IT'S NOT QUITE LIKE HOME:
A STUDY OF INSTITUTIONALIZED SENIORS' EXPERIENCES
by
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ABSTRACT

The focus of this research is to understand the experiences of institutionalized seniors existing within contemporary models of care and the impact of their institutional policies. This research examined how 8 institutionalized seniors, ranging in age from 65 years to 90 years, experienced daily living in a facility setting where a client-centred model of care is established. These personal experiences were then linked to a governing set of institutional policies. This study looks at the impact these policies have on these seniors' experiences. Qualitative data was gathered through in-depth interviews. These seniors recognized the irony of their marginalized experiences despite client-centred models of care. This evolved as the major or overarching theme of this research. This theme was built on four paradoxical dimensions referred to as “incongruencies”; 1) home, but not home, 2) hurry up and wait, 3) very busy being bored, and 4) safe, but silenced. The informants worked in a variety of ways to cope with the incongruencies and contradictions in their environment including, lowering expectations, adopting dominant social language, values and beliefs, developing a survival support network, and manipulating the system to meet their needs. A discussion regarding the omission of key issues in policies, residual ageist policies contradicting current goals and philosophies of care facilities, and the failure to achieve genuine holistic client-centred care provide insight for social workers and health care professionals into the needs of frail institutionalized seniors.
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Next, I would like to thank my parents, Lillian and Jerold Grammer for their constant faith that I would finish this paper...one day. They were the essential motivation and inspiration for this paper as were my grandparents in the hope that facilities may provide a different perception of the value of old and frail. I am especially grateful to my husband who threatened, bribed, dictated, cajoled and begged me to finish my thesis. I'm happy to say, "we're still married".

Finally, I am most grateful to the eight residents who gave of their hearts, their minds, their souls, and their time. You have provided a strong voice for your peers which I hope will carry you through the winds of change to better things ahead. Thank you for your courage to speak out and your determination to live a life worth living.
I'm standing at the door to Jennie's room. It is open and I can barely make out her figure. She is sitting in her wheelchair by the windowsill. It's a sunny day, but you would hardly know this with the blinds drawn and the lights off. There are slivers of light streaming through where the blinds don't quite meet. It is the only light illuminating her room. She is staring at something – the television? The television is off. The wall? There is nothing on the wall -- it is difficult to determine at this point whether she is looking at anything visible to me. Whatever she is looking at, she appears to be almost in an intense, silent, trance.

I am reluctant to disturb this silence, but the omnipresent feeling of despair is in the atmosphere. Jennie looks very sad today. I gently knock at her door. She blinks several times, looks towards me, and squints. I am standing in the light and I realize my identity is difficult to make-out. She seems annoyed with me. I think I may have disturbed her like so many others today. She then demands that I step closer – out of the light that bothers her eyes – she recognizes me and suddenly breaks out into a terrific grin. Jennie has one of the best smiles you have ever seen. She has several teeth missing and most of her remaining teeth have yellowed and are broken to some degree, but her whole face smiles and her eyes absolutely sparkle -- one of the best smiles ever.

Jennie beckons me to enter and offers me a seat. She offers a set of stock apologies when she realizes her room is too small for a seat now that she's, "...always in this damned contraption." followed by some inaudible
grumbles of, "not enough room" and something about, "...as big as a shoe box...". She then recites another series of apologies, like psalms from a book of testaments, about her "crippled hands" and how she "is in too much pain to wheel her chair", "the prominent lack of a tea kettle to make a spot of tea", and her general appearance as she tugs at the impossibly crooked seams on her "easy living" clothes in a futile attempt to align them properly. She suddenly throws her hands up and voices frustration with her inability to change her situation. I have heard these apologies, from many of my own clients, a hundred times before. They always end in a coda of frustration.

This day I am visiting Jennie because it is time for one of our on-going discussions about her feelings regarding her increasing functional dependence. Since Jennie's physical condition has deteriorated, she has expressed great difficulty adjusting to her new limits within the confines of her existing environment. She exhibits on-going signs of depression and despair of her situation. She holds no hope for her future and has voiced repeatedly that she simply "wants to die". She begins to weep uncharacteristically and complains that she is deeply unhappy. This is Jennie's experience of being frail and living in an institution.

While Jennie, herself, is a unique individual with her own story, I have found her experiences, of living in an intermediate care facility, are regularly echoed by other residents living in the same kind of institutionalized setting. Having worked as a Social Worker in long term care facility settings for some time now, I find that my greatest challenge is supporting these seniors in their
efforts to remain independent while residing in a large communal environment with a general set of rules and policies that shape their daily life experiences and redefine their perception of "self". Assisting residents to reframe their point of reference from the policies that govern them to the inherent value of their unique existence has engaged me in an impassioned conquest to discover the origin of these recurrent issues in an effort to resolve them. What I believe I have discovered is that, it is not the Care Aide's fault, it is not the Nurse's fault, it is not the Housekeeper's fault, nor Cook's fault or any particular single person's fault. Besides, placing blame on people does not inspire solutions only hard feelings. Of course, I have to blame something. I choose to blame policies, or if you like, the "rules".

I am a "micro-macro thinker". I observe and experience life through a localized lens and translate this information by viewing it through a macro lens. As a result I often review positive social initiatives, which may have created an unintended set of consequences, once implemented. I began to question how these well-intentioned initiatives were mediated in an institutional setting with seniors. Operating under the assumption that policies are merely textual reflections of particular discourses in our society, I focused my attention on how these social processes were being mediated through texts. My curiosity led me to investigate several levels of policies in the British Columbia long term care system that seemed to contradict the improved results that they had intended.

In an effort to understand the challenges experienced by my clients, I needed a better understanding of the texts by which institutional seniors are
governed. Operating under the assumption that policy is simply a written or "textual" medium with which a dominant social group's ideology can be enforced or maintained, led me to focus on how these seniors experience this type of textual enforcement in their daily lives.

Policies may intend to support the right for seniors to perceive themselves as significant self-determining contributors, important and vital to our community. However, our frail, institutionalized elders have been further challenged by a multi-layered web of policies, which include interdisciplinary and professional policies, floor unit policies, the general organization's policies, facility licensing requirements, continuing care policies and, in B.C., the Ministry of Health and Responsible for Seniors (MHRS) policies.

While these policies may intend to support and protect frail seniors, often the values implemented within each set of these policies can contradict each other. One problem arising with these contradictions is policy-makers' unintentional neglect to recognize the existing contradictions may have deleterious effects on institutional seniors' lived experiences in facility settings. Further, while social values are changing in our contemporary society, some of the basic policies that exist in British Columbia have not been revised since 1978. A most discouraging thought, when I consider the sweeping changes that have occurred several times over the past decade, alone.

Perhaps we are waiting for some kind of permanency in our health care structure before we resolve to change basic policies. Of course, policy development is a dynamic process, as well, but this has largely been ignored or
misunderstood perhaps because of its exclusivity; Policy handbooks are difficult for the average lay person to obtain, much less a frail institutionalized senior. Once obtained, policies are often verbose, technical and generally unclear. Finally, let's face it...policy analysis for many seniors may be considered BORING. You will find I passionately disagree with this last statement, but my friends and clients' eyes roll heavenly upward once I begin my rant on policies and eventually they glaze over.

In this study, I ask the reader to consider how power can be maintained by the dominant group in our society via the language of text i.e. policies that permeate through our every day lived experiences. I implore the reader to keep in mind how dominant social processes are effectively mediated through exclusive texts, which keep the subordinate groups in our society at the margins.

Finally, I would challenge the reader to think critically about how the written word i.e. policies, can effectively enforce and maintain the dominant group's desired social order and fail to support the needs of our oldest, most frail adults. The core of my investigation rests on the discoveries I found when policy fails in its objectives by presenting absurd and impossible choices for institutionalized seniors to make in their daily struggles to survive.

Suffice to say, tackling all levels of these policies and rules is an impossible task for one person. It is my hope that this research may inspire a fortified multidisciplinary team – or perhaps an army of Social Workers and institutionalized seniors – to initiate a full investigation into the unintended consequences created by all levels of all policies in British Columbia's Long Term.
Care community. Our efforts should be aimed at simplifying and unifying policies and enacting them in the spirit in which they are intended. It is my hope to create an environment of empowerment, from these refreshing policies, for seniors in facility settings.

In my research, I will focus on a selection of institutional policies, which govern eight residents' daily life experiences; Maggie, Walter, Susan, Doris, Nadim, Marie-Lise, Helen, and Tony. Each of these eight seniors has his or her own unique and fascinating story about what it is like to live in an institutionalized setting for him or her. Each of them offers legitimate suggestions for a genuine change in the current structure. Each recognizes, in some form or another, that changing policies can change basic beliefs and values about who they are and what they want.

This thesis is organized in the following manner. Chapter One introduces my motivation and personal experience with frail seniors aging in long term care facilities. I review the formal knowledge existing on the topic of institutionalized seniors using demographics on old age, what we know about the social processes of institutionalization on seniors, the challenges our seniors face with the process of placement, and alternative models of care that have been proposed to improve life in care facilities, specifically, the Empowerment model, the Gilmore model and the Eden Alternative™. I then reflect on the current knowledge we have on the textual elements that may be impeding our quest to improve the quality of institutional care. Finally, I discuss what is missing from the body of knowledge that currently exists namely, the institutionalized seniors'
voices. As an addendum, I offer my thoughts on the power of policy and how policy may be strongly linked to the daily lived experiences of institutionalized seniors. Here, I ask the reader to consider the link between seniors’ experiences and the policies that govern every aspect of their daily lives. Gaps in our understanding of these links are highlighted throughout this chapter.

Chapter Two outlines the methodology for this study. I begin with the rationale for choosing a qualitative approach to this study followed by the conceptual framework within which I am working. In the conceptual frame I discuss the theories and principles that have informed this study and provided strong guidance for the design of this study. While the reader will recognize a number of structural and feminist principles in action, my primary source of information on this design is borrowed heavily from the principles of the Institutional Ethnography (IE) first introduced by Dorothy Smith. I follow by discussing my research question and my position as the researcher in this study before I review my process for data collection. My data analysis discovered one overarching theme built on four paradoxical dimensions, or more accurately, "incongruencies" that emerged from the data. These are outlined in Chapter Four. I complete my analysis by reflecting on my process of policy review and how the informants’ data is intrinsically linked to the policies that govern their daily lived experiences. Finally, I close this chapter with a reflective section on the validity of my design and approach to each section in my methodology. Here, I struggle with the weaknesses in my design and my efforts to compensate for the gaps that may still remain with this study.
Chapter Three introduces the profiles of each of the informants. I introduce the reader, on a more intimate level, to each of the informants' brief autobiography. The informants provide the biographical information in this chapter. Their choice of font and pseudonym are also included in each of their profiles. Some details were confirmed by existing health records, and by staff or family members for greater thoroughness. The intent of this chapter is to bring the reader closer to the informants' experiences and provide a deeper understanding of how each of these individuals perceived their daily lived experiences in a unique way. In this chapter you will meet Maggie, Walter, Susan, Doris, Nadim, Marie-Lise, Helen and Tony.

Chapter Four is the Discovery portion of this study. Here I discuss one overarching theme of seniors' experiences of being pushed to the margins with the current “client-centred” model of care. This concept emerged from four dimensions, I refer to as “incongruencies” based on the informants' data and related policies; 1) home, but not home; 2) hurry-up and wait: the conditions of caring; 3) very busy being bored; and 4) safe, but silenced. I reflect on how these policies present impossible paradoxical experiences for these seniors. In addition, I investigate the idea of the “work” they must complete to cope with these incongruencies in an effort to make sense of their daily lived experiences.

Finally, Chapter Five provides a discussion on three significant points regarding the resulting incongruencies; 1) the sins of omission, what the policies neglect to say, 2) a discourse on ageism, and 3) a discourse on holistic care. In this chapter, the contradictions that present themselves to institutionalized
seniors are discussed at a macro-level. I try to stress the impossible tasks that confront these seniors (when living within a textually inconsistent and paradoxical rule governed system) in their work to make sense of textually absurd world within which they exist. I close this chapter with reflections on the future role of social workers and social advocates endeavouring to re-story these experiences for this group and provide some hope for these seniors in changing their negative experiences of institutionalization to a more positive existence.
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CHAPTER 1
EXISTING KNOWLEDGE ABOUT INSTITUTIONALIZED SENIORS

I will begin with my own experience and observations during the placement of my three grandparents in institutional settings (nursing homes) over a period of fifteen years. I reflected on how they perceived their lived experiences in an institutional setting. Though their voices have been silent for many years, the experiences they have imparted, and the residual imagery of their lifestyles, remain vivid in my memory. What seems most impressive to me, now, is the different ways in which each of my grandparents, all placed at different times in various facilities, coped with and related their experiences to me and my family in an attempt to increase our understanding of their situation.

My maternal grandmother was the first to be placed in a brand new “state of the art” care home, culturally sensitive, large and very modern, after a debilitating stroke left her paralysed on one side. With few community resources in the ‘70s there was little choice for my mother, but to place my maternal grandmother where she assured “safety” and “good care”. While she was cognitively alert, her impaired physical functioning left her completely dependent on others for all her activities of daily living (ADLs). Unfortunately, her daily lived experience was one of humiliation, sadness and horror. I watched my mother, struggle to improve her circumstance with bi-daily visits to feed her, wash her and listen to her tales of woe until she died. Soon after, my maternal grandfather,
suffering from a series of small strokes and uncontrolled diabetes, was eventually placed in yet a different home, older, smaller and run by a church. Though he could express little verbally, he was more physically independent then my grandmother, able to walk, and able to communicate with visual cues and hand gestures. He seemed, to me, more content and my mother appeared happier with the staff, but still he seemed troubled by the lag in attention to his care and his loss of independence. Finally, my paternal grandmother was placed, many years later, in the same home as my maternal grandmother. The facility had grown and changed both physically and administratively. There was a larger staff population, a focus on education for staff, increased recreational programming, and it was becoming internationally recognized for its research into care of the elderly. The facility had a very long wait list, but my grandmother was not in a state of emergency placement and had time to plan and choose where she wanted to live, and this facility was her preferred choice. She always stated that she enjoyed her time in this nursing home, once vilified by my maternal grandmother, and stated they treated her like a “queen”, a far cry from my maternal grandmother’s cry of abuse, neglect and injustice.

These experiences were so different from each other that I was left with many questions, which remained unanswered as time passed. How could three institutionalized seniors, from relatively similar backgrounds and values have such paradoxical experiences? How did they create meaning from their experiences and in what way did they do this? Ultimately, I found myself working
professionally in the same field with seniors in facility settings and discovered that these varying experiences had not changed much over 25 years.

My clients experienced a wide range of perceptions about institutional living ranging from joy and appreciation to dismay, humiliation and despair. Older and hopefully, a little wiser, I began to critically question why there continued to be these incongruencies between institutionalized seniors. What was causing such a wide range of perceptions about facility living with these seniors? Why were so many institutionalized seniors struggling and so unhappy while others seemed content? Probing further, I began to ask the question differently, "How do institutionalized seniors experience their every day lived world?". Because of my personal focus on the social process of language and institutional policies, this question was then augmented by a secondary query, "How do texts, such as organizations' policies, impact the every day lived experiences of these seniors?". Soon I narrowed my inquiry to understanding institutionalized seniors' daily lived experiences and how these experiences are related to the Organization's rules (governing policies) that permeate every aspect of these experiences. The clients (residents) and I understood this query to be important. Now I only had to convince everyone else that this was a critical question to ask and that maybe the residents could shed some new light on this topic.

**Formal Knowledge Existing on Institutionalized Seniors**

In addition to the above personal account, I hope to guide you through a map of accumulated knowledge that has already been established on the
demographics of seniors, the process of institutionalization, transition challenges with placement, alternative models of care in the quest for quality improvement in facilities, challenges with organizational change, and what we know about textual elements impeding improvements to care. The gaps in our knowledge about institutionalized seniors will be highlighted as spring-board from which to launch my rationale for this particular study on aging.

The Demographics of Old Age

Do the Math. Aging is an issue we should focus our attention on. The demographics on the growing elderly population are impressive. In 1980, 12.6% of the British Columbia population was 65 or older increasing to 15.2% in 1990 and further 16.2% in 2000 (BC Statistics, 2001). This is 4% higher then the national average. It is projected that the elders in our province will continue to increase in numbers to 18.3% in 2010 and 22.4% by 2020 (BC Statistics, 2001). Nationally, Statistics Canada projects that seniors will almost double in numbers from 3.5 million in 1996 to 6.9 million in 2020 (Statistics Canada, 1998). Those 65 years old and older will peak over 20% of the total population in Canada by 2020 (Marshall, 1987) making this group one of the fastest growing populations in Canada (Statistics Canada, 2002).

