to her earlier story of the stolen biscuits and dip, Florence also proposed segregating cognitively intact residents and those who are confused:

That is another thing that makes me disgusted with this place. Now this lady that took my stuff, I told the nurse that brought me the biscuits, the one that talked about putting the rope up. I said, I don't see how that is going to help matters. I said, people like that should not be in a place like this with people--where there are other people with at least the same mentality that I've got. Now that woman shouldn't be in here, should she?

Aware that within the Juan de Fuca Hospitals Society there is a small, specialised dementia care unit she continued: "One of your hospitals has got an awful lot of Alzheimers doesn't it? Yes, well that is where they should be, whether she is an Alzheimers or not I don't know."

That participants' coping strategies were often strained was evident

from their descriptions of day to day life in the different integrated, extended care environments:

I have really come up against the hard to understand. How do I put it? (pause) I don't know if they are not with it because a lot of them know what they are doing. As a matter of fact I've sometimes wondered--is something [confusing behaviour] for show or is it real....You wonder how a person can be like that because they get a lot of attention....I know a few of them do it for attention getting. But then how do you figure out which is which?

All participants described situations which were difficult to understand. Ish found:

It is difficult to talk to people or to have anything to do with people who won't respond. And so many of them will not respond. I don't know, in some cases I think it is because they don't want to respond.....Like this morning when I said 'you are early' to this lady, she didn't answer me at all. Now I don't know whether it is because (pause); I don't know if she is deaf and didn't hear what I said, or whether it is that she just doesn't want to talk to me.

Annette on the other hand was very much aware that the resident who continually sampled her lunch was cognitively impaired:

I just told the nurses: if I come for lunch, my cottage cheese is gone.

That happened twice in one week. I thought that's enough. I've got to move or I'll go nuts. And I can't come back and argue with the person. What is she going to do, she's already eaten it (silence). It's very hard. I try to be nice to them and I get abuse....As soon as you are nice to somebody that you think needs help, you either get pinched--one of these ladies, I know she is very demented, she came after me with her fork one day. I had to yell blue murder to get somebody to come and take it away from her....I know she is very confused.

In trying to express how profoundly difficult sharing space with cognitively unwell persons can be, one respondent offered:

I am going to tell you something. It is a good thing you are not using my name. When I went to the [specialist]...when he found out what it was, he gave the ultrasound. And then he went on to say an operation is possible, definitely, but it is entirely your decision and nobody else's because you may not come out of it. Word for word...so that is out isn't it. But you know what I thought? I thought of a damn good mind to have it done....It would be complete. [She would die.] Now isn't that a think.

I responded, that it was hard to hear, and she with: "well, I thought seriously of it and then knocked it out of my head. One reason was my son is still living and he will be down for Christmas."

As stressful as living in an integrated institutional environment was, respondents continued to struggle to understand the confusing behaviour of residents with dementia and to maintain a level of tolerance, empathy and compassion. Susy May remarked:

I'm sorry to see these people this way...one thing it makes you realise, but for the grace of God there go I. And you just, at least I try to be as understanding as I can. Because if ever it happens to me and nobody says that it won't, I'd like somebody to be considerate of me.

But she also cautioned:

when you are on the outside you don't realise how much diminishing is going to be done when you come in. We know they are nice places to have and the people are lucky to be in them and what not. What you don't realise until you are actually in them yourself, and have to participate in it all, just how much diminishing there is. You know, it's a big difference being on the outside looking in. Everything seems so rosy outside. People saying "Thank God aren't they lucky to be in there." Actually some place changing could take place; people on the outside come in and just try it for a while.

Summary

As our first conversation was concluding Annette made the statement "I think I'll write a book when I leave. I might start writing it while I'm here. My

Life in the Crazy House. It was through her explanations of day to day life in extended care, and the narrations of the other women in this study, that the predominant themes emerged.

Respondents' lived experience of hospital schedules and nobody listening, led to the the first theme "precedence of routine over person". The second theme "alone and nothing to do" emerged from participants' descriptions of being alone among many, with no meaningful way to fill their days. Participants' expressed fear of retaliation, and the feeling that cognitively intact residents represented trouble, was captured in the third theme "penalties of difference". The fourth theme "no escape" arose from respondents' depictions of their experience of not being able to get away and having no privacy. Susy Mae's simple statement, "it's not a rose garden," captured the simple truth of participants' day to day lives at the different integrated, extended care hospital sites; and became the concluding theme of this study.

In addition to presenting the major findings as inter-related themes, derived from the participants' portrayal of their lived experiences as long term residents of extended care hospitals, the women themselves were introduced. This was a group of cognitively intact, mature, wise women. The findings, documented in this chapter, represent a compilation of their words and noted silences. The concluding poem, A Place for Mother: In

Conclusion, reflects something of the sense of responsibility and pathos respondents expressed. Having become profoundly, functionally dependent and physically frail, these women came to appreciate that had no other real option than choosing to accept residency in an extended care facility. All needed more care than they were able to receive in their homes.

In Conclusion

Not wanting to be a burden
on your children
you sign yourself into a nursing home.

You become active
in every group
and serve on every committee.

You are voted
resident-of the-month
a role model.

Mother would be proud.
(Seltzer, 1987, p. 61)

CHAPTER FIVE

Discussion of Research Findings

Introduction

The predominant theme which emerged from this study was the “precedence of routine over person”. Respondents suggested that the systematic procedures, practices and policies of the institutions, where they resided, came before the needs they themselves identified as important. The women who participated in this study did not feel heard. Every issue and/or concern raised and described by these women was connected in some way to the organisational demands of the hospital environments in which they lived; including being alone among many; having so much time and so little to do; being seen as trouble makers and feeling vulnerable if they voiced their concerns or opinions; and having no privacy or reprieve from the stresses of integrated, institutional life. Through a review of the data, I will illuminate the meanings and significance of the lived experiences of Annette, Amanda, Ish, Florence and Susy May and bring into text the knowledge produced by their “speaking presence” (Rule, 1994).

Some of the longstanding issues, identified by the women who participated in this study, are reviewed in relation to the art of M. D. Hennessy (1993) and the research studies of Diamond (1992) and Laird (1979). These bodies of work have been drawn upon because the individual

experiences of institutional life, lived, described and portrayed, by the authors and artist, reflect and resonate with the lived experiences of the women in this study.

Perspectives Shared

The purpose of this study was to thoughtfully present the perspectives of older, cognitively intact women on the impact of living in an environment where the majority of people, with whom they reside, are cognitively impaired. Some of the issues identified by the participants are familiar to people working in the field. It has been argued convincingly in Chapter Two, for example, that human care rather than medical care is more highly valued and of greater need to frail, elderly people in long term care institutions. The data in this study would suggest this to be true and that the medical model of patient care is followed routinely and takes precedence in the institution described. Susy May captured this reality with her statement "I can sleep in an unmade bed" but as she explained, the staff "work on a time schedule and the time schedule doesn't have any space for anything out of the ordinary to happen" including finding the time to "be with" residents. From my experience as a social worker in this hospital system and in discussions with other members of the health care team, I realise that we are not listening enough or as much as would like to. Perhaps this research will help lead us to work together, to come up with solutions and creative structures to

enable us to listen to our clients with greater care and more time.

The example of regimented toileting schedules was used by all but one participant in this study to illustrate how medical tasks and the recording of tasks take precedence over the care of residents' expressed needs. It was not unusual for respondents to have to choose between the risk of incontinence or being labelled as trouble makers, should they need to be toileted at other than their scheduled time. From Annette's perspective, her bladder is ready "when its ready" and although staff may think otherwise, accidents are never "on purpose". It was infuriating to respondents, that someone "sitting behind the desk in the RN station," could dictate when they would be toileted. Florence spoke of being faced again and again with having to let her bladder go on the early evenings, when "staff get busy", because she "couldn't hold any longer". The solution in her case was to "use one of those nightall paddy things"-- adult diapers. Although it may be both appropriate and indicative of good nursing practice to ensure that all residents are toileted or cleaned if incontinent on a regularly scheduled basis, as was the initial intent of the bowel program, respondents suggested that to impose the same procedure on the minority of people able to direct their own care is not good nursing practice.

The issue of toileting, from the perspective of nursing assistants, was addressed by Diamond (1992) in his ethnographic study of an American

nursing home. His data, as did mine, suggested that the scheduling of medical tasks can take precedence over human care. In his experience, "nursing assistants had to snatch time when they could to take people to the toilet, and that time did not always coincide with residents' bodily needs" (p. 87). Indeed, Susy May spoke about being left half dressed while the staff were "down the hall doing something else" and at other times being told "you're going to have to wait another 10 minutes" when she was "just busting to go".