While 92% of seniors live at home, 8% live in an institutional setting (Statistics Canada, 1991). Statistics Canada (2002) reports seniors are living longer with an average of 18 years past the age of 65. Elderly women are living even longer with an average of 20 years past the age of 65. While seniors have a longer life expectancy, it is has been noted that with an increase in life
expectancy comes an increase in disabilities (Statistics Canada, 2002). This
data may imply that, while the majority of our seniors live in their own homes, as
the oldest old live longer, they are more likely to experience a series of health
problems and disabilities, which may result in being placed in an institutional
setting to accommodate their care needs.

More impressive are the demographics of the older elderly in our country.
In 2000, the population of seniors aged 80-84 years was approximately 525,700
in Canada (Statistics Canada, 2002). A projected increase in this group's
population to 627,500 and subsequent increases to 942,300 by 2026 should
draw our policy makers and politicians' attention to their needs and issues.
Further, the oldest old, 90 years and older, are projected to increase in
population from 149,000 in 2000 to more than double this, 402,900 in 2026
(Statistics Canada, 2002). Four-fifths of seniors living at home report they suffer
from a chronic health condition (Health Canada: Division of Aging and Seniors,
2002). Twenty-five percent of these seniors have long term disabilities. This
rises sharply to 45% for the group 85 years and older. Further, those seniors
older then 85 years are 70% more likely to experience traumatic injury and be
admitted to acute care settings never to return home (Health Canada: Division of
Aging and Seniors, 2002).

It should also be noted that 85% of institutionalized seniors are older then
75 years and the majority are female (NACA, 1999: 44). The NACA states, "...it
is likely that the need for beds in institutions will continue to increase in tandem
with the increase in the number of people who are very old...numbers of seniors
in institutions have increased from 203,000 to 240,000 from 1986 to 1996 in Canada...” (1999: 44). The implications of these statistics set the stage for reviewing our social policies on health care for frail older seniors as this group is anticipated to double over the next 25 years -- many of whom are likely to be living in institutional settings.

I would like to bring to the reader's attention that, often, these demographics have been used by the media to satisfy our dominant social group's ageist ideals with alarmist reports of escalating health care costs, calling it, "a fiscal black hole", and projecting, "apocalyptic demographic forecasts" (Gonyea, 1997). Researchers warn that with the increase in sheer numbers of seniors in Canada we must focus our attention on increasing the awareness of a need for improved institutional services for the frail elderly as a result (Fabiano, 1992). While the evolution of Canadian nursing homes are described in Forbes, Jackson and Kraus', *The Institutionalized Elderly in Canada* (1987) and in Gifford's, *Canada's Fighting Seniors* (1990) as a triumphant achievement for seniors, the authors implicate the current terminology affecting seniors' image has not gone farther then exchanging derogatory terms such as "poor houses" to a less critical use of "nursing home" and "long term care facility" (Forbes et al, 1987).

I found I was often reading about a congregate culture where little was mentioned about contributions to our society, but much was discussed about the drain on it (Curtis et al, 1999; Rosenthal et al, 1993). The concept of drainage can be supported by the demographics implying there will be new demands
placed on the system by older more frail clients. The demographics can be used to create a sense of urgency about the burden that our frail seniors will soon be laden upon our society. This sentiment will further marginalize an already chastised population. The interpretation of this quantitative data begins to paint a foreboding picture of the impossible burden that the elderly impose on the health care system and are often blamed for the crisis in health care today.

Simultaneously, these numbers urge that these new demands require an immediate response to impending changes in our social values and expectations of a baby boomer culture growing old (Fabiano and Martyn, 1992). Armstrong and Armstrong (1996: 88) reinforce this contention and declare that, "With over 200,000 Canadians in residential care – three quarters of which are in nursing homes for seniors...attention must be focused on a radical change in the current operation of our health care sector". This data implies a change is required in our current approach to care for our institutionalized seniors who occupy the majority of residential care settings in Canada (Statistics Canada, 2002).

Aronson (1994: 20) draws attention to the movement towards maintaining frail seniors in their own homes, describing the perpetuation of blaming frail seniors in the following example:

"...in an article entitled Bed Blockers Blamed for Emergency Ward Crunch, author D. Grant quotes the executive director of the Hospital Council of Metro Toronto. He describes long-term care patients as."... imposing on the system. Nobody wants them..."
This statement implies even greater distress about the marginalization of elderly women, as they represent the larger portion of the oldest old and occupy the majority of spaces in facility settings (Statistics Canada, 2002). Aronson (2000) warns that the frail elderly women are painted as, "passive bearers of needs" to be efficiently managed in our society. She further states that while the reductive images of elderly people are embedded in dominant policy discourse, we hear little from the seniors, themselves. She goes on to recommend that our focus needs to be on elderly female interpretations of elderly females receiving care. Freeman (1999) develops a specific discourse on this issue by discussing the damaging portrayal of the frail elderly women in light of the presentation of the socio-demographic and media information and demonstrates how elderly females' reflect this position when experiencing acute care settings.

In contrast to the foreboding sentiments made above, a more positive spin on the demographic reports have been published by Statistics Canada who point out that: “Canadian seniors form 12% of our current population, they are living healthier longer” (Statistics Canada, 1998). Most seniors are considered healthy and fit in recent years and this is good news (NACA, 1999). However, this still tends to marginalize the remaining 7% of more frail seniors who depend on the care of others and rely on the current residential health care structure to support their quality of life (Statistics Canada, 1998; NACA, 1999). No encouraging information about this 7% of seniors is currently imparted on us and the few positive images we receive in pamphlets and advertisements (Richmond Lions Manor, 1998; Amica 2001), for long term care facilities, are unconvincing. The
National Advisory Council on Aging (NACA, 1999) does warn that these improvements in our elders' lifestyle should not overshadow the needs of frail elders who become marginalized by the manipulation of this information. While the focus on our healthy, independent seniors may suit the policy-makers' fiscal agenda to justify a reduction in funds to seniors issues, health care workers and social workers must be ever vigilant in bringing attention to the plight of the frail, institutionalized senior. The NACA states they are currently striving to, "... take a broader view of the issues, looking not only at what an older population "costs" but also at what it contributes to the overall well-being of society..." (1999: 7).

The NACA (1999) highlights seniors' contributions in time and money for their families and voluntary organizations, a point largely ignored in policy development. The NACA also raises awareness about our obsession with demographics, which may not be the most important factor in determining future health costs and revenues. This is a sharp reminder that society makes little use of its elder members, perpetuating ageist internal policies of enforced retirement based on age, not skill or abilities.

In further studies on our aging population, quantitative data from Moore, Rosenberg and McGuiness (1997) use variables such as gender, mortality, and immigration to link the issues of health related institutions and the living arrangements of seniors in a socio-demographic context. Curtis, Grabb, and Guppy (1999) profile the impact of these demographics on public policy in the 65 and older group. Their data links these variables of age, income and shelter to the development of public policy initiatives but, does not provide much insight into
what specific policies exist and what specifically needs to be changed. In other
research the forecast of the health care "burden" that Canada will experience
over the next fifty years is somewhat overwhelming (Rosenthal, et al, 1993). As
a result, a picture of economic strain on the health care structure begins to form
and tends to blame a minority of frail elders for all of our socio-economic woes.

My concern is that, while all these authors intended on improving the
reforms for seniors at a policy level, the unintended consequence of the
demographics may allow policy-makers, in an age of neo-conservatism, to
interpret these numbers anyway they want in an effort roll back on funding for
institutionalized seniors and transfer the remaining available funds to caring for
seniors in the community setting. This ideal, while providing much promise
towards supporting aging-in place initiatives, further marginalizes institutionalized
seniors and those seniors requiring future care in an institutional setting. My
concern is, while we are concentrating our research and funding efforts on
maintaining our seniors in the community, we may be neglecting the issues our
seniors face in institutional settings.

The Social Processes of Institutionalization

When I looked at the process of institutionalization I found qualitative data,
which informed me more specifically about my interest in the experiences of
institutionalized seniors. I found a number of narrative pieces on health care
workers' institutional experiences in aging. Gubrium (1975), in early work, uses
qualitative methods to provide insight into the staff hierarchy of labour
established in long term care organizations and the behaviours of seniors within
this hierarchy. Gubrium (1975) focuses on how the administration is removed from the everyday work world of the floor staff and the consequences of this established practice with respect to staff attitudes. Cox and Parsons (1994) interview institutionalized seniors in an effort to relate their experiences to multidisciplinary team conferences in an effort to improve the client centred/client empowered model used during these conferences about seniors' care. The focus and goal is to empower these seniors and improve their care in the specific area of staff/team meetings and care conferences conducted in care facilities. More specifically, I found information on particular staff experiences by authors such as Vesperi (1983), who gives us a glimpse into the everyday life of care aides in long term care and Diamond (1992) who produces a groundbreaking piece of research on care aides in facility settings. Diamond provides insight into a care aide's lack of initiative and why they follow orders and refrain from asking questions. He proposes that as a result of a care aide's marginalized status, the residents may be receiving the message that they are passive recipients of care. Diamond continues to provide insights, as a care aide, himself, into the assumptions that are made by seniors as a result of the dominant group's social processes at work. Again, this work focuses on how these dominant social processes of the administrative staff are imposed upon the subordinate frontline care staff in institutional settings. The goal of Diamond's study is to enlighten the administration on a care aide's challenges and solutions through new models of teaching and training. However, the residents' voices, in this piece, are heard only in an effort to validate the focus of a care aide's plight in long term care, not
a resident's challenges. A gap in our knowledge of the residents' experiences remains.

**The Challenges Seniors Face with Placement**

Hoping to find more first person accounts of experiential data in long term care beyond the employees and administration, I expanded my search to any personal accounts or interviews on the subject. Most of the information provided came from the caregivers' perspectives. There are key pieces of research on the care giver's perspective on aging and institutionalization provide greater insight into their challenges with frail seniors but, focus primarily on the caregiver's voice and issues (Kitwood and Bredin, 1992; O'Connor, 1999; Pearlin et al, 1990). More specifically, these authors are concerned with the challenges of caring for frail seniors living independently or with family in the community – a much needed area of research but, providing little or no further insight into the institutionalized seniors' experiences and concerns.

Hoping to get closer to hearing from frail institutionalized seniors I began to search for their voices in our current knowledge base. I discovered that Agich (1993) conducts an exciting phenomenological study on the subject of autonomy in long term care. To my surprise, however, he does not actually involve any live participants in his study, rather, he obtains his information from other written sources. Without actually interviewing a single institutionalized senior, he comes to the conclusion, however, that "elders find the world of the nursing home a foreign and forbidding, purgatory, a fate worse then death..." (Agich, 1993:52). He does, however, raise an interesting issue about the "work" that seniors do in
remaking their new world of experience and reconstituting the meaning of structure for their lives as related to the concept of autonomy within an institutional setting. I would like to have read more insights about the "work" that institutionalized seniors do everyday to create meaning from their lived experiences-- from their perspectives.

Fabiano (1992) confirms that there are many elements that exist within a care setting that reinforce a client's loss of control and choice in their environment i.e. using the label, "resident" or "patient" within a care home setting and that acceptance of these kinds of labels may lead to resignation on the part of the resident. Fabiano boldly states that 100% of the clientele within a long term care setting are candidates for depression but, this could be said for anyone of anything so the statement seems to be misleading. Another study (Cooper, James, Harris & McGready, 2002; 526) show that sadness in frail, institutionalized seniors leads to death within two years after the age of 65. However, gap remains in the data about institutionalized seniors' experiences of depression, which may provide a richer picture of institutionalized seniors.

Savinshinsky (1991) begins to interview some seniors in community to reveal that placement is seen as a last resort for those who can no longer help themselves. They perceive these seniors to be the "rejected" elders neglected by society and banished to its margins. Savinshinsky (1991) focuses on the issues of rejection and loss as it is voiced and perceived by seniors living independently in a community setting.
Forced to go further back in time in my search, I found three authors who conducted autobiographical accounts of institutional living (Baum, 1977; Bohuslawky, 1989; Laird, 1979; Mead 1991). All these authors provide a first person account of institutional living and the experience of getting old. These pieces approach the realm of answering my questions but, I found gaps in my knowledge base still remained. Baum (1977) chastises the nursing home industry, but does not provide any insight into the shaping and construction of his perceived world. Bohuslawsky (1989) provides first person accounts of life in nursing homes told by both the residents and staff with a goal to expand home care programs, in particular, and discuss an alternative model of care (to be discussed later in this chapter). Bohuslawksy has a clear agenda for promoting his alternative model of care home but, provides a compelling quote from one institutionalized senior who states, “Life in a nursing home is a thousand small indignities…” (1989: 16.).

Notably, Laird (1979) journals a detailed account of these “small indignities” in her personal experience of getting old in a facility setting. She discusses such issues as her profound loss of control over everyday life, her preoccupation with her bodily functions (eating, excretion etc.), her feelings around her financial insecurity and, her overwhelming sense of isolation. This single issue, a sense of isolation, is further investigated by the Association of Advocates for Care Reform (AACR) when they interviewed institutionalized seniors for their study, Alone in a Crowd, 1997. They discuss the irony of seniors in a crowded facility setting and their experiences of feeling alone and
lonely. Laird (1979) also provides insight into the distortion of her own perception of reality and sense of time and acknowledges her loss of self-identity. Though this piece is compelling, it is a small piece with little insight into how she feels she has lost her self-identity and why her reality and sense of time are distorted. Mead (1991) supports these contentions with her narrative approach but, falls short of providing a link to how these meanings are constructed and why. Mead's (1991) first person account of her nursing home experiences seems to echo those of Laird's (1979) with an expanded understanding of the impact of a medically oriented institution on her experiences and does provide some recommendations for change.

Thus, my question of how institutionalized seniors’ everyday lived experiences are shaped by the ideologies mediated through textual elements of rule governing systems is partly answered. Further, none of these authors provide any insight into why some residents enjoy living in a facility setting and argue their experiences are very positive.

Rojiani (1992) conducts an enlightening case study on the disparities of the social construction of long term care and begins to answer these authors’ experiences on “how” their experiences are constructed with a case study on one elderly woman. However, I was disappointed to learn that the interviews were conducted in the community setting as she recalled her experiences with hospitalization and community care. This study, while an excellent platform for the voice of one senior, provided me with less information than I anticipated, regarding a variety of seniors’ perceptions of institutionalized care while in the
setting. I had come to a dead end. My quest to find the voices of institutionalized seniors experiencing everyday life through rule governed systems seemed to come to an end. My question was still unanswered and the answers I had, I was beginning to question.

**Alternative Models of Care: The Quest for Quality Improvement in Facilities**

What seemed consistent in my readings, so far, was the impetus by these authors to suggest policy reviews and provide initiatives for alternative models of care in an effort to change particular social processes at work in institutional living. Gubrium and Holstein (2001) in *Institutional-Selves: Troubled Identities in a post-modern world*, describes the cultural impact that institutionalization has in the shaping of self-image on such groups as inmates in prison and residents in nursing homes. Here dominant social processes create negative experiences such as, feelings of great loss, mortification, and degradation. Gubrium and Holstein (2001) further describes the dismantling of the signifying aspects of one's former life, and the erosion of liberty and privacy, which contribute to the reconstruction of one's identity. These experiences are studied to determine the extent to which restrictive, rule governed environments can reshape the individual's self-image.

This same effect is investigated and paralleled in the culture of frail institutionalized seniors in Bowker's (1982) *Humanizing Institutions for the Aged*. This qualitative piece incorporates the concept of psychosocial roles that staff, management and residents play in relation to each other in an institutionalized
setting. Bowker discusses a variety of role types that residents adopt in institutional settings and draws comparisons to the roles inmates assume in prison life. Both Bowker (1982) and Wells et al (1992) discuss a radical departure in models of residential care from the current dominant medical model to a more humanistic, empowering, resident focused approach to care. The NACA supports these kinds of initiatives. The NACA briefly points out that health and social services can adjust and respond to the evolving needs of the aging population to encompass institutional care needs based on residents’ needs rather than on organizational requirements (1999:13).

At this point in my search I discovered there were efforts being made to suggest alternative models of care in the quest for improving the quality of life for seniors in institutional settings. Wells et al (1992), as mentioned above, collect narrative accounts from institutionalized seniors in addition to staff and family in an effort to develop an empowerment model of care. This model presents a client centred approach to care where the focus remains on the client with a stronger psychosocial approach and departs from the current traditional medical model approach to care. Another model suggested is the Gilmore Lodge Alternative, founded by Bohuslawsky (1989). He suggests that care for frail seniors should occur in a smaller setting of 75 residents or less. This would reduce the stress of high ratios of residents to staff and create a more intimate home setting. This would increase the ability of the staff to provide individualized, dignified and client centred care. Finally, there is the Eden Alternative™ founded by Dr. William Thomas (1996; 1999a; 1999b), which
advocates a resident and staff driven philosophy of care. This is a radical departure from the traditional models of care we see in most nursing homes. He proposes 10 principles (Appendix F) from which to guide staff and families through a more resident driven model of care. Some promising research has been conducted on the Eden Alternative™ (Chevremont, Fuschberger and Miller, 1999; Ransom, 2000) and many narrative testimonials have been submitted online about the success of facilities using this philosophy of care (EdenAlt Website, 2003). There are even a number of long term care facilities in British Columbia adopting this philosophy. However, after much searching, I found that the current narratives that exist originate from staff and family and seem to dominate the websites. Again, the voice of seniors regarding the value of this model of care is missing. Further, while it is growing into a very comprehensive and promising practical philosophy of care, little has been noted about what facility policy changes are required to support this philosophy of caring in institutional settings.

**Textual Elements Impeding Improvements to Care**

Hoping to find some information on textual issues combined with narrative experiences, I turned to those studies using institutional ethnography as their methodologies. I revisited those more recent qualitative studies exploring nursing homes and the social relationships between institutionalized residents and staff (Diamond, 1992; Gubrium, 1975; Kayser-Jones, 1981; Wells et al, 1992). However, discussion about the organizational policies that shape the attitudes and roles of this culture is only briefly mentioned in these works. This
suggests that more research is required on the link between institutional policy and the residential senior's lived experience. Wells et al (1992) also links personal experiences to policy initiatives but, most of the data seems to come from the interviews of staff and family and little is heard from the seniors, themselves.

To my dismay, I found the information connecting institutional policies to residents' lived experiences through narrative discourse was scarce. What there is of the existing research linking polices to these residents is compelling but, narrow in its focus on issues or limited to staff and family as targets (Association for Advocates of Care Reform, 1997; Campbell, 1998; Hepburn et al, 1998).

Finally, I remind the reader of Campbell's, Institutional Ethnography and Experience as Data, (1998) which draws linkages from organizational policy to its impact on staff experiences in nursing homes. This is the closest I came to investigating the links that individuals in an institutional setting i.e. seniors, make to the policies that govern them and the barriers these policies may present. There is no qualitative data, to date, linking the impact of specific organizational policies on the daily lives of the seniors who are governed by them. Therefore, my research is a continuation of this quest for understanding the link between residents' and institutional policies, as you will read in the following chapters.
What's Missing from this Picture? The Voices of the Institutionalized Frail Elderly

After review of the current literature I recognized that a gap still remained in our knowledge of institutionalized seniors experiences. Given the current projected demographics and the existing knowledge base, it seemed relevant that the resident's narrative experiences be included. I couldn't help but wonder why such an obvious voice had not been heard from. Indeed, Diamond (1992), Gubrium (1975) and Mead (1994) are to be applauded for their radical narrative approach in bringing the resident's voice to the academic table. However, while there is some discussion about general policies in relation to these seniors' stories, the focal point is on the resident's experience of "care" in the facility. This tends to perpetuate the image of dependency that drives quantitative research and policy-makers to justify their bottom-line approach. There is more to the culture of facility living then just the "care" aspect and there is a deeper connection to how the specific institutional policies impact on these seniors' daily lives, which is not mentioned in the current research.

The Power of Policy

"Meals are at eight, noon and five pm. Lord, help me if I want to sleep-in or eat at six [pm]. Ain't no way that's ever gonna happen. Eight, noon and five. That's the law." (Jennie reflects on the structure of her day, 1999)

Policy is very important to me. When residents begin to express similar issues of concern to me, I tend to question how policy fits into the picture. A
resident's self-image is often a reflection of the policies, which shape and govern them day by day. In my experience, many of my peers understand the importance of policy, but would rather intervene at the frontline in their practice then spend their very precious time pouring over reams of dry, wordy policies. I, on the other hand, find policy very exciting. To me, policy is a living, breathing, dynamic process that holds the potential to shape attitudes and drive practices. I believe policy to be the foundation upon which a social structure is built. Once a policy is developed, it becomes a rule or, as Jennie so aptly described it, "...the law". Institutional policies are a set of rules or laws by which staff and management are guided to perform their daily tasks within a large, organized environment. In Model Standards for Continuing Care and Extended Care Services (1999:6), the Ministry of Health and Ministry Responsible for Seniors (MOH) defines policy as:

"...written statement that identifies and interprets the organization's position on a given subject. Policies prescribe limits, assign responsibility, set out expectations and serve as a basis for on site decision making."

Policies can come in the form of "residents' rights", organizational visions, administrative mission statements, union job descriptions, and resident handbooks. Policy occurs as a multilayered, multifaceted and entangled set of rules, which govern our society at all levels. Policy can be experienced a macro level i.e. government, public health, economics, education and welfare. Private and non-profit organizations have policies, which provide the framework for their operations. We even have policies, albeit unwritten, in our own home. Family
rules, values and expectations all develop from personal policies. Policies shape our roles in society, guide our practice and manage our behaviour. In this research, the focus is on institutional policies. In my practice, I always ask to see the facility’s current Policy and Procedure manual. All licensed long term care facilities require at least one manual on site (Community Care Facility Act, "Adult Care Regulations", 2000). I regularly have to search for it and dust it off, but it exists within the construct of an organization's setting.

The struggles of policy makers become evident as the language of a policy begins to unfold into a verbose edict of patriarchy. Often the language is formed in "legalese", incomprehensible to the lay person and obtuse to all but, the most articulate of lawyers. From the Resident Handbooks I have read, in the Lower Mainland, B.C., seniors are not often provided with the overall policies that govern them. Instead, these policies are substituted by a set of "rules", which are explained to the resident upon admission. Language is by no means neutral or innocent in this process. It is plagued by "...presuppositions of Western metaphysics" (Coward & Ellis, 1977: 123). My hope is to better understand how institutionalized seniors perceive themselves and their existence under the influence of the values imbedded within these policies. This is my attempt at reframing the nature of policy to develop a stronger enthusiasm from the reader for involving himself/herself in the creation of policies in general.

To understand the power that policy wields in a social construct is to be empowered. Miller-Chernier aptly defines policy as, "...sets of interrelated decisions about the selection of goals and the means of achieving them within
specified situations." (1995:2). Who are the designers and analysts of public policy? Policy is generally forged by the dominant group in our society. This group tends to come from a privileged background of education and/or wealth, which affords them the opportunity to grasp with thorough efficiency one of the most powerful expressions of human communication, language. Policy is built on language that possesses an inherent set of dominant values within it.

The Foucauldian idea that language is always located in discourse refers to an interrelated "system of statements which cohere around common meanings and values...[that] are the product of social factors, of powers and practices, rather than an individual's set of ideas" (Holloway, 1983:231). This group, however unintentional, tends to inscribe its values and beliefs on our society through their selection of language, which is then defended under the edicts of "policy changes" and "developments". The inherent oppressions felt by the minority group in this construct are concealed within a complex series of layers of institutional and rule governed language. These policies are infused through every facet of an individual's life. Identifying which policies are oppressive or contradictory is an enormous task, given the dynamic behaviour of our social policies.

Canada's public health policy can be quite fickle. While our public policies could remove barriers to good health, this is not often the easy or accessible choice (Truman & Trueman, 1995). Further investigations into BC Long Term Care Facility licensing laws and the expectations of the Canadian Council on Health Services Accreditation on their philosophical approach to the dictating of
standards by which nursing homes are recognized for their "good care" are
desperately needed. Deconstructing this complex set of laws, regulations,
policies and mandates would aid in understanding the empowerment barriers to
institutionalized seniors. While there is a strong understanding that these
regulations and standards are created in the spirit of "accountability", this has
often meant a double-edged sword of quality of care tempered by fiscal
responsibility. The current approach for improving the quality of life for
institutionalized seniors is presently fragmented and incomplete (Truman &
Trueman, 1995).

Thus, the challenge for institutional policy-makers becomes evident as the
language of a policy begins to unfold into a verbose edict of patriarchy. Often the
language is formed in "legalese", incomprehensible to the lay-person and obtuse
to all but, the most articulate of lawyers and administrators. Seniors are not often
provided with the institutional policies that govern them. Instead, these policies
are reduced to a set of "rules", which are explained to the family of an exhausted,
anxious resident upon admission. The resident may never actually be
introduced to these rules and tends to learn them along the way through trial and
error. Policy-makers must begin to recognize the power language wields on the
shaping of human experience.
Linking Policies to The Social Behaviour in Institutional Settings

Mullaly's (1993) work on structural social work begins to explicate the link between micro and macro level practice. He contends that policies are used as a manifestation or means of controlling behaviour. Both Carniol (1992) and Moreau (1980) offer social workers a challenge to review our practice methods and include the concept of social structures imposing the dominant group's values and beliefs on the behaviours of its subordinate actors. Explicating the link between macro level ideologies and how these values and beliefs are experienced by seniors is a critical gap in our knowledge about institutionalized seniors' needs. If we look at seniors' experiences of these macro level ideologies and their link to written texts we may begin to understand the behaviours these policies support and shape in institutional settings. Explicating the link between policy makers' values and beliefs that often reflect the dominant group's assumptions may help us better meet the needs of the seniors subordinated by these social processes in their everyday lived experiences.

The purpose of this research is to understand frail seniors' reflections on the discourses of ageism and holistic care in institutional settings. It further strives to reveal the level of awareness that residents possess regarding how the “rules” or organizational policies directly affect not only how they live their daily lives but, how these rules reshape or reinforce their self-perceptions in an institutional environment. A first person perspective from residential seniors will help us to better understand how the context of their daily experiences is directly
linked to the policies that govern them. What results from this insight may change how we, as social workers, perceive our own roles in relation to these residents and the policies that impact our services, as well. Perhaps, we will transition to a more appropriate role as “social advocates” providing critical alternative policies, which better reflect these residents’ perceived needs rather than servicing the current organizational agenda.

**Summary**

The above literature review demonstrates that, although the current knowledge about the experiences of seniors is well documented in a variety of arenas, it is still lacking the significant voice of the institutionalized senior his/herself. The institutional policies that shape these daily experiences have only been alluded to. Highlighting specific policies, which create a social structure of personal experience upon which frail residents reflect, requires more attention and investigation.

This study seeks to enhance the current knowledge base regarding institutionalized seniors experiences from a first person perspective. Hearing their personal stories may help professionals in the health care field and policymakers develop a more humanistic approach in long term care facilities that meets the needs of the residents rather then those of the organization. Therefore, this research proposes to:

1. Hear from residential seniors, first hand, about their daily experiences living in an institutional setting;
2. Raise awareness about the link between these seniors' personal issues and the policies that govern them;

3. Recognize the work that institutionalized seniors do to reconstruct the meaning of their daily experiences under a textually rule governed system;

4. Provide recommendations for improving services to institutionalized seniors through policy changes;

5. Identifying which policy changes and initiatives are practiced in real life settings. By suggesting ways in which Administrators, Policy-Makers and Social Workers can improve their practice through proactive leadership within institutional settings that focus on a resident driven model of care.
CHAPTER 2

METHODODOLOGY

This chapter intends to guide the reader through the methodology I used in the design of this study. I begin with a discussion of my rationale for choosing a qualitative, instead of a quantitative design approach. Next, I build a conceptual frame, which informed my techniques for collecting and analyzing the data. In the conceptual frame section, I will discuss the principles and theories from which I draw guidance for mapping my research, the development of the research question and my positional relationship as a researcher in this study. Following this, I introduce my techniques for collecting the data. In this section I review my techniques for informant recruitment, interviewing, reviewing policy and managing the data. Then I elaborate on my process for analyzing the data collected. One overarching theme built on four incongruences emerge from the analysis, which are introduced in this chapter and discussed, in-depth, in Chapter Four. Finally, I will review the validity of this study through an examination and evaluation of the gaps and limits this study presents.

A Place to Begin: Choosing a Qualitative Approach

The question that drove this study was, "How are institutionalized seniors' daily lived experiences shaped by the policies that govern them?" Reflecting on this question, I felt the best way to gain an understanding about the connection from the subjective experiences of institutionalized seniors to textually rule governed systems, was to "hear" from the seniors, themselves, and then review organizational policies. Therefore, a qualitative research design, with its focus on
experiential data (Crabtree & Miller, 1992; Creswell, 1998; Maxwell, 1996) was selected as the best approach to understanding the daily experiences of residential seniors and how these experiences link to institutional policies. I decided on a qualitative approach based on Creswell’s (1998:17-18) criteria i.e. the nature of the research questions requires an exploration of what is happening in a particular instance, the desire to study individuals in their natural setting, and the behaviour patterns are not easily explained by current theories and require developing. Further, I had personal interest in writing in a literary style, I had sufficient time and resources to conduct a qualitative study and a desire to portray my role as an active learner in this process.

A qualitative design provided me with an opportunity to investigate and question the relationship between the lived experiences of these seniors and how they are linked to the multilayered rule-governing texts within which they live out their daily lives. A qualitative investigation affords me the opportunity to better understand how dominant social ideals are maintained and mediated through written texts such as, policies and then reflected or supported by seniors governed by these texts and ideals. For example, the language that both seniors and policy makers use can help to identify and articulate the experiences of institutionalized seniors with a better understanding of what their needs are. The term used to describe the environment in which these seniors live has meaningful implications depending on the user’s frame of reference.

Personally, I have found that professional consultants, administrators and policy-makers tend to define these environments as "long term care facilities", 
staff often refers to them as “nursing homes”, families can be heard to call them “residential care homes/nursing homes” and the residents range in their interpretation of their environment from referring to it as a “home”, a “hospital” or, worse case scenario, “prison”. The very term these groups choose to use, when describing the institutional living environment, seems to change the way in which living in this setting is perceived on a day to day basis.

A qualitative research design enabled me to investigate these language discrepancies. Maxwell (1996) defends qualitative research because it seeks to understand how participants make sense of events and how their understanding influences their behaviour. Qualitative research has naturalistic, discovery-oriented, descriptive and interpretive qualities that easily lend themselves to the field of social work (Maione & Chenail, 1999). Qualitative research has no set or pre-constructed design as qualitative researchers use a variety of methods, procedures, and analysis techniques “to create unique, question-specific designs that evolve throughout the research process” (Crabtree & Miller, 1992:5).

I chose a qualitative design based on my assumption that, because the subjective lived experience is ever-changing the research should provide the arena in which to reflect this dynamic process. In addition, the flexible emergent nature of the qualitative research design allows the researcher to discover and explore new understandings during the data collection stage (O’Connor, 1996). As the participants’ stories evolved and changed at their prerogative, my approach was allowed the same dynamic flexibility.
To further illustrate my choice for a qualitative approach to this research I would suggest that this method encourages open-ended questions such as my initial probe, “Tell me what it is like for you, living here”. This shifts the position of power from the researcher to the informant as the “story-teller” and the “expert” in his or her personal experiences. The informant explains how meaning is constructed through his or her interpretation of these experiences.

Collaboratively, the researcher and informant can guide the conversation through a set of follow-up questions and responses, if desired, which are directed by the informant. In this case, I consider the textual elements of these ruled governed systems, in particular, institutional policies. I engaged in this research with a prior assumption that these policies may dominate meaning in the daily lived experiences of these seniors.

A qualitative approach proved challenging for me. I am comfortable in quantitative investigations and found the initial part of my journey through this qualitative research unfamiliar and tenuous (Maguire, 1993). My confidence grew with my choice of design. Over time, I came to understand the larger significance in providing an appropriate arena for these residents’ voices to be heard on their health care issues. Perhaps, one day, we can begin to provide an amphitheatre for their stories. For now, this “soap box” will have to suffice.

The Conceptual Frame: Theories and Principles Informing this Study

I began this investigation by learning about ethnographic research. In this study, my role as a kind of “ethnographic” researcher is “participating covertly or
overtly in people's lives for an extended period of time, watching what happens, listening to what is said, asking questions" (Hammersley & Atkinson, 1995:1). Gubrium and Sankar (1990:11) defend the use of a variety of ethnographic studies:

"Policy initiatives run the risk of inappropriate targeting, inadequate implementation, and unrealistic goals. Taken together, these understandings suggest the broad outlines of an emerging, ethnographic research agenda. It is important that studies of the home care experience be flexible enough to explore, be open to the natural characteristics of the home as a setting, and aim for the kinds of analyses befitting the native dynamics of the household and the institutions to which it is linked. Findings from this type of research can provide the basic information required for effective policy development and implementation".