What occurs from a focus on routine over person is a lack of sensitivity to the expressed felt needs of people in care. This was borne out by Amanda's teary story about not feeling heard when she asked not to be bathed by a man. Amanda is a woman, and she is old, and her age and gender matters. Her needs appear to have been given less consideration than the assignments of the staff to particular tasks at particular times. Once again a voice was not heard. Is it possible that this insensitivity or perhaps imperceptiveness is suggestive of legitimised ageist and sexist care practices? In the process residents like the women in this study risk losing their personhood; which as noted in Chapter Two, identifies us as unique members of the human community.

Buzzell and Gibbons (1991) suggest that patienthood rather than personhood tends to be the norm in long term care institutions. The data in

this study supports their argument that the medical model with its narrow emphasis on the physical, is inappropriate in long term care settings and can be severely damaging to individual residents. The women in this study, like the vast majority of people living in extended care facilities, have medical conditions which are incurable. In theory, not unlike hospice, the primary treatment goal is to keep people comfortable and pain free.

Residents are not content to be treated as objects of medical practice, but rather as whole persons, active subjects in these circumstances they find themselves in. Residents and their families are put under incredible stress when it is assumed in practice there are no differences between acute and long term care.

That stress was captured eloquently in Hennessy's (1993) pen and ink drawing, Family (Figure 1) as well as in the words of the respondents. Words could not truly express the despair, helplessness and frustration Hennessy felt in witnessing her mother's undignified care experience in a Vancouver long term care facility. Weakened by lung disease and congestive heart failure her mother Dollie, who was cognitively intact, did not have the energy to protest or endeavour to direct the medical treatment she received. As did the women in this study, Dollie was faced with the terrifying reality that she was first and foremost a chronically ill patient. Like Ish, Annette, Amanda, Susy May and Florence, her beauty, strength, intellectual

Figure 1: Family, M.D. Hennessy, Victoria, 1993.



capacity, and dignity of person was less obvious to the staff assigned to her care than her physical condition. It was Dollie's body, as it was Amanda's, that was lifted by a mechanical sling, put into a tub, and bathed by a stranger.

Hennesy, a working sculptor, produced a series of drawings as part of her own journey in dealing with the grief of her mother's disturbing residential experience and death. Aging (Figure 2) has also been included in this study because it, along with Family, visually echoes participants' verbal descriptions of their everyday lived experiences as "old cognitively well women", residing at different British Columbia, integrated long term care facilities in the 1990's. In this piece Hennesy's mother sits in the foreground. Her frail, aged, body is wrapped in bandages and her head remains unbound. Dollie's eyes are sharp, indicative of her keen awareness of the confusing world around her. In the background sits another old woman, physically capable but with her head bound; suggestive of her demented condition. Of the 75 residents with whom Dollie lived, less than six were cognitively intact. Like Dollie, the minds of the women in this study were alert and their bodies bound by disability and physical frailty. They too were but a small minority among a majority of old, cognitively unwell women.

Like the women in this study, Dollie struggled to maintain her sanity in an atmosphere which appeared unmindful of her intellectual capacity. Her

Figure 2: Aging, M. D. Hennessy, Victoria, 1992.



image brings to mind respondents' astonishment at being a minority among so many people with dementing illnesses. As Susy May said, "I should never of been in a place like this...demented [is what] they call it". Ish found it very difficult to communicate "or to have anything to do with people who will not respond". Another participant, who worried about letting the repetitive, confusing behaviours of some residents affect her sanity, stated "rather than letting myself fall into that trap, I try and get away from it as best I can".

Getting away from the stresses of living with cognitively impaired people was not a task easily accomplished by the participants in this study. One would assume for example, that if a resident had a private room there would be a real likelihood that she could, when she needed to, retreat to the sanctity, safety and privacy of her room but this was not the case. Participants' personal spaces were invaded whether they shared a four bed ward or had a "private" room. Every woman in this study had to cope repeatedly, with confused residents rummaging through her drawers, taking her belongings, handling her food, and/or urinating in her bathroom or her bed should someone mistakenly climb in. These kinds of behaviours can be tantamount to assault. They place unfair demands on the minority of old, frail, cognitively intact residents, and diminish the quality of their lives. The following statement is indicative of the incredible stress one respondent experienced, as a result of the invasive behaviours of a confused resident.

"There is one man who goes into every room he can get in....one of these days I am going to throw something at him and he may never get up again and I'll be up for murder, but I will so help me." The frustration level of lacking a voice can be high.