Hodgson (2000) further defines the rationale of this approach by aligning the researcher more closely with examining the world in its natural state in which the researcher adopts an attitude of respect and appreciation for the social world. While "ethnography" represents one tradition in qualitative research (Creswell, 1998; Fetterman, 1989), I chose to narrow the use of this approach to borrowing heavily from one particular area of ethnographic study, *Institutional Ethnography (IE)*. IE is a newer, emerging path of inquiry. I must clarify, at this point, that my study is not an institutional ethnography, itself, but rather, a reflection of many of its values and principles. I chose to use many principles from this dynamic mode of inquiry because of its focus on the social processes of
a cultural experience by a collective group through individuals' personal experiences within it. DeVault and McCoy (2002) state;

“Institutional ethnography takes for its entry point the experiences of specific individuals whose everyday activities are in some way hooked into, shaped by, and constituent of the institutional relations under exploration. The term ethnography highlights the importance of research methods that can discover and explore these everyday activities and their positioning within extended sequences of action.” (p.753)

Frail seniors are often forced into a fabricated communal “custodial” culture that is generally foreign to any prior experience they may have (Armstrong & Armstrong, 1996). An IE design provided greater insight into how they perceived this new meaning of their lived experiences in a formal rule-governed system. Therefore, many principles from the IE approach seemed most appropriate to my study of understanding the link between residential seniors’ experiences and the system of policies that rule them.

The term “institutional ethnography” originated with Canadian sociologist Dorothy E. Smith (1986; 1987; 1995; 1999). Institutional Ethnography is both a theory and a method of social inquiry that draws linkages among the physical environment, everyday events in time and the social relations with which they are coordinated i.e. administrative agendas, professional practice, policy making, and the various rules that impose a structure of governance upon these actors.
The principle of this design enables me to use institutionalized seniors’ everyday lived experience in order to explicate the rules and organizational policies that shaped it.

I attempted to navigate the reader through my process of engagement in this study and its subsequent organization. Below, I explain the process of: 1) Developing my research question and my position as a researcher; 2) Collecting the data which includes the evolving recruitment process of the informants, recording the interviews in localized settings, the collection of the organizations’ textual data; 3) Managing the data; 4) Analyzing the data and finally; 5) A section on the validity of this study. At this point, I remind the reader, once more, this is not an IE design, but instead a design which draws on IE’s techniques and principles.

**The Research Question and My Position as a Researcher**

The research question drove the engine of this study. When considering my direction of inquiry and how I wanted to approach my research, the framing of my question was very important. The formal question changed many times throughout the interview and analysis process. As the interviews progressed, I was gaining a deeper understanding about the large-scale effects of textual elements that acted upon and shaped the perceptions of these residents in ways, they themselves, did not understand. I eventually settled on the formal question, "How are institutionalized seniors’ daily lived experiences shaped by the policies that govern them?" In order to obtain a deeper understanding of the social relations acting on and between these entities, I tried to engage my informants in
interactive, informal and conversational dialogue rather then a series of predetermined questions.

I wanted to introduce an open-ended question that encouraged the participant to discuss, comfortably, his or her experiences of living in an institutional setting. I was aware that even the language and the phrase construction of the introductive question could influence the direction and atmosphere of the interview. I had to struggle with an even more controversial issue of my conflicting role as a “researcher” and a former “service provider” in one of the facilities. While I was sure that this insider approach would benefit these seniors in some way, I carried with me many assumptions about some of the informants, which may or may not have limited the quality of the data and the analysis which followed. Thus, I was aware of the tenuous situation I had put myself and my informants in for this study and tried to remind the informants and myself of this problem frequently. Despite this, my purpose was clear; to understand how organizational policy is linked to the daily lives of institutionalized seniors’ experiences.

**Collecting the Data**

*The interview question.*

My interview question was selected carefully; “Tell me what it is like, for you, living here”. Though it seems a very simple question, it took time to develop. I chose my terms deliberately. In breaking down the question, “Tell me” was chosen because of both its implied demand and for its purposeful direction that the dialogue would take.
The “tell me”, portion of the question is fairly obvious, as I am the only researcher in this study. It also provided a more intimate atmosphere for my participant and was a less formal approach to the interview. My intention was to relax the participant and provide a safe and familiar environment for them, in which to speak. I then switched the question around to more of an invitation to dialogue by following with “…what it is like…”. Positioning the query into the middle of the sentence was an attempt to provide an “out” for the participant if he or she was not comfortable with the direction of the interview or the process itself. If I had placed the question at the end of the sentence, there would be a power differential imposed upon the informant, placing myself as the expert awaiting an “answer”.

I then decided to address each participant informally, “…for you…” and also stress that my interest was in their experiences and interpretations of those experiences. I did not want their families’ or the staff’s or anyone else’s input. Based on the existing literature, I believed we had plenty of that, already. It was time to hear from the residents, themselves. By overtly stating, “…for you…” I focused the attention on the informant’s voice, the informant’s story and the informant’s experience. The situation of power then changes to the informant’s as she or he is made to understand that this query is clearly about him or her.

Finally, I deliberated for some time on how I would close the question. I began with using terms such as “…living in a nursing home” and “…living in this facility…” or “…living in a long term care facility.” But, all these terms were loaded with assumptions about the kind of environment they lived in. It was essential for
my study to understand how the informants viewed the place in which they lived without the "wisdom" of my institutional language. It was also important to neutralize the ending because of how they might reflect on the question based on institutional language verses their own words. Therefore, the only appropriate wording to use was a more vague, "...living here." It was up to the informant to decide what "here" meant to him or her. Now that I had a question that I was comfortable with, I could move to the next phase of recruiting informants.

**Informant Recruitment.**

Once permission was granted from the University of British Columbia’s Ethics Review Board for my study, a notice of recruitment was published in local residential care facility newsletters and submitted to each resident council (Appendix E). I believed this would be sufficient advertising as I had the advantage of working in one of the facilities I was to study and many of the other facilities’ residents recognized me from prior community involvement (see Validity section for details).

As I was familiar to many of the seniors living in these facilities I felt it was appropriate to target gatekeepers (Creswell, 1998:117-119) to assist in my recruitment process. The gatekeepers are generally third party high profile residents who can advertise to their community of seniors and provide information to potential recruits for a study. These two methods of recruitment snowballed and soon even family and staff members of these facilities were approaching me to target their particular residents of interest. While this additional enthusiasm was encouraging and helpful, I had to ensure that the
recruits participating chose to be there of their own volition and were not coerced by myself or anyone else. This process of third-party recruitment helped to alleviate my worries about any sense of coercion that may otherwise have been felt by the informants for this project.

Beyond need for general informants, I decided on a purposeful sampling technique (Creswell, 1998). Purposeful sampling enabled me to recruit those residents who could best articulate their experiences living in a residential care setting as my data and understanding evolved (Campbell & Gregor, 2002; DeVault & McCoy, 2002). In addition, my initial criteria for participation included:

✓ That the resident be located in a long term intermediate care (IC2/IC3) facility or extended care (EC) facility in the Greater Vancouver Regional District (GVRD)

✓ That the resident be 65 or over (this is the recognized “senior’s” status though nursing homes are known to admit residents who are 65 and under on occasion)

✓ That the resident be linguistically and cognitively able as recommended by the Association Advocacy for Care Reform in Alone in a Crowd (1997), note: this did not preclude languages other than English, however, the advertising was in English only.

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1 seniors unable to manage their functional activities of daily living in the community or who have a cognitive and/or physical challenge but, are stable able to ambulate short distances and transfer independently

2 these seniors are classically categorized as the most frail, able to perform a limited number of activities of daily living and requires one to two people or mechanical devices to transfer them
That confidentiality and consent be obtained and sustained throughout the interview and research process

I was able to recruit eight informants. I recruited 5 females and 3 males, ranging from the age of 65 to 90 years old. Five residents lived in an intermediate care facility with ranging care levels of IC2 to IC3. I was familiar with three of the five residents in this facility as I was their former service provider. The remaining 3 residents lived in an extended care facility. The two residential care facilities were located in the Greater Vancouver Regional District (GVRD). As the sole researcher my resources were limited and my time finite in which to complete this project and recruit more candidates. Seven candidates were interviewed for one hour each during the initial interview session. At least one follow-up interview with each informant was conducted that ranged in time, between 20 minutes and one hour, based on the content and discussions that may have ensued.

These interviews were taped and transcribed by either myself, or a professional transcriber (See Appendix D). One informant chose to journal her experiences based on my question and submitted a copy of these journal entries for analysis. Following her initial written submissions, upon my request, she provided an in-depth follow-up journal of how she felt about the events of the day. She stated that, while she wanted to participate in the project, she felt she expressed herself better through the written word and was uncomfortable with the idea of being audiotaped. I accepted this as a genuine vehicle for communication and a powerful way to give voice to her ideas. It was essential to
my research that my approach be as accessible as possible to improve the participatory nature of the study (Maguire, 1993).

All informants were provided with a copy of their own transcript for review and some corrections were made at the informants' request. I returned for a final discussion on their review of the data and my analysis to ensure I had provided an accurate reflection of their stories and experiences. Some revisions were made to include or omit data at the informants' request. The omissions were all technical and language related. Most informants requested I delete the "fillers" e.g. aahs, uuhms, hmmns and stutters they may have used in our dialogue so it was easier for them to read.

A time and place was negotiated and established with each participant that was most convenient and comfortable for them. My only input was to remind them that the initial interview would be approximately one hour and to choose a time when they were most alert during the day. One hour was an appropriate amount of time. I found that these seniors tired easily and would tend to lose focus after about one hour. I noted that most of the informants desired the privacy and comfort of their own room as their first choice.

While this presents compelling data in itself about the safety and privacy of their own rooms, it also proved very practical for me, as the interviewer. Their choice of venue made the tape recording process easier and the discourse more intimate. These participants often spoke softly and required an increase in the recording volume with minimal background noise if I was going to transcribe their
It was important to me to provide a detailed description of each informant in an effort to give their voices deeper meaning to the reader. This meant a lengthy description of each informant's autobiography, and my observations on their presenting characterization during the interview process. I was reluctant to eliminate any of the rich descriptions provided because of their significance in understanding their stories through their eyes. As a result, I have dedicated an entire chapter (Chapter Three) for the sole purpose of introducing the reader to the unique presence of each resident. It is my hope that the reader departs with a deeper understanding of these fascinating individuals and their inherent uniqueness in this study.

The Interview Process.

As mentioned earlier, participants were given a choice for the location of the interview. All but one chose to conduct their interviews in their respective rooms. Informed consent was obtained at the start of each interview (see appendix B). The interview was deliberately unstructured with one initial question, “Tell me what it is like, for you, living here”. This iterative style (Kvale, 1996; Rubin & Rubin, 1995: 46) of interview provided for an open dialogue and subsequent probing to understand the vast nature of “A day in the life of...” theorizing. While an unstructured interview may not be suitable for all studies, this approach of richly intrinsic cultural language used by the participants e.g. “grooming”, “feeding”, “bathing”, “toileting” and detailed descriptions of their stories accurately. One informant insisted on conducting our interview in the Social Worker's office. She offered no explanation for this.
experiences of these events provide a deeper understanding of how the meaning of these experiences are shaped by larger structures. One participant was not sure she had anything to say but after some consideration approached me the following week and submitted a week's worth of journal notes, which were in short form. These notes tended towards a record of events that occurred within her immediate surroundings. This illustrated two developing issues to me; 1) that residents may feel so devalued that they do not believe they have anything of importance to say, and 2) the importance of how a resident perceived the events in her day as flat, uneventful, emotionless experiences. On the other hand, many residents would wait for me, anxiously, at the door and without even a "hello" would launch into a particular experience that they felt I needed to know about. This suggested to me that these residents had much to say and were eager for someone to listen.

As I listened to their stories, I would interject with prompts such as, "tell me more about that" and "could you expand on that thought" when I wanted more information on a particular topic that either of us found striking. When I was confused by a description I would interject with, "we were discussing..." or "do you mean to say...". I used this technique only if I sought clarification on points the participant made that I found contradictory or confusing. I would repeat the last sentence or general nature of the topic if the resident had forgotten what he or she was talking about. Occasionally, I would re-direct the conversation in the event the participant lost his or her train of thought and requested prompting, "you were telling me about..." or "could I revisit your feelings on...".
During the taping of each interview, I recorded cursive notes on the informants' gestures and deliberate changes in voice intonation, other environmental influences and my field analysis that was developing. These notes were short in an effort to prevent any distractions from actively listening to the participant. At the closing of each interview I invited each informant to choose their own pseudonym ensuring anonymity but, still providing some flexibility to allow for their individuality and how they wished themselves to be portrayed. In addition, I invited them to choose their own font selection out of a large series of choices to reinforce their individuality without compromising their confidentiality.

Following each interview, I reflected on my short memos for any additional thoughts I had about each interview experience, any further analytical ideas and general observations I made about the interview process. This information enriched the verbal textual data I collected to provider a deeper picture of the overall textual experience and begin making sense of their stories in the analysis phase. I transcribed the first two interviews, myself. The interviews that followed were immediately transcribed by a transcriber from whom a pledge of confidentiality was obtained (see Appendix D) and filed by informant pseudonyms. All identifying information was removed from the transcripts and tapes. Tapes were labeled and stored in a locked cabinet for further review when reading the transcriptions.

The transcription process was a challenge in itself. Often my participants would end their sentences by “trailing off” or whispering without
noticing the decrease in their output volume. I was reluctant however, to suggest they speak clearly. They seemed uncomfortable with trying to speak louder—it required great physical effort on their part and tended to focus their cognitive energies on speaking “up” instead of speaking “out”. In short, it became a great distraction and was, therefore, avoided at the sacrifice of sound quality. Because of this sacrifice, inaudible data was lost. In hindsight, I realize this might be one of the many factors, which prevented these seniors’ voices from literally being heard.

Managing the Data

I required the interviews be transcribed literally and noted significant gestures including all the hesitations, pauses and stutters. My intent was to provide the reader with the most accurate depiction of the voices of the informants, uncensored. However, this concept did not translate well to text and it became difficult for both the informants and me to understand the content of the interviews in this way. The informants revised their transcriptions and I acknowledged that total accuracy in this study did not serve the informants or their stories any better than their edited version of the data. In a separate document file I copied and filed a variety of policies according to the developing incongruences.

Analyzing the Data

I began my data analysis after my first interview with my first informant. After each interview I transcribed the tape I flagged phrases and words that I thought significant in understanding the experience of frail seniors in a care
facility setting (Coffey & Atkinson, 1996). My analysis continued throughout the interviewing and policy review process and often overlapped with the data collection phase of the study.

I sifted through paragraphs, sentences and words for signs of developing ideas, concerns or problems. Though I went through a cursive cut-and-paste process, I was specifically focused on the larger meaning within the texts and transcripts. During this process I continued to ask myself, “what does this data tell me about how these events happened/were experienced as they were?” (Campbell and McGregor, 2002). Other policies that shared a strong relationship with the informants' language was, also, grouped and marked (DeVault and McCoy, 2002). These clippings of informant statements and organizational policies were placed in new folders which identified “incongruences”. Included in these folders were words, relevant regional policies, my memos, my journal notes, some literature references and my field notes.

At this point I began naming and organizing the incongruences I noted between institutional ruling texts and how they related to the stories of these seniors (Campbell and McGregor, 2002). Going back and forth through the data provided a vehicle for conceptual linking from the raw data to the emerging incongruences from which they developed and evolved.

In the one level of the analysis I focused on the smallest text portions of data like, “condition”, when Maggie is attempting to describe her disability; “rambunctious”, when Walter is describing his challenge of authority; these developed a focus on the ideas of; dependency and challenging authority.
respectively. My investigation of language, developed by these institutionalized seniors to reflect their perceptions of the “self” in relation to the world in which they lived, revealed a micro-view of how each experienced their world. I then review policies to try and find any links to the rough concepts I was developing, elicited by the lived experiences of these seniors. I reflected on the impact that the existing textual policies may have had on the language used in these kinds of statements. For example, when I considered the category of “dependency” I then chose to review the “Resident and Family Care” sections of these manuals and found several examples of policies which may influence the frustrating experience of dependency and shape the language these seniors used, as a result.

While I was still conducting one level of analysis, I initiated another level of analysis with passages that provided ample narrative descriptions of events, feelings, or understandings that the informants storied as insight into how they experience daily living in their facility. For example, I placed a larger chunk of data elicited by Helen from our first interview in a more polished data group that describes the experiences of these informants in greater depth. Here Helen’s quote was placed, with many of the others’ quotes, in a file labelled, “overcrowded and still lonely”;

Helen: Well they have so many people, either several, I don’t know how many in this thing women or men but about 200 all together.

I: And that’s a lot?
Helen: Well, do YOU live with 200 people? Eat with them all and stuff? Of course it's too many people! Who wants to live with so many sick people?!

Once several groupings of chunks of data were established I introduced a final level of analysis. Using the data from the other levels I began reorganizing the data to include even larger chunks of text, sometimes, entire topics of conversation were emptied into these files. I continued to re-check the all level of analysis of the data throughout this process. This was to ensure I had not lost any critical data in the process of expansion. Finally, the policies of interest were folded into the appropriate sections according to the emerging incongruities that began to take focus. This process required a deeper investigation into the relationships linking an individual's personal construct in an institution with the policies that shape these constructs (Cambell and Gregor, 2002; DeVault and McCoy, 2002).

This final level of analysis yielded an overarching theme based on a client-centred model of care which marginalizes frail seniors. This theme, for lack of a better term, was built on several issues with marked incongruencies:

- "...you should get fun out of it no matter how stupid it is."—the quest for a meaningful existence in an institutionalized setting
- "It's not quite like home"—experiencing the living space of an institutional setting
- "Poor little Maggie, beggin' for help"—increased feelings of disability and dependency and the hurry-up and wait syndrome
- "Often, I speak, as if I'm a trouble-maker" – maintaining safety at the expense of resident autonomy

I wanted to share these incongruences with the informants so, I presented them this raw analysis on which to reflect. For example, I noted Helen, Doris, Walter and Tony's stories all expressed the frustration and anxiety following confrontations with the staff or the rules; Marie-Lise, Nadim and Maggie had resigned themselves to following the rules and not questioning them; Susan, on the other hand, had little to say about challenging the rules of the facility and readily accepted most of the policies as fair and just.

By sharing my analysis with the informants, I hoped to ensure that their experiences were accurately represented and interpreted. Therefore, in a third visit, five informants received a brief written summary of the study's emerging incongruences, which I reviewed with four of the informants. One informant requested I leave her with the analysis and return in one month at an arranged time. I was able to engage in an exciting discourse with the other four informants at least once more during this stage of the process.

These informants dialogued with me further about my discoveries and I made notes and memos on the analysis, which I filed later at home, accordingly. I was unable to continue to collaborate with three of the participants in any future discussions. One informant became critically ill and was admitted to hospital and two informants had died in the meantime.

Following the gathering of the participants' feedback I reflected on my process and commenced an in-depth analytic procedure as follows:
1. I re-read all the transcripts for an overall understanding of the data (Sandelowski, 1995). I then reviewed all the policy and procedure manuals, once again, for a structural understanding of what theoretical framework the organizational policies were founded upon. The most pervasive theme came from the neoconservative foundation upon which these residual policies existed against the backdrop of mission statements, which touted a progressive structuralist vision of care, but failed in the eyes of these seniors’ experiences.

2. Pursuing the link between policies and institutionalized seniors’ experiences, I turned to the data again and questioned why was there a difference in the intensity of feelings such as loss, dependency, helplessness, boredom and hopelessness once in an institutional setting? What was so very different about being in one’s own home, frail and dependent and in a facility, frail and dependent?

I returned for a brief fourth visit to collect the additions and changes made by my remaining informant. In the meantime, I ran into two other informants who noted they were pleased to see their suggestions for themes materializing in my analysis. My remaining participant provided written revisions to both her transcript and the findings, she also provided me with many exclamation marks on certain themes, I took these to mean she approved. Armed with the revisions and suggestions, I returned, once more to the data.
Policy Review

In the latter portion of the analytic process I began to review the organizational policies of these facilities (Cambell & Gregor, 2002). I requested and was granted access to the Policy and Procedure manuals on each site and began reading the policies section by section. I would often return to these policies immediately following an interview while an analytical idea was still fresh in order to delve deeper into the links between the participants' storied experiences and the language that the policies used. I will discuss the links between experiences and policies I noticed between what was written in policy and how it translated into practice in my findings and discussion sections. Suffice to say, I would often note discrepancies between the policy edict and the residents' experience of these policies. I made many notes on the transcripts as they related to different policies and combined this data with my memos and cursory notes to enable me to view the data as a whole and in its textual parts. Finally, I used a journal at home to keep a record of my own thoughts about my data collection techniques, my analytic process and rationale behind my methodological decisions (Maxwell, 1996). As a result of this policy review and reflection of the data and my analysis, incongruences began to emerge. There existed a series of paradoxes between the intended textual achievements of the organization and the perceived experiences of the seniors living with these texts.

Finally, I sought guidance from my research committee, colleagues, frontline staff, policy-makers, peers and family members who were familiar with the issues
I was studying. Seeking feedback from the above groups encouraged me to settle on these four incongruences. I now had confidence that these problematics would provide some insight into the experiences of frail, institutionalized seniors and the impact that policies had on their daily lives.

Validity: In Defense of My Methodology

By this point in this chapter, I hope I guided the reader to “the findings” or “Discovery” part of the study. This section determines whether I have succeeded in this task, or not. In addition, I will highlight a number of limitations that I encountered with this study in the hopes that further research can be pursued in this area of investigation.

While some validity concerns were addressed throughout this chapter, I decided to provide a separate section on validity in my attempt to reveal any further questions or challenges I encountered throughout this study that may have compromised my research and conclusions. In the first section on The Research and Interview Questions and My Position as a Researcher I encountered a number of challenges regarding the evolution in my formal research question. Upon the onset of this study I had proposed one research question, but felt it became an inappropriate line of inquiry after the first interview. This only reinforced my decision to use a qualitative design, which allows for this kind of evolution in the research process. There is no tolerance for this dynamic process in the quantitative realm of investigation, which may have forced my inquiry in a direction contrary to the informants’ experiences.
A second complication arose with regards to my role as “researcher” in this study with three of my informants. As a researcher, my role was particularly questionable in this study due to my dual role as a former service provider for some of these informants. I wanted no confusion regarding the misappropriation of my former service provider role and my role as researcher. My hope was that if they were to be affected by my former role, as their social worker, that my influence would result in the encouragement to provide a richer source of data due to the long developed trust we had established over time. Upon reflection, I believe that working with these individuals in this environment for so long actually assisted me in obtaining a greater resource of genuine data as trust was already established by some of the participants. I also knew their personal history far better than a stranger conducting this research. I believe that I understood many nuances of their dialogue and gestures that they made to illustrate or highlight a point that may have otherwise gone unnoticed by a stranger. I also had the ability to understand their historical references of personal events at times, which they may have referred to. The downfall of this “insider’s” approach was the false assumptions I may have made in reading too much into their gestures and intonations.

I have remaining regrets about my Informant Recruitment process. The purposeful sampling I conducted in choosing informants for this study eliminated many voices. As I mentioned earlier, I felt eight informants, given the detailed data investigation that would ensue, the transcription process, the relationship building process and the interviewing times, was a manageable number to create
an adequate database for analysis. I would not risk a smaller sample because it may not have provided enough rich data where additional interviews would add little new information to the data already collected (Rubin & Rubin, 1995). A larger sample is unnecessary, as I am not attempting to generalize my findings or represent individual experiences as one unified “truth” from the data. While I am confident that some of these frail seniors’ voices were heard, I deliberately kept my group small. More frustrating was my deliberate rejection of the frailest portion of this population -- those cast beyond the margins of our society -- seniors suffering from severe dementia. I confess that this is one significant limitation of this study. It is an injustice to the residents who are severely cognitively impaired or unable to communicate in a rich didactic style. It is my short-coming as a researcher, that I have not found an effective way in which to communicate the stories of these seniors using their voices and their experiences.

This study also eliminated non-English speaking residents from the group. Unfortunately, my limited apprehension of other languages and my theoretical approach of attending to text and language are incompatible with these residents because a translator would be necessary. Inherently, the translator would be telling their story and the text would be inaccurate. An interesting follow-up project could focus on stories from non-English speaking residents, or those residents with dementia and/or those residents with verbal communication challenges. These voices remain silent.
The interview process reminded me, again, of my challenges playing a dual role as researcher and service provider. I was keenly aware of the traditional power differential between researcher and participant in traditional quantitative studies. It was my hope that my established former relationship with some of these informants actually encouraged a deeper discourse and a longer dialogue during the interviews and follow-up process because they had already grown to trust me. We had developed a rapport over time and they understood my intention to amplify their voices among the knowledge that currently exists on aging in long term care facilities. Further, they were already keenly aware of my personal and political agenda and my focus on textual elements that mediated the current, rule governed, relationship within which they existed.

Beyond my personal conflicts discussed above, the reader may question structure and content of the interviews. The interview process was unscripted and open-ended with spontaneous probing questions as the dialogue progressed and a story unfolded, a process rejected by more traditional positivist research. Further, my initial interview question, in its textual state, may appear to the reader as a demand rather then a request. I fear a great deal of data was lost in translation to text even if transcribed word for word, a risk textual qualitative researchers take when collecting and analyzing data.

In the Analysis portion of this study I found further challenges with my collaborative approach to this study. It was interesting to note the reaction that many of the participants had to their transcripts when I gave them a copy. First they were surprised to even get a copy. Once the initial shock of my inclusive
approach faded, they became more involved in the process. A number of them complained about how they spoke and were surprised to see so many pauses, stutters, “uhms” and “aahs” in their speech. Two of the participants requested that I removed these fillers from the text as they felt uncomfortable knowing their speech was not as fluent as they had initially thought and wanted to sound more polished. I reluctantly agreed to remove these fillers for any participant who chose this option as I recognized that it was more important that they be confident with their voice then the orthodoxy I desired with my method of literal translation. Most of the participants requested this revision. This compromise may have affected the analysis of the data. Further, the more polished version they insisted on belies the reality of our actual interview and so the reader does not achieve the full flavour of “being there” without being present.

Finally, there were some challenges during the analysis stage of this study. As I commenced by analysis during my very first interview, I did not foresee the cumbersome and meticulous process that would be required to keep track of my analytical thoughts. Thus, I had built a mass of colourful posting notes by the end of the final series of second interviews and no place to put them as I had not fully developed my entire set of files and categories in which they could go. There was some confusion about the organizing of this information and some concepts, most certainly, were lost in the process. In addition, the three levels of coding I used could only accommodate data which was actually stated. In other words, what was left unsaid was left out of this analytical process. To compensate for this, I highlighted notes that I had left in the margins
of transcripts and field notes that described intonation and gestures the informants would use when making a point or avoiding a direction of conversation. In future, I might use a different system of analysis that was less restrictive and concrete than the coding system I used in this study.

One unforeseen and disturbing problem arose during the analysis stage of this study. I attempted to revisit all of my informants to discuss my analysis but, failed in many of my pursuits. Death and illness became very personal for me in this study and it was difficult to remain focused for some time after this. I was beginning to understand the impact that death, illness and companionship imposed on their daily lives. Death, it seemed, was relentless. It was an ominous reality that permeated the existence of these participants' experiences and now, mine as well. Therefore, a final note about working with very frail, ill and palliative groups, time becomes an essential issue, for both the researcher and the informant, to the process of studying these seniors. Every moment with these individuals was a gift of time they gave to me. I am deeply grateful for it.

Summary

It is not the intention of this study to generalize the findings beyond the experiences of the eight participants interviewed (Sandelowski, 1995). It is our (mine and the informants') hope that the reader is given a deeper understanding of the experiences of these seniors and how they are shaped by the policies that govern them. The sample consisted of eight frail, institutionalized seniors of a mixed-sub variable group of gender, race, religion, ethnicity and economic status. This was to emphasize that each individual's experiences are unique, yet policy
can impose a common influence upon them to shape common meanings from their experiences.

A qualitative approach to this study provided a vehicle through which to better understand the social and environmental context in which these seniors experience aging. Borrowing heavily from the institutional ethnography theory, helped inform my research design. It is my hope that this design helps reveal a culture within a long term care facility setting that is largely experiential and analyze the policies which govern and shape these experiences. Informants had the opportunity to provide on-going feedback from their transcribed interviews to the emerging incongruences. They were eager to be involved at all levels. This on-going dialogue, while time consuming and exhausting at intervals, proved very helpful in assuring that the five emerging incongruences in the next chapter, the Discovery chapter, accurately reflect their experiences in a ruled governed system mediated through text. It further served to heighten their awareness to the policies that existed and governed their daily lives as they began to question the policies, themselves. Finally, I reviewed the validity of this study and its design and discussed the shortcomings of my research and my methods.
CHAPTER 3

INFORMANT PROFILES

In an effort to provide the reader with the participants' lenses of their worlds, I have compiled a brief snap-shot of each participant in order to afford the reader a clearer image of each participant. Though it does each of these participants a great disservice to their highly valued respective life experiences, for the sake of manageability, I have condensed historical facts, which were offered by these participants with their current medically defined status and my impression of them. Each participant selected a pseudonym, which best defined him/herself and reflected his/her current situation. In the spirit of a post-structural approach, I also provided various fonts from which they could choose to further define themselves and differentiate their unique voice from the others. This provided the participant with more control over the resulting data, which was generously welcomed by all.

Maggie

In our first conversation, Maggie defines herself as a "typical institutionalized senior". She was recruited through the Social Worker at an extended care facility. I have a prior relationship with Maggie through my professional services. Both Maggie and I agreed that she would be an excellent candidate because we felt comfortable with each other and I understood her use of narrative communication and she felt I understood her plight. Maggie is the kind of person who has the confidence to find her voice and the courage to use it. She will tell you that this courage is backed by the support of her family.
Maggie is in her late 80's, but she's not inclined to tell you her precise age without a sort of trivia game prior to divulging it. Maggie likes these kinds of games. Maggie was born on the prairies of Canada, which is fitting, given that Maggie encompasses the spirit of the prairies. She is a rugged individualist. She presents a tough exterior with a twinkle in her eye and a "bring it on" attitude towards life. At first meeting she presents a confident, alert and grounded individual deeply connected to her prairie heritage and strongly grounded in her Christian faith. She strives for simplicity in her life and focuses on the more spiritual aspects of existence. She cares little for material artifacts and defines her wealth in terms of her family and her independence.

Recently, less then 6 months ago, she involuntarily transferred from an intermediate care facility to an extended care facility due to her physical functional decline. Maggie could no longer ambulate or transfer without assistance and met the policy requirements of “total care” for all her activities of daily living. Maggie will tell you she is, “confined to a wheelchair but, doesn’t let it slow me down”. She is quick witted with a dry sense of humour and fire in her watery blue eyes. She proudly declares she is a, “trouble maker” with a smile that dares you to challenge this. While she was very active in the intermediate care facility she has resigned herself to enjoying listening to the radio, dialoguing with the younger generations and helping others less fortunate then herself in any way she can. This is Maggie on our first meeting. Maggie would later state that it was a “good day”, which was rare for her.
These days you will often find Maggie sitting rigidly in her wheelchair staring intently at the wall in her darkly lit room. It looks and smells antiseptic and uniformly very pretty with typical "institutional" decor. A plaque is prominently displayed for being a member of a prior Resident Council and perhaps as a reminder of her former glory days. A few family pictures are sprinkled on the ledge by the window. A clock radio sits beside her hospital bed and a television at its foot. I peer in to see that she is staring at the calendar. Is she watching time go by? It seemed to me as though she sits isolated, frozen and forever waiting—for someone or something? This is how I find her on both of our meetings. It is a lonely picture that leaves a lasting imprint on my mind.

I met Maggie one week prior to the interview to discuss and explain any concerns around the project and gave her the question during this meeting. She requested that the interview take place in the privacy of her room. We settled on a time in the morning on the weekend as this was her most alert and energetic time of the day and I suggested a time about one and a half hours before lunch to bring the closing of the interview to a natural and comfortable end.

In our first interview, Maggie sat intently staring at the calendar on her wall. I was her "biggest event of the week", and she stated my project focussed on, "...a very, very badly needed subject. The ones that don't get discussed..." I explained that this was a collaborative project in which she too, was going to help change the way she lived. She quite liked this idea and was excited to commence the interview. We cleared-up the "technicalities" (signing the consent form and testing my minidisk system and microphone) and she
chose her pseudonym, Maggie (she chose “Maggie” because “That’s how I feel. Poor little Maggie...Begging for help”. She preferred a Lydian 14pt font because it was, “It’s clear, distinct, and precise just like me.” I entered the discussion with, “Tell me what it is like, for you, living here.” Though Maggie had a tendency to regress to a different time in her life, I was able to retrieve a vast amount of information about her daily life during the interview process. In the analysis, following, you will hear her voice as she struggles to make sense of her daily experiences and how they are shaped by the social policies that govern her.

**Walter**

Walter is an articulate and energetic man. While he is in his early 70’s and lives in an intermediate care facility, he presents himself as much younger then his years and holds great interest in current events and contemporary technology. He functions at what a Social Worker would consider a “high” intermediate care level 2 (IC2) and reports he is independent with almost all his activities of daily living. I have known Walter for two years now on a professional basis.

Walter voluntarily placed himself in a facility because he felt he was unable to manage independently in the community during his episodes of mania and depression. Walter was raised in an impoverished environment in an urban setting where his physical disabilities from polio, encompassed him in a world of shame. With little support from his family, he learned about the “shame” of disability and dependence in the urban Canadian construct of capitalism and
rugged individualism. Walter existed on the margins of society—an oppressed minority. Surprisingly, his strong Christian faith and support from his sister and his church community, pulled Walter from a self-defined hell into a more promising existence. His community and Alcoholics Anonymous program helped him to re-define his experiences and reframe them in a more purposeful and hopeful manner in relation to his world. This is the confidence with which he entered the facility.