Susy May reminded me that there is "a big difference" being an outsider "looking in. Everything seems so rosy from the outside.... You don't realise how much diminishing is going to be done when you come in". I found it interesting that Hennesy also used the outside and inside of windows metaphorically. She drew my attention to the fact that the only color in Aging was the yellow-red in the windows; symbolic of life ongoing "outside" the facility her mother resided in. Participants described in numerous ways the timeless monotony of their day-to-day lives inside the different hospital sites. One woman remarked that she wasted far too much rubber going up and down the halls in her wheelchair, trying to find something to do. She lamented:

perhaps I'm too with it. A lot of people can sit for hours and do nothing....I just can't sit and twiddle my thumbs and watch because the more I do that, the more frustrated I get. The more I realise what I am missing in life.

Respondents certainly had the opportunity to attend the scheduled activity programs offered throughout the Monday to Friday work week and often did

participate. However, the stories shared suggest sessions were seldom purposeful or fulfilling for the minority of cognitively well residents. One woman's straight forward statement "we find it very boring" captured respondents daily lived experience of residential life "inside" the different long term care, hospital sites.

I came to appreciate that respondents' experience of not feeling heard greatly eroded the quality of their lives in institutional care. Finding voice is essential to the liberation of oppressed persons, and speaking empowers people to become subjects rather than objects in their life choices. What these women are saying however, is that they are not being heard when they do speak. One respondent stated simply "listen to me: I know what I want and what I need". Another woman in the study tried to clarify the importance of being heard by noting that "a lot of the residents don't make sense...but for the ones that [staff] know are [cognitively intact, please] just listen".

One participant made note of how difficult it was for most residents to voice their concerns. She questioned some of the women who attended the resident council meeting as to why when given the opportunity they chose not to bring matters of concern, particularly about their dining room experiences, to the resident council. Laird (1979), in her lived experience as a resident of an American nursing home, described a similar situation. Like

respondents in this study, Laird was given the opportunity to make her voice heard specifically around meals. The dietitian explained the efforts she had made to ensure residents were provided well balanced meals, and proposed that "surely" Laird and others would understand that individual tastes could not be catered to in a large institution. All found themselves "meekly" agreeing to everything the dietitian said. All indicated that the meals were fine and that they understood the problems involved. And afterwards "wondered pointlessly why [they] had not spoken of any of [their] true feelings". The women in the study also had responses which were similarly meek and agreeable. Laird struggled to understand her behaviour because like the participants in this study she knew that she was a strong, articulate woman. Yet she found herself pondering as did Annette, the "curious lapses, the failures of nerve and of purpose, that afflict those who are institutionalized, who feel themselves at the mercy of others...surely they make a bitter sense": and in the end proposed that perhaps "the helpless one will bear the ills he has rather than court others he knows not of (p. 93)".

Summary

What I have come to know, is that the women who participated in this study took a risk in breaking their silences. Rather than remain silent they became a speaking presence. They spoke of the unadorned truth of their residential lives. They shared how difficult it was to be integrated among so

many confused people; how difficult it was to feel vulnerable; how difficult it was to have no privacy and no break from the stresses of the institutional environments they found themselves living in. My hope is that this study will further advance the possibility of these women being heard.

CHAPTER SIX

Insights, Recommendations, and Implications for Social Work Practice

Introduction

This phenomenological study was designed to present an interpretive description of the lifeworld of five, cognitively intact, old women living at different sites of an integrated, extended care hospital, in Victoria, British Columbia. Through in depth interviews I have endeavoured to make explicit the lived experiences of the women who participated, in terms of their minority status among an overwhelming majority of confused elderly people. Reflections on the meanings of respondents' lived experiences and the questions raised, recommendations, and implications for social work practice are presented in this final chapter.

Insights

Although referred to as residents rather than patients, at the facilities where they lived, what the women in this study described were medical rather than residential or social environments. The data brought to light the conflicting perceptions of the hospital administration and staff, and those of participants. From the perspective of respondents, the administration and staff viewed the institution primarily as a work place whereas respondents knew it as a place of residence. What respondents regarded as trivialities, of the daily hospital routine, took precedence over their felt needs. These

women were concerned that they could be transformed from cognitively well, pro-active human beings into passive objects of care, undervalued and at risk of losing their dignity of person--their personhood. It could well be that staff, in their busyness and in the expectation that they fulfil given tasks within a limited time frame, also experience a negative transformation. In meeting the everyday demands of operating the different hospital facilities, the organisation itself may forget to respond to client needs. Participants identified a number of recognisable issues and concerns and in the process gave rise to serious questions. What can long term care hospitals do to enable the relatively small population of cognitively well residents to be heard? What can they do to recognise that these residents also have special needs that require a response from the organisation.