He had relied heavily on his friends and family and felt he “was becoming a burden”—enter the institutionalized context. Though he entered the facility voluntarily, the transition was, nonetheless, difficult and he has experienced much, good and bad, over the past two years, living in a nursing home. Although I work with Walter, I did not feel this conflicted with my research, as we were both very clear that his participation and/or withdrawal from this project had no bearing on my services to him professionally. In fact, we both agreed that this was an ideal situation as I have come to know Walter very well and believe I interpret, accurately, the nuances of his narratives and his intended meanings.

On most days you will find Walter with a warm smile and energy abounding. Walter enjoys writing and reading and often goes for long walks in the community, when he is able. Walter can be very outspoken and filled with ideas for improving the life of others and the facility. This is not always welcomed by the staff and administration and is reflected in Walter’s perceptions of his existence in relation to institutional living.
Whether by coincidence or setting, in the interviews, Walter appeared somewhat depressed. It is my belief, that in the privacy of his own room, Walter allows himself to express the genuine nature of his feelings. In the safety of his own room he waits anxiously for my arrival and seems quite troubled by the interview process and the “unknown” nature of my probing. We ascertained his readiness to do the interview and at his insistence we proceeded. Walter appeared to relax ten minutes into the interview and our discourse in both interviews flowed for over an hour. Later in the first interview and during the follow-up interview, the dialogue became more fluid as he attempted, less and less, to censor his expression. Walter selected his pseudonym because this is his middle name and he always wanted to use it. He chose Impact font 14pt because he stated “I never could write this nicely and I always wanted write so you could read it...”.

Susan

Susan is 65 years of age and lives in an intermediate care facility. She entered the facility several years ago due to the progression of her Multiple Sclerosis (MS), which rendered her “disabled” in her community environment and prevented her from functioning independently in her own home. Susan, being the ever-persistent pragmatist, decided to voluntarily place herself in a nursing home anticipating further decline in her physical abilities as the MS progressed. Susan is an educated librarian and a self-pronounced bibliophile. She was born and raised in suburban Canada. She describes herself as non-religious, but spiritual and is very independent and active in the nursing home.
Susan sits on the Resident Council and sat on a number of other Committees prior to this year. She has recently decreased her participation on these committees as her MS progresses. This frustrates her and leaves her more tired, saddened and weary. She spends most of her days in her wheelchair, but continues to attempt ambulation in her room and can manage most of her ADLs independently. She is a proud and fiercely independent woman. Though her family visits on occasion, their support seems peripheral in comparison to the support she receives from her friends and staff at the nursing home. Last year she tried to manage independently and fell in her room and broke her writing wrist. This had dramatic effects on her independence levels and her self-esteem. As a result, she has decreased her activities in the Home and tends to isolate herself more often. Susan spends most of her days writing and reading and entertaining her guests to tea and conversation.

Susan chose to “journal” her account of her day with a follow-up description of how she felt and perceived the events of this day. She felt this was the most natural way to express herself and was uncomfortable with being taped. My decision to include written text to this research provided a perspective I had not anticipated and added richness to the analysis of the text. It also served as a reminder that not everyone wants to be or is able to be audiotaped. There are many ways to record an interview. The written word remains a powerful and natural resource for information. Susan chose her pseudonym because she stated, “It was my best friend’s name and I would
like her to be remembered.” I was able to match her script to one available in my font selection, though, had I a scanner, I would have scanned her handwriting into this document for more accuracy.

**Doris**

Doris resides at an intermediate care facility and is an IC2. Doris ambulates without any aids and requires little or no assistance with her activities of daily living. To most Continuing Care Case Managers, Doris presents as a borderline acceptable admission to facility care. She barely meets the minimal requirements, functionally, but found herself in a socially desperate situation. Lonely and recently widowed, Doris’ problems begin with financial hardship and are compounded further by social isolation and an alcoholic addiction. She is an atypical example of the stereotyped “frail” institutionalized senior and she often presents an altogether different perspective on her rationale for voluntary placement. Doris suggests that one of the many advantages to facility living is the communal aspect of being among one’s social peers. The activities abound and one is lonely only by choice, according to Doris. At first, this belief catches me off-guard, however, I soon realize that Doris has the physical and cognitive privilege of choosing to be active and social. She is a vivacious and independent woman of 65. She has lived her whole life a “content Canadian”, although she has struggled with poverty most of her life. Based on my observations during our meetings, I will confidently state, Doris is a going concern. You will not find Doris in her room often—only when her emphysema slows her down. She was
the only participant to insist on doing her interview in an office setting. Doris had much to say and was excited to tell a story in her words. I found that Doris often relayed prior conversations with others as a narrative technique of storying her experiences. At first this technique was difficult to interpret and analyze, as she often spoke on the behalf of others, however, I soon learned that this was Doris’ way of making sense of her world. She valued her experiences via the conversations she encountered with others and paraphrased their responses as she recalled them and re-lived them. Doris seems to define herself by her relationship to others.

Doris relies intermittently on an oxygen concentrator and puffers these days. She battles with the struggles of nicotine and alcohol addictions shaped by many years of life’s hardships. Since her admission to institutional living, she has been able to manage her addiction with staff support and daily structured routines. Doris is one of the rare informants who reflects the intended consequences of policies in a structured environment. Doris expresses confidence in most institutional policies because they provide the structure she desires and is unable to achieve alone. Doris’ interviews were often lively and very unstructured. It was necessary for me to re-focus her on several occasions, but the material was very rich in detail. Doris chose her name spontaneously with no explanation and liked the 14pt font, Bernhardt as it was “real pretty…”

Nadim

Nadim is in his 90’s. He appears humble and soft-spoken but, his extensive vocabulary, level of intelligence and a hint of aristocracy belie his
current state. He was recently placed in an intermediate care facility. Nadim tells me he has transferred from an acute care setting where he was being treated for his cancer, prognosis "palliative". Nadim represents to the medical system a typical *bed-blocker*. This is the in-house term for seniors who are unable to return home but, cannot be immediately placed in facility. He describes his understanding that the objective of the hospital was to discharge him as quickly as possible from an acute care bed to a "residential hospital". At first, Nadim resisted placement but, was left with no options. He finally acquiesced to move to this new home. He states that he has tried to stay positive, but moving from an exclusive penthouse to a small room has taken its toll on him.

Nadim has always been a single, independent and adventurous man with no immediate family living locally. When he immigrated from Turkey to Canada, he immediately started building a strong Muslim community. He states that his community is very loyal to him and they visit often. During two of our meetings his friends made a point of informing me, proudly, that he single-handedly built their church. These strong ties to the Muslim community and a handful of very dedicated friends provide a strong support network for him. He speaks broken English at times and reverts to a Turkish dialect occasionally during our interview or in times of great pain or strain. Despite this communication challenge, he is able to articulate his needs and express himself clearly.

He presents himself as alert and oriented and ambulates without any aids, however, he requires a great deal of assistance with his personal care.
Nadim is currently on the facility’s palliative program, which offers him a little more attention and flexibility than other residents due to his heavy care needs. Nadim decided to spend some of his precious remaining moments with me. He tells me in our first interview that he wants to contribute something to my research and to seniors before he dies. He chose his pseudonym for his nephew who has Power of Attorney over his financial affairs and has been a great source of comfort to him in this time of need. Nadim was amused by my offering of a selection of fonts but, felt it was less important than the content and decided to go with a times new roman type for simplicity.

**Marie-Lise**

Marie-Lise and I have known each other for some time. I admitted Marie-Lise to the intermediate care facility that I worked at and we interviewed each other during the pre-admission stage of transition. Though Marie-Lise presents herself as generally a joyful person, she is often plagued by the internal family dynamics around her functional abilities and her deteriorating health. Marie-Lise resents being a diabetic and often craves cakes and cookies. She feels she is being denied when she cannot have the simple things she wants and this makes her sad and frustrated. Marie-Lise will often confess to me her recent cache of cookies and snacks that she hides in her purse and she giggles with delight that she has tricked the staff with the apple that sits prominently upon her walker. Lately, Marie-Lise confesses a more serious fear she has about her current state. She is very aware that she lives in an intermediate care facility, which cannot provide her with proper extended care. As Marie-Lise has always
been a hard worker, labouring most of her life as a nanny and cleaning woman for the wealthy families of Montreal, she has never liked formal “exercise”. Because of her disdain for exercise and physiotherapy her ability to walk is deteriorating. At 82 years of age, Marie-Lise states that she, “...is not expecting any miracles” nor does she desire a change her lifestyle. She resides more, and more frequently in her wheelchair and becomes increasingly dependent on her oxygen, she perceives an erosion in her quality of life. The demise of her ambulatory capabilities is not what worries her however, it is the constant reminder by family and staff that if she does not walk she will have to move. Marie-Lise has pleaded emphatically that she does not want to move.

Marie-Lise stated that she joined my project because she was hoping to tell the experts her story and because she had established a trust with me. She also stated that it was her Catholic, Francophone background, “...that stubborn, fiery side...”, that spirited her to join my group. She took no interest in the font styles and told me to choose one for her that I think would best represent her. This presented a problem for me as I wanted this to be her choice and her voice. To my dismay, she would have none of this and insisted I choose the font, myself. Left with this dilemma, I chose Lucida Handwriting because of its simple and genuine nature, something I believed reflected her personality. She relieved me of the onerous additional duty of choosing a name and selected “Marie-Lise, because it sounds very French...” Marie-Lise, while a lover of conversation, was nervous about the interview as she often feels she does not adequately articulate her feelings or her needs. She is fluent in English
and yet, unsure of herself in this language and often reverts to her mother
tongue, French. I am not sure whether this is due to her mild memory
impairments, which are evident, or because she is nervous. Nevertheless, these
delightful bilingual conversations (I am able to speak and understand French)
were inevitably transferred to the tapes. What is more charming is her continued
surprise at my ability to speak French. Every time I remind her that we have
changed languages she is delighted to discover I speak French...I have known
Marie-Lise for over three years now. While she remains proud of her
Francophone heritage, her self-esteem appears affected by her voiced feelings of
inadequacy around her education levels, her family’s social history and her
tenuous dynamics with others.

**Helen**

Helen is a 91 year old resident who has lived in the extended care facility
for over 1 year now. Helen loves to socialize with younger people, "...it makes
me feel so young!". Helen was delighted to discover she was able to choose her
font and chose comic sans because it looked like fun. As you can probably
surmise, Helen is a going concern. I felt compelled to ask her how old she
thought she was and she beamed, "35!".

When you first meet Helen, you are likely to assume that she is a very
frail extended care resident, however, after some brief introductions you will
begin to feel as if you’ve been duped. A stroke has left Helen confined to a
wheelchair with little strength or mobility in her upper body and paralysis on her
left side. Helen’s speech has been profoundly affected and audio taping our
conversations became futile. Helen was gracious enough to speak slowly and allow me to write all of the conversations down while I continued to tape the interview. It is my opinion that Helen has the patience of Job and seldom has a negative thing to say. She enjoys living in the facility and spending time with her peers and tries very hard to accommodate others, including the staff.

Helen's life has been impressive as she has suffered many losses over the years of both her son and most recently, her husband. She champions her daughter with caring for her and attending to her daily. Her daughter brings her the foods she enjoys on a daily basis. Helen immigrated to Canada from Hong Kong, China 25 years ago with her family. Helen had to reframe a world governed by filial piety when her son died and has spent many years understanding a new world where her daughter manages her finances and cares for her.

Helen's struggles are mostly with her speech, which is further complicated by her broken English and her feelings of social and cultural isolation at the facility. Helen requested that I include her in the project because of our mutual interest in developing a Mah Jong group at the facility. She is finding the process of integration very challenging because of many western barriers that do not blend well with her cultural background. The lack of Chinese speaking peers increases her feelings of loneliness and helplessness. She is curious to observe the results of my research and the impact it may or may not have. Helen chose her name randomly and offered no explanation as she seemed somewhat
uninterested in this process. She became excited by the choosing of her font, however, and chose comic sans 14pt, "...because it's young like me!"

Tony

Tony became curious of my presence at the extended care facility and joked of a "conspiracy" on the unit. Tony eventually became my eighth and final participant. This pleased him. Tony is a "...brass tacks man..." and tells me he does not suffer fools lightly just as a confused resident wanders into his room asking for her mother during our first meeting. This strikes me as ironic as Tony's chart states he is suffering from early stages of dementia and has infrequent bouts of confusion. Tony describes himself as popular among the residents and staff with a few exceptions. It is widely known by staff and residents, alike, that Tony takes issue with one or two of the care staff and I am convinced this is true as I am provided with "sound advice and warnings" to mind myself with Tony by the staff.

By the second interview, Tony is too busy "flirting" with me to be irritated by any queries and probing I may have. I have already been offered two dinners and a beer (all of which I decline due to circumstances but, in the company of Tony it takes a great deal of self-restraint). Tony "wanders" around me in his wheelchair, which he smoothly operates independently.

Tony is a proud Italian-Canadian immigrant who worked as a labourer most of his life. His family is large and his daughters visit him often. He likes to go out with his "gang" of friends for a smoke, to the pub or for dinner. I observe that Tony is 87 going on 17. When you are around him, you get the constant sense
that there is mischief to be had. Though his current income is low, he spends more then he earns on cigarettes and alcohol and this makes him happy.

Tony's main issues deal with his personal care and his incontinency. He gets frustrated and very angry at times with a select group of staff and can become verbally abusive if his needs are not immediately met. Tony has become very dedicated to the project in the hopes that he may understand why he cannot maintain his dignity and why he continues to suffer humiliations around his personal care.

Tony immediately asked me, which was the font I felt was most "appealing" to me. I refused to help him with his choice so he decided on Lucinda sans typewriter 14pt because it was, "...strong and powerful...like me!" he declares as he laughs and pounds the arm of the wheelchair in mock demonstration of his physical prowess.
CHAPTER 4

DISCOVERIES: EMERGING INCONGRUENCIES

"...Everything is three inches away from me. I just have to sit here and forget what I’m trying to do. ‘Cause I can’t reach it. Three inches away, I say...it’s by 3 inches, or so. And that’s with eating or with moving or anything. Everything is just out of my reach..."—Tony

In this section I discuss one overarching theme of institutionalized seniors experiencing further marginalization despite “client-centred” models of care. This theme was built on four significant incongruences that are identified and examined; 1) Home but, not home; 2) Hurry-up and wait: the conditions of caring; 3) Very busy being bored; and 4) Safe but, silenced.

In an effort to maintain simplicity, clarity and consistency with my research design, I have organized this chapter to describe a personal experience followed by introducing a compelling statement(s) that an informant(s) made to introduce each incongruence. I then discuss the relevant policies that are linked to and support or elicit these experiences. I chose to use policies reviewed from both the Community Care Act, “Adult Care Regulations” section (Appendix A) and the participating facilities’ Policy and Procedure manuals. These policies and regulations play a very large part in influencing the shaping of perceptions of these informants’ understanding of their environment. Institutional policies are derived by using the Act’s regulations to establish their organizational policy manuals. Organizations’ policy manuals are required, by law, to maintain the standards dictated to them in the Act. Looking at both levels of texts may provide
a better understanding of the disharmony experienced between the dominant social processes that are mediated through these texts and the actors upon which they are imposed. A discussion about the resulting effect that these policies create with each incongruity is included at the end of section.

**Client-Centred Care Pushing Seniors to the Margins**

What seemed a significant theme throughout this study with these informants was the experience of being pushed even further to margins of society while these facilities attempted to provide client-centred care;

"I spend most of my day in my room. I think about the past [smiles]. I don’t dwell on the future, I don’t have one, so why waste time thinking about it. I can’t do much and I am a lot of trouble for the nurses, I’m afraid…mostly I am just waiting to, you know…[He pauses. I shrug my shoulders indicating I didn’t “know”, he shifts awkwardly and whispers] I just want to die now…" – Nadim

I have organized the following four incongruences much like a story that tells of the work these informants do to negotiate the absurdities and conflicts they experience when their personal expectations, facility promises and provincial policies play out in an institutional setting. These incongruencies demonstrate how the experience of reshaping senior’s self-image creates a futile understanding of the world in which he or she now lives. In much of the data, the informants use vivid language to story their experiences of their own self-worth i.e., “…I just want to die now…”. It can be seen in each section that a struggle ensues for each of these seniors to define meaning in the institutional world. This is arduous work. It is a full time job for these residents and, at times, an
impossible task. The current policies creating disharmony in their universe do not allow these residents to control the events in their daily activities of living or the decisions that are made on their behalf.

The policies fail in preventing a disturbing common sentiment among these frail institutionalized seniors—preferring death, over the experiences of being a burden on their family and the health care system. With little control over their own bodies, no control over their environment and no hope for a future, these informants cope with a cascade of losses by isolating themselves in their limiting living space and refocusing their energy on life review, bodily functions and food issues and lowering their expectations to minimally exist until death. They express little concern or hope for a future. Maggie tries to explain this experience in her understanding of her current situation;

"Well, I need help and I can't uh, uh, avail myself of this condition. You know... footless [laughs and shrugs her shoulders], immovable. And right now I can't see, my eyes have watered up from the strain of that thing [mechanical lift] and I can barely see your face. How would you like to live like that? Not very well, I think. Wait until you're my age...then you'll understand 'good for nothing'..."

We will see that Marie-Lise makes a statement in a later section in this chapter, when expressing her feelings about her imminent transfer to an extended care facility that she has arrived at the conclusion that she is "no good to anyone" and that if she were to be transferred she would, "...just
die...” Both Maggie’s and Marie-Lise’s understanding of “self” have been dramatically altered from their former roles as primary care givers, based on their profiles. Neither Marie-Lise nor Maggie, were prepared to become a “care receiver”. No where in the policies is their direction for these residents to learn how to be effective in their new role as “care receivers”.

In fact, the policies provide no direction for these seniors, at all. The policies direct and guide only the staff and the administration’s roles and actions. Therefore, the policies reinforce the assumption that these seniors are passive actors in their environment. These informants are left with no alternative, but to define themselves by the policies that govern their self-image and by the physical world that limits them. In Nadim’s, Maggie’s and Marie-Lise’s case, the reader will see that they all perceive themselves as “dependent” and a “burden” based on a physical world and a set of policies that define them as such. Perceiving these concepts as undesirable, they all express the wish to die as a preferred choice. I ask the reader to consider the impact of this theme carefully. I reflected on these confessions, at great length, to arrive at the conclusion that, perhaps, the personal choice to die may be the only experience left in their lived world that policy cannot dictate or control.

The data in the next several sections show that these residents have each experienced the systematic shrinking of their lived world by a textual one. Their world and sense of “self” then begins to collapse as they find their ability to remain independent more and more difficult. It may be at this point, that the institutionalized frail senior, robbed of meaning from their world by the policies
that govern them, cope by beginning the process of life review, introversion and isolation from their peers and community. I agree with the idea that life review is an important process in anyone's life. However, the gaps in policy may initiate the desire to life-review prematurely with institutionalized seniors. This may limit a senior's experiences to those of the "past" and reject any notion that he or she could experience a "future". As a result, residents may abandon all hope of a future existence and, instead, long for an end.

There is an ominous message, which prevails in the culmination the following sample of incongruent policies. Ageist assumptions linger in a set of residual policies heavily weighted by a patriarchal medical concept of "care" and, yet challenged the contemporary visions of client-centred and "edenized" philosophies of care. I believe that the current message these participants receive is ageist reminiscent of the disturbing film Soylent Green, "you are old, and you have lived your life, now it's time for you to... die...". While no health care provider would ever agree with this overtly heinous sentiment, it is embedded in our ageist values of rugged independence and youth, our cultural beliefs of patriarchal care provisions and in the very language of our society. These values are translated into our geriatric policies, which continue to create a culture of dissatisfied institutionalized seniors reflecting this sentiment with a strong desire to die. In the following pages, the reader is provided with the four dimensions of incongruencies that create the foundation for this profound dissatisfaction which continues to plague geriatric institutional models of care.

*Home, But Not Home.*
“Everyone is very nice here, really. They take good care of me. It’s just that...well...it’s not quite like home...” – Nadim

When describing their experiences of the environment that surrounds them, these participants had a great deal to say about their accommodations. The data highlighted in this section indicates that a great deal of effort is made on behalf of these residents to reconstruct this new, institutional world, as their “home”. These informants discussed the struggles they faced when trying to make sense of this world. The informants discuss how the residents, staff and the policies are launching a valiant effort at producing a home-like experience, but fall short of the actual experience of feeling “at home”. Nadim articulates this struggle best in the opening quote, above. Nadim praises the staff and the care, but is still unable to feel “at home” in his environment.

Nadim elaborates on his experience of his private living space, his room, to reveal his great sadness at the loss of his personal possessions, “...I’ve lost everything, my bed, my desk, my sofa...I don’t even have my own bureau. I have a lovely armoire at home”. While, Nadim is relieved that he is in the hands of what he expresses as “...very good care...they are wonderful here...”, he appears deeply saddened by the realization that at the end of his life he must sacrifice his “home” for an exchange in full-time care;

“...I’m safe here, this hospital takes very good care of me...[looks down at his lap and begins to weep softly, pauses to regain composure and with teary eyes looks at me]...I miss my bureau, my pictures. You know, I had a very big bed at home, very big, indeed. Not that this is a bad bed, it is fine and I
sleep good but...my bed...[he smiles]. The floors were marble and so many plants! I had a cat. “Vindi” was his name. I miss him so much. The neighbours took him when I moved in here.”

Nadim often speaks of missing his pet cat, Vindi, and repeated this sentiment or referred to her more then any other topic in our interview. After reviewing this idea I wondered why Nadim felt he could not bring his cat with him into the facility. Nadim understands the facility rules do not allow outside pets. This is not, literally, what the policy states, but Nadim has interpreted the text in this way. Somewhere between the text and Nadim’s interpretation of it, the ideology of the organization has managed to influence a negative response to the acceptance of personal pets within the facility. Thus, Nadim’s work to adopt his new living space as “home” becomes futile without the possessions and pet companion that defines him.

Doris discusses her struggles to make the facility her home and identifies her small personal possessions that surround her in her room to illustrate her point. Doris remarks on her efforts to make her room “homey”, but still refers to the overall environment as a “hospital” and notes that her private living space is limited;

“I don’t mind live’n in this hospital. I had no choice. I didn’t want to live with my kids. My daughter has too much on her shoulders, already. I couldn’t live alone. They’re friendly here. My room is small, but I’ve tried to make it ‘homey’ [waves her hand around at all her pictures and dolls and shrugs her shoulders]...”—Doris
While both Doris and Nadim work to accept their altered environments, they both refer to the facility as a "hospital" because of its medical limitations. This may be one strategy these seniors used to cope with their institutional living space. This experience may be further perpetuated by the residents, themselves. There is no explicit policy to counter these assumptions therefore; these informants operate under the assumption that an action is not permitted if it is not overtly stated. In this way, Nadim and Doris may be helping to create the experience of living in an institution by not decorating their rooms or bringing in their pets. Many participants described experiences of the rules limiting their habitat in some way by making assumptions about the regulations that were not literally in the policy texts. The texts may be providing subliminal messages which residents pick-up on and experience as limitations in their habitat. These interpretations may conflict with their efforts to feel at home in their environment and perpetuate the experience of institutionalization.

In addition, the informants often used medicalized language to describe their experiences with words that seem unnatural in a home setting. Upon deconstructing the text in the data, I noticed the data revealed that the informants, whether they considered their place "home" or not, had quickly learned and adopted the institutional language of their setting i.e. "being toileted", "feeders", "meds" etc.;

"...and then she [the nurse] gives me my meds at meal time and afterwards we are toileted..." Nadim.
"...and I sit next to a bunch of feeders. I can feed myself, so I don't need their [the care staff's] help. Sometimes I even help the others..." 

Helen.

This language may be found in several levels of texts from licensing policies to nursing and care staff tasks and checklists. Reviews and evaluations of residents often include this medical language that is somehow translated from the texts to these informants' negative experiences about their institutional home and their understanding of the institutional "home" setting.

In Marie-Lise's experience is somewhat different, she states she feels quite at home until she is told she cannot remain in her current environment and must be transferred elsewhere. It is only at this point, once marginalized because of her physical limitations that her space reminds her that this is not her home;

"This is my home. I have no where else to go...they tell me if I don't walk, I won't be able to live here no more [begins to cry]. I can't walk sometimes because I'm sick...I try to walk, I really do..." -- Marie-Lise

Marie-Lise explains that she has been told by staff that she must be transferred to another facility. In Marie-Lise's case, the facility's policies prevent her from remaining in what she considers her "home" because of structural limitations and funding issues. She recounts a lengthy conversation regarding the facility's explanation for why she can no longer remain in her living space and was directed to the policy that confirms this "rule";
"They say that the room and the halls are too small for my wheelchair...but I fit fine! They say that I have to move because I am now extended care and use the wheelchair too much...’cause I can’t walk. I don’t know why they can’t keep me here no more."

She complained further that if she was to rely on the wheelchair she would then have to move. Her only alternative to remaining at home was to continue to transfer and walk independently, but no one was able to help her work towards achieving this goal and no formal rehabilitative programming seemed to exist for her in this setting.

Marie-Lise’s experience helps us understand that when her functional abilities begin to deteriorate disharmony is introduced into her living space, which is limited in its ability to change with her needs. She and the facility are faced with the impending dilemma of transferring her to an extended care facility that meets with licensing standards of wider rooms and hallways for her wheelchair or break from policy and licensing regulations to support Marie-Lise’s aging in-place philosophy; “I love it here, but I can’t stay. They say the rules won’t let me stay here, unless I walk, they must not want me here, because they won’t help me walk!”.

This government regulation is transferred to this facility’s policies reminding Marie-Lise that the facility is not her home and therefore, not her choice. If the facility were to choose to keep Marie-Lise and ignore provincial regulations, they would not be supported with the necessary funding they need in order to meet her increased physical and rehabilitative needs. This may leave
the facility and Marie-Lise at risk for substandard levels of care. Here we see her
desire to stay in this facility contradicts institutional issues of safety and lack of
rehabilitative programming. This results in a disharmonious and stressful
experience for Marie-Lise. As a result of this incongruence, blame is shifted from
the society's failure to meet her needs, to her physical limitations, therefore,
requiring her to move somewhere else. She understands that the responsibility
rests with her and that rehabilitation is not a priority for the institution. Marie-Lise
is not at all convinced that moving to a larger space would benefit her well-being
but, feels she has failed in her attempt to walk and states further;

"...They think I am a liar but, I try to walk when I can... nobody ever comes to help me walk...I don't want to move
again. I like it here and have my friends here. I like my room. I don't want to move again. I'll die if
I move...[cannot continue speaking as she starts weeping uncontrollably]...I'll just die."

Marie-Lise's desire is to stay. She clearly states that remaining at "home"
(her current facility) takes precedence over any safety issues. Marie-Lise has
been successful in her work to make an institutional environment her "home" by
identifying her social relationships as a primary feature in her living space. This
contradicts the licensing's requirements to have her age "safely" in a larger
space. As a result of this conflicting pressure, Marie-Lise begins to internalize
the existing policies. Marie-Lise's perceptions of herself and her world begin to
deteriorate as she personalizes the policies that govern her existence;
"... I'm no good to anyone anymore. I used to take care of everyone else [begins to weep softly]. They [the facility] don't want me anymore. I'm too hard for them to care of...even my family want to ship me off to that other place [extended care facility]..."

This sentiment is echoed by Tony's statement at the beginning of this chapter. For Tony, everything in his living space seems just out of reach. Tony's environment shapes his understanding of his abilities or in this case, inability to reach items he needs every day. He is reminded constantly of his shortcomings by the physical set-up in his environment. In addition, he is further reminded that this is not his home with licensing regulations stating many times over, "...alternative arrangements...apply if the medical health officer approves..." allowing the power of decision making to rest ultimately on the medical health officer. No where does it mention that the decision making is shared with the resident. Tony reflects this message when showing me his inability to reach things from his wheelchair in his extended care room,"...you see! I can't even reach the bloody phone from here! [he grunts as he demonstrates stretching for the phone unsuccessfully]...nobody asked me what I thought of my room, they just put me here and said it would be best for me". As a result of this lack of input in the decision-making process, conflict arises when seniors who have worked to make the facility "home" no longer fit the expectations of the institution. Licensing and the facilities' concern
for a population's "safety" have a direct effect on Tony and Marie-Lise's loss of power and self-determination because of his/her physically "safe" environment.

Then there is the issue of building and population size. The issue of personal living space then becomes magnified when set against the largeness and diversity of the population in the facility. The physical size of the building and the increased population size and type seemed overwhelming to many of these participants who had stated they had to move from a single dwelling home or a small family environment to their current communal setting of 100 to 200 residents with an extreme range in abilities;

"...it's too much really. I can't really meet anyone because this hospital is so big. So many people eating all at once and then everyone disappears to the toilet or to their rooms. There are so many people here and I cannot meet one person. I lived alone, you have to understand...now so many people...my whole life I lived alone...[there are just] too many people here..." – Nadim

Helen expresses the same feelings and differentiates her own situation from some of the "other" residents in the facility;

"... well they have so many people, either several, I don't know how many in this thing [hospital] women or men, but about 200 all together..." (I enquire as to whether she finds this highly unusual), “Well, do you live with 200 people? Eat with them all and stuff? Of course it's too many people! Who wants to live with so many sick people?!"
With so many frail seniors to house, the size of the building and the rooms within it become compromised. These seniors work to negotiate the overwhelming increase in population with their own private sensibilities and struggle to make social and emotional connections in such a large crowd of diverse, frail, and elderly individuals.

Upon reviewing the informants' data, they all reflected on the challenge of existing in a cognitively mixed population in their "home" as a barrier to achieving the experience of living at home. A rift is inherently created between experiencing the intimate setting of a "home" and the impersonal largeness of a facility setting. The data is saturated with statements and words that indicate the tension experienced with integrated populations. All the informants expressed dissatisfaction with having to co-exist with a more frail and confused population.

While physical frailties were welcomed by these seniors (if not the facility), cognitive deterioration was perceived as an affront to them;

"Oh, I enjoy helping the sicker ones, you know, the ones in wheelchairs that need help eating or getting somewhere...it's the crazy ones I can do without..." – Doris

While all of the participating facilities had "special care" units for the most confused and behaviourally challenging residents, organizational policies did not address moderately confused residents in an integrated environment. This issue highlights one of the advantages and disadvantages of communal and institutional living. While it provides an opportunity to isolated seniors to re-congregate in a supportive, structured setting, these participants expressed a
strong desire to reinstate their social isolation when confronted with the pressure to interact socially in a cognitively mixed population;

"Well, it's not that I don't like them...we're all God's children, you know. It's just that...well, they need help find'n their way around, eating. The staff have a lot of patience with them. I have to admit...uhm...when they come down for a program...uhm...well...I steer clear, if you know what I mean" -- Walter

All the residents interviewed had issues around living with peers who suffered deterioration in their cognitive functioning. They all referred to these residents as the "others". High functioning residents seem to have little or no tolerance for the "others" and perceived their confused peers as separate and distinct from them. These residents seemed to choose to focus much of their energy on working to segregate themselves from this population rather then tolerate and integrate with them. The strategy of using personal segregation was admitted to be employed by all the informants when questioned about their strategies for coping with more confused residents. The fear of mentally deteriorating was highly disturbing to all the informants and they made great efforts to remove themselves from the integrating mandate with this population spending the majority of their time in their rooms - their "homes";

"Lord, I think I'm loosing it like them others...soon you'll see me drooling with the rest of 'em [an off-comment when Maggie forgot her train of thought]" -- Maggie;
"...just take me out back and shoot me if I ever get like that...Just shoot me, I say..."—Doris;

"I just thank God I have all my mental faculties, you know, nothin' loose up here...yet, anyways..."—Walter.

Susan enjoys her facility lifestyle and when I questioned Susan about her transition experience in a follow-up interview, she was very positive about the move. She stated she knew this was the best thing for her and she already had friends in the facility. However, the one negative experience she reflects on is an encounter with other residents who are experiencing advanced stages of dementia. This has deeply troubled her as of late as she writes in her journal about a special care unit programs now taking place on the main floor;

"...3:30 Church group very loud – headache – find nurse – 3 Tylenol... They're getting sicker and crazier these days, they wander into my room. Oh, I know they're confused but, can't they do something about it?".

Tony became very upset upon recounting the former night's events regarding a resident with dementia entering his room accidentally;

"...that crazy bastard keeps walking into my room and tries to sleep on my bed! And they want ME to lock MY door so I am the one who is caged-in...they want to cage me in like an animal...he's the animal! Well he IS. He eats with his fingers, he shits on the floor...we got
into a fist fight a while ago...I'll punch him if he comes near me again. I'm not a violent man, but if he comes near me again...I'll punch him! [Tony punches the air for emphasis].