Recommendations

The findings suggest that for cognitively intact people to be rendered passive and voiceless is a disturbing experience. The institution from the perspective of respondents, appears to be serving its' own needs rather than the voiced needs of its' clients. As one woman said "I've never known so many meetings being held, everyday, in any institution....Don't the residents needs come into it at all?" A good deal of energy has gone into developing special programs and environments for residents with dementia type illnesses The same cannot be said however, for the minority of

cognitively well people residing in extended care facilities. The literature suggests that special programs and controlled, low stimulation environments are needed to maximise the health, quality of life and functional abilities of cognitively impaired residents. The number of health units specifically designed to provide dementia care have increased dramatically in the past few years and the hospital in this study included such a unit. On the basis of respondents expressed concerns, it is recommended that a plan be developed focussing on the needs of the minority of cognitively intact residents. Programs could be initiated which stimulate their intellectual capacities.

My data suggest that integrating cognitively well residents with people who are confused is not in the best interests of alert residents. The hospital society which is the residence of the women in this study, appreciate that residents with dementia benefit when the staff providing care understand dementia. Indeed when staff have the knowledge, the understanding, skills and patience, they tend to help individual residents maintain their capacity at as high a level of functioning as is possible. What respondents in this study have indicated is that the needs of cognitively intact residents are not very different from the residential needs of people who are confused. Alert residents also need to feel safe, in control of their day-to-day lives and honoured and respected as individuals. The data suggest that these kind of

needs can best be met by staff who are comfortable with cognitively well residents and understand their emotional needs. It would also be helpful if staff were trained in working cooperatively with cognitively well residents. Possibly, courses like "Serving It Right" and "Food Safe" would be helpful for staff to understand the basic etiquette skill which respondents said was lacking in their dining experiences. The issues raised by participants in this study suggest that without sufficient staff, more staff training and funding, care geared to specific client needs will not be possible.

It would appear that in meeting the everyday operating demands of an institution and meeting the budgetary requirements of maintaining the different hospital sites, the organisation is unable to respond to this specific client group. How quality time for individual clients can be structured into the system when everyone is so busy and even overextended, remains a difficult question. As a practising social worker in the long term care hospital system under study, I can appreciate that it is often difficult to find time simply to talk with, listen to and hear the people we are expected to serve. This fact does not go unnoticed by the resident population as Florence's words suggested: "You know you are a nice person to have on the job, because you have heard things from an actual resident and I guess you don't get that opportunity very much in your daily work". The hospital routine does impinge and make it difficult for staff to take the time to be present in a qualitative way

to residents. It is recommended that the organisation assess the way work is defined and allocated, and restructure where possible to allow for greater flexibility.

Annette proposed that reading sessions be made available to the minority of cognitively intact residents. This suggestion if followed could well be one way of valuing the human person and building a sense of community for this small segment of the resident population. I am convinced, that the hospital would get a response from the volunteer sector if it was made clear to the community that there are cognitively well, elderly people who need opportunities to keep their intellects alive. The opportunity to share the company of people able to communicate in challenging and supportive ways; to read and talk about books; and to share a variety of experiences, could dramatically increase the quality of respondents residential lives. If the organisation must continue to be an integrated facility, then meaningful experiences for cognitively well residents need to be implemented. It may also mean an expenditure of dollars should the organisation for example create spaces for conversation in shared rooms; which could enable residents to converse or have reprieve from the stresses of 24 hour integration. My assumption is that cognitively well residents would be given the opportunity to room with other cognitively intact persons.

If "the powers that be" according to Susy May, are serious about

making residency in extended care institutions a "home experience" the engagement and commitment of the organisation will be necessary. One suggestion would be to form a system wide task group or committee to look at the issues identified by the respondents in this study, who are cognitively intact, mature, wise women. They, like other cognitively well women living in integrated, extended care facilities, are the knowers and authorities about the experience of being a minority among an overwhelming majority of confused people. Perhaps some structures also need to be created which enable cognitively well residents to have a voice in the organisational goals and objectives.

Juan de Fuca Hospitals Society which was the site of this study, is known as a centre for learning and may well be one of the most progressive, resident focused, extended care hospital systems in North America. Indeed each of the respondents in this study purposefully chose Juan de Fuca Hospitals when faced with an admission decision. Resident councils and advisory groups are already in place. Among other systematic efforts to get to know residents more holistically, social histories are taken by social workers, as part of the admission process and are recorded on each person's chart. Nonetheless, the cognitively intact women who participated in this study did not feel heard in the dailiness of their residential lives; or that the established resident and advisory councils were responsive to

residents' felt needs. I believe that it must become a priority to empower clients to give voice to their experiences. Structures could be created to ensure those working in the field, time to listen to their clients' voices.

The findings in this study also suggest the need for further research efforts.

- 1) A limitation of this study is that gender specific issues associated with growing old and the work of caring for frail elderly people were not discussed in detail; and do warrant further investigation. Also a complicating factor is that old women are not a valued group in our society.
- 2) A review of the literature on integration in schools and the work force could add to our understanding of issues associated with the integration of cognitively intact people and others who are confused as a result of dementing illnesses.

Implications for Social Work Practice

I believe that a feminist social work practice approach, committed to the contextual understanding of the lived experiences of old, cognitively well women residing in integrated extended care facilities, is required to effectively empower this group of people. Participants in this study found themselves to be powerless as well as marginalized; not only because of their advanced ages and sex but because of their mental capacity. Social

work values the inherent dignity and unique individuality of persons and is committed to fostering a more just society.

Isolation is one of the mechanisms that keep older women oppressed. The women who participated in this study felt a profound sense of aloneness in the midst of the hospital busyness, among a vast majority of confused elderly people. Helping residents, individually and through group work, recognise that they share a commonality of experience with other cognitively well women, in extended care environments, will enable them to deal with some of the hardships, issues and concerns identified in this study. There is a power in shared conversation and the potential to build community by working to change our collective powerlessness. Nancy Wood's (1995) poem, Alive Alone, reflects something of the sense of aloneness the women in this study described. It also captures the inter-connectedness of women, struggling with the hardships of being old, wise and alone.

We are all alive alone.

Neither friend nor lover

Child nor mother

Can light our way for very long.

Out of loneliness

Arises the self we never knew.

Out of fear

Comes the wisdom of our ancestors.

Out of impatience

Grows the persistence of old age.
These shadows of our memory
Create new pathways to the soul
So that in being alive alone
We become alive together
(p.17).

What the women in this study said, was that they need to be listened to. Cognitively well residents want the opportunity to have a voice in their own care and to engage in purposeful activities. The data suggest that respondents do not feel that they are empowered in the hospital environment. It also reinforced the need to continue working at practising the skills of active listening, collaboration, advocacy and partnership. Applying group work skills to working with the health care team, residents and the hospital administration may help to generate alternatives to current care practices. Health care policy could also be included in these discussions. Respondents clearly stated that 24 hour integration was undesirable. I would suggest separate units and/or environmental as well as social opportunities for respite be provided by policy makers.

In conclusion, the poets, novelists, artists, researchers and staff want to empower these older people. Women in care need to have their voices heard. My hope is that this piece of research will help that happen

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APPENDIX A

The University of British Columbia Office of Research Services

Behavioural Sciences Screening Committee for Research

Involving Human Subjects: Certificate of Approval

APPENDIX B

Juan de Fuca Hospitals Society

Research & Ethics Committee

Approval

APPENDIX C

Letter of Information

APPENDIX D

Resident Consent Form

APPENDIX E

Interview Guide

Interview Guide

Through a series of relatively informal, open-ended conversational interviews I hope to discover, to understand and to accurately interpret the personal perspectives of respondents on living in an extended care facility where a great majority of the residents are elderly people with dementing illnesses. I am interested in discovering what issues participants raise. Is the quality of life of individual women, affected by their inevitable contact with cognitively impaired residents?

The opening statement will be "what I want to do is get a better understanding of what it is like for you to live at Juan de Fuca, with people who have difficulty with their memory".

As interviews proceed, respondents may be asked to elaborate upon or to describe:

- a typical day,
- what things give quality to daily life,
- what things create a quality living environment,
- what things detract quality from your living environment,
- and what their views are on living with confused individuals.

APPENDIX F

M.D. Hennessy Letter of Permission
To Include Her Pen and Ink Drawings