Functional disabilities did not seem to weigh as heavily on their daily psyche as did the observation of the behaviours of the more confused residents. All the informants experienced meal times as particularly challenging when they were seated with confused residents or in view of them;

"...there isn't much going 'til lunch time and then you're supposed to go down to the lunch table and eat with the ones that have to be spoon fed by the volunteer that feeds them and dishes the meal up to them... 'Feeders', we call them. The first few times I went down there I was horrified. I thought I couldn't join there, all those people. Then I went and one or two tried to talk to me, you know, and so I accommodated and talked. And then there's all languages, you can't understand them and then one day I helped a woman with her pudding and she slapped me...The first day it was horrible. I thought, "My God, if that's the way I'm going to take my meals here, with people who can't even speak and they're clawing at the table to get a sandwich off it and all that kind of stuff." — Maggie describing the communal mealtime in her facility.
Marie-Lise admitted she often got into fights with one particularly confused woman;

"...she keeps taking my seat and she yells at me...well, I yell back, I tell you. No one yells at me, that crazy woman, elle est fou [she is crazy]!"

She and the other participants do not seem to have the know-how to deal with this kind of integration. The facility policies provide no genuine guidance for staff or residents in these instances except to refer to "mutual respect" in the "Rights and Responsibilities" section of the Handbook for Residents.

The interviews indicated that many conflicts arose between those residents with profound cognitive impairments and residents who were cognitively alert and oriented. Policies, which aim to assist residents in "adjusting" or "transitioning" to institutionalized living, improve their quality of life and increase their safety, fail to provide any guidance in this important part of making the facility less like an institution and more like a home.

I found that the ideologies of different policies tended to clash when specific policies contradicted each other or the expectations of the resident experiencing them. Thus creating a significant incongruence, home, but not home experience.

Let's revisit Nadim's situation with his cat, for example. The facility's policy states, explicitly, that pets are welcome in the environment, however, the specific wording of the policy states, "The facility recognizes that pets are
important companions to seniors and provides these residents with a number of facility animals..." This statement implies that the residents are provided with sufficient pet companionship by the facility, yet neglects to mention residents can bring in their own pets. Some residents, like Nadim, may interpret this statement in the negative to mean pets are provided for them and to leave their own pets behind. This may be said of the policy on personal furniture, as well. The size of the room, itself, lends a strong impression to leave most of your personal belongings behind. Fold the variables of increased populations size and extreme diversity in cognitive functioning into a resident's experience and the result is a foreign environment which is anything, but home.

Licensing ensures that detailed guidelines regarding room space are provided. Attention to ample square footage, lighting, bathroom space and even window placement is given to ensure that seniors are provided with adequate living space. These government policies even encourage personal possessions be admitted into a resident's room. The facilities' policies echo this sentiment. The policy-makers appear to recognize, to a limited degree, the tremendous material loss that seniors experience when moving to a facility setting. These policies attempt to salvage the remnants of a resident's home world and transfer it to their new space in the hopes of emulating "home like" experiences.

However, these informants continue to experience a hospital environment. I examined whether the language of the policies consists of paradoxes that may perpetuate these conflicting experiences. I found it curious that in all the policies I reviewed, there is no mention of ensuring a "home" setting only a "comfortable"
setting. So why do these seniors struggle to define it as such? Where do seniors receive the cues that this new living environment is their home? If we look deeper we see an incongruity between larger governing policies i.e. licensing and localized polices. While government regulations overtly state their intent to transfer the power of decision making to the local regional and facility level, cut backs to funding force contrary policies at the facility level to accommodate both the care needs and safety requirements issued by provincial regulations.

These seniors experience this incongruence by assuming they are to work to make the facility their home at the same time, they are constantly reminded that it is not their home. The notion that they should work to experience the facility as their “home” is not mentioned in either the facilities’ or provincial policies. What prompts these informants to assume they need to make this facility their “home”?

It may start with our perception of what a “home” and a “home life” should be. In our own home, we define the decor, furniture, appliances and living space. Our style reflects ourselves in our environment. On the contrary, in these care facilities, furniture and bedding is uniform and supplied by the institution with little room afforded for personal possessions. This contradiction is identified in government regulations. For example, on the one hand, one licensing policy insists on an acceptable minimal amount of space, “...not less than 11.00m$^2$ ...” and closet space, “...not less than 0.50m$^2$ ...” (Community Care Act, “Adult Care Regulations”) to prevent a facility from designing inappropriately small rooms to
accommodate larger populations in a smaller space. On other hand, it does not require more space for each resident, which then limits the amount of personal possessions that may be brought in. Of greater significance, perhaps is the language missing which indicates that this is the resident's only personal space. This may have been why almost all the informants chose to be interviewed in their respective rooms, as this was the only living space they could call their "home".

With such limited space available to each resident, the following regulation is diminished in its attempt to transfer power to the residents through the appropriation of personal items within their rooms, "...within the limits necessary to maintain the health, safety and well-being of all residents of the facility, must permit each resident to bring into the facility, and keep in the resident's room, furniture, ornaments or other personal possessions." (Community Care Act, "Adult Care Regulations").

In addition to the physical dictation of their environment, seniors are reminded that there is a governing authority that may overrule their preferences. Government policies state quite clearly that safety precautions can always override personal preference by the Medical Health Officer (MHO), who is understood to have the final say. Thus, these participants are no longer the masters in their own home; the MHO has replaced them in this role, and conjunction with the facilities, assumes control of the decisions making process regarding all aspects of their daily lives. In this case, we see how pets, décor,
size of private living space, population size and population variance are influenced to support the institutional experience.

By using terms such as, “them” and “the others”, these informants cope with incongruencies in their living environment by adopting the dominant social structures values, thus elevating their status to more closely associate themselves with the dominant group and distancing themselves from the cognitively impaired residents that share their living space. These attitudes and values are supported and maintained by the facility policies, which then become the guidelines for professionals when implementing their practice initiatives. For example; according to the organizations’ policies, social workers are expected to provide transition and adjustment counselling to newly admitted seniors in an effort to encourage acceptance of the new home and its rules. Nurses and Care Aids are required to review the rules of the facility, again, for each resident newly admitted. The resident is then handed a Resident Handbook, which reinforces these policies/rules. The resulting effect is a substantial impression upon new residents to “comply”. Any fundamental challenges of organizational policies are not warmly welcomed and require a very lengthy, complicated process to change. In the case of integration issues, these seniors are infused, instantly, into a foreign environment where they are left to fend for themselves against all the elements including their greatest fear – the loss of mental capacity, with no help from the facility policies.

The conclusion drawn from what is left unsaid by the text is its assumptions about residents having the ability to independently acquire the skills
to tolerate large and integrated populations or adjust to new surroundings. For example, Susan, Helen and Nadim all discuss how they experience the unnatural sudden increase in the population size in their new home. The Community Care Facility Act's policy does not impose a maximum limit of residents upon these institutions nor does it address the physical size of the facility, instead they require only that;

"...a licensee must have a sufficient number of health care professionals on duty at all times who have the appropriate experience, training and qualifications to meet the identified needs for the residents..." (Community Care Facility Act, "Adult Care Regulations", Sect.6.7 (1)).

Upon reviewing the policy in light of recent funding cut backs, one could draw the conclusion that facilities seemed to be encouraged to house a maximum number of residents to the most allowable minimum number of professional caregivers caring for them. A Community Care Manager, who wished to remain unnamed, advised me that, "...75 residents is a good number, anything more becomes a challenge, but we are given the same money for a facility housing 75 residents as a facility housing 130 residents so why would we use the minimum number when we can accommodate more? I'm not saying it's the best method, but it's the most financially responsible method to manage our shrinking budget..." A smaller optimal number of residents is reinforced in both, a Quebec study, which indicates the maximum number of residents in any facility should be 75 (Lefebvre-Girouard, 1986) and the Gilmore Lodge model, which provides placement for 75 residents (Bohuslawsky, 1989). These informants
support the view that the number of residents in facilities seems to be overwhelming for seniors.

**Hurry Up and Wait: The Conditions of Caring.**

"...its times like these that I keep think’n ‘poor little Maggie, beggin’ for help’..." – Maggie

The second incongruity noted overlaps with the experiences of an increased population size. These informants experience extreme population explosions in their new “home” from their former single living space or nuclear family setting. Personal attention and care may be perceived as “compromised”. This seems to contradict the expectations of these seniors when they experience institutionalized personal care.

Helen states her failed expectations of her caregivers as a result of her recent increase in dependence on them to provide her with her personal care. She complains of the decrease in time they provide for her to effectively complete this care with dignity and privacy;

"...when they toilet me, they do it on their time when they’re ready...I could be sitting in wet panties and they don’t come until they are good and ready!"

Helen buffers her statement by following with blandishments towards her staff;

"But, they are so good to me and they really know what I want...at night they give me my cookies and juice without even asking. They
just know what I need...it's not their fault [care aides] they have little
time for me, they have so many sick people and so much to do...”

Helen rationalizes her quality of care using the coping tools of
understanding and acceptance. She excuses the workload issues of the care
staff to help her tolerate the inconsistencies in the method by which the care is
provided. Helen sees her care giving as strictly functional on the one hand, and
deploying caring in other instances. She even adopts the institutional language i.e.
using “toilet” as a verb/action word, as a strategy to better cope with her
increased level of dependency and decreased quality of care. This experience of
disharmony in her personal care seems to occur with several of the other
residents who, while they express frustration and sadness over their increased
reliance on others, perceive their primary caregivers as highly valuable and very
attentive in many areas of their care. In addition, the informants who discussed
caring issues all noted how overworked the frontline staff were and excused their
rushed approach to care as a result. This may be the work that these seniors are
compelled to learn in order to cope with and tolerate a less personal and more
task-oriented approach to personal care. The result, however, may be
devastating for these seniors as Maggie admits:

“...its times like these that I keep think’n ‘poor
little Maggie, begg’in for help’...” – Maggie

The erosion of an individual’s self-esteem due to increased physical
dependence in the frail elderly can be exacerbated by the feeling of being
“rushed” and the paternal “checklist” approach to care practiced in the facility in
order to meet the care needs of all the residents. The unintended consequences of these "checklists" are Helen’s concern of becoming a burden and Maggie’s experience of begging for help. Hence, these residents experience disharmony in their personal care between their informed expectations and understanding of "personal care" and their lived experience of disappointment in their "personal care". The residents experience this pressure towards task-oriented care and have little choice but, to work with this system. The result is the unintended objectification of these seniors in their daily activities of living. Maggie describes this process of objectification and dehumanization by recounting her daily grooming routine:

"...well, here at this place they do help me quite a bit, [for example] say they bring you a wash rag, [then they] tell us to ‘wash your hands and face’ and [then] you’re suppose to wipe that wash rag ‘round your face and wipe it with a towel and be clean. Well, it’s dehumanizing wanting... want’n to go to a meal after being in bed all night and being towelled off and all that. [It’s] very sad to have to be wiped, your hands wiped with a wet face cloth and the towel flicked by it to dry it."

Helen echoed many of the same sentiments about her increased dependency on her care givers to provide her with her activities of daily living. Maggie’s self-esteem is deeply impacted upon when she comes face to face with some of the care policies that govern her activities of daily living;
"We have a buzzer and that gives a beep, so you press that and they come and quite often they say, 'What do you want, Maggie?' and I'll say, 'I want to go on the commode' or, 'I wanna be toileted'—whatever—and uh, they say they 'can't' or they're 'busy' and they 'can't' and switch the buzzer off telling me that I can only ring it so many times per day...Today they came and I told her I was getting diarrhoea. Course that would scare them into cleaning you quick because it's better for them! So, I get good service if it's better for them...The [staff] interaction with other patients is terrible here. RRRring the bell at night and they cut you off and this kind of thing [points to the buzzer which is clipped up by the light over the bed, beyond the reach of Maggie's arthritic hands and arms]. And that shouldn't be allowed in any medical or other institution as far as I'm concerned but, the rules make 'em do it that way. Those are the rules..."

Maggie use of text is deliberate. She constructs a series of sentences to express her interpretation of the neglect she experiences from staff with her personal care. Maggie works hard to accept that she now relies totally on the staff for her personal care, which if not accepted at the times scheduled by the nursing staff are simply not responded to. She makes the connection to the rules of the facility and the approach to her care. This understanding of the system helps Maggie to recognize that she must now work to manipulate the system to
attend to her needs and provide her with the quality of care she feels she is entitled to. The reader might have noted her brilliant strategy to encourage staff to tend to her toileting needs by the sheer threat of "diarrhoea" and the burden of work for staff that, if neglect, may increase tenfold.

In another interview, Walter suggests, in our conversation, his critical issues through the repeated use of his disclaimer, "...let's put it this way..." , before he finishes more controversial ideas on his independence with his personal care; 

"Let's put it this way...I'm doing all right now but, I wouldn't want to be, you know, in a wheelchair depending on others, you know, for my toileting and bathing...I'm real lucky right now..."

This negative image of dependency is entrenched in the culture of institutionalized frail seniors. Both government and organizational policies have the ability to transmit the dominant social processes through a language that creates a negative social construction of dependency. Though this may not be the policy makers' intention how the informants storied their experiences seem to reflect this belief and some identified that they were aware of the terms they were using to describe their experiences. For example, both Walter and Maggie indicated that I should note the language they were using and significant points they were making through compelling body language, as if stating these are critical points, overtly, was somehow treacherous. All the informants, cautiously, expressed concern over the connection they made between the degradation of individualism and the decrease in independent functioning in their abilities.
These informants made it apparent that the edict for limited staffing numbers has a great deal to do with the attitudes of care providers. Both Helen and Maggie alluded to how they received this information, but neither articulated how they knew that the staffing was short and resources limited or that there were so many other residents in need of care.

I can only assume that the care staff, themselves, told these informants of their situation. It may be that with limited staffing available and increasing needs and demands of the residents, personal care becomes more functional in nature. The pressure to complete a list of duties orients the staff more to the tasks then the individual for whom they are providing these tasks. The resident then works to absorb the expression of this pressure by re-shaping his or her experience of personal care to cope with the objectification that ensues.

Another care issue that was raised was the use of patronizing speech. The idea that they have had to give up their independent lifestyle is proving a difficult challenge to overcome. While some have worked to accept the label of "dependent", others work to reject their current "dependent" status. It is difficult to imagine the work these seniors do to maintain any sense of dignity when having to "report" on their most intimate bodily functions such as, daily bowel movements, urine output and sleep cycles. Add to this, the impossible task of having to accept the most intimate of personal care from strangers who address them as children and the result is a devastating increase in their experience of profound humiliation. While there is no diplomatic way to inquire about the daily bowel movements of a resident, some approaches are more offensive then...
Tony expresses deep rage and humiliation over the approach of one care aid who inquired about his toileting routine;

"...she comes in all smiles, bats her eyelashes, and then ‘whammo’ she winds ya. ‘Did Mr. Tony have a poo-poo today?’", she asks me! [begins to shake and swallows hard] Do I look like a baby to you?! [Tony rips off a series of superlatives at this point that I have chosen to leave out] Next time I’ll shit on her head! Then she’ll be able to check it off her damned list without ask’in!"

Maggie expresses similar sentiments when a male care aide requires the mechanical lift she is using for the toilet during our interview;

"[behind the closed door of the bathroom] Sometimes you’re wait’n forever, it takes quite a while... and sometimes it [the mechanical lift] gets taken away immediately. Then they put you on the sitter and haul you up, all the while, they call ya ‘dearie’...on the commode and then you urinate or whatever and such and then you get a wash down ‘there’ and keep on going. Then...He rinses my hands off ...[a male care staff enters the bathroom, without knocking, where Maggie is and tells her he needs the lift and removes it, stating he will return with it]. Now I just have to stand here and wait for someone to take care of me.” [The care aide leaves the door to the bathroom open and I am jaw-dropping surprised to see Maggie hanging on a contraption, hovering over the toilet with no pants or underwear. She
shrugs her shoulders and I ask if she wants the door closed. She shakes her head no, gestures to continue and smiles. I turn away to allow her some privacy and I ask how long she will be this way]... Oh, I don’t know, 10 or 15 minutes, I guess...just sitt’n or er, if you call it sitt’n, hang’n up in that thing. Just hang’n around and wait’n...”

The image of Maggie, being referred to as “dearie” and rushed to the toilet and then left to wait – hanging -- was deeply disturbing for me. It was an unforgettable experience for me. However, it was difficult to read her feelings on the matter. She seemed almost resigned to the idea of hanging over a toilet. This resignation suggests that it is a common occurrence in her daily routine. She mentioned a lack of equipment and, in this instance, excused the care aide’s approach as she implied this situation was not his fault. She makes no reference to the fact that it was a male care aide who entered her bathroom, without asking, to remove the mechanical lift.

The terms “dignity” and “privacy” are used throughout all the organizations’ policy manuals. The Act requires these concepts be strictly observed however, no where do the policies discuss how dignity is to be preserved, nor do they address the issue of opposite-gender care. While it seems less of an issue for the male informants, all the female informants made mention of this fact at one point during the interview process. All the female informants expressed concern over having their intimate personal care provided for by a male care staff, on occasion.
A final note about Maggie’s comment suggests she exists in an absurd paradox where she spends a lot of her time being rushed through her daily activities of living and then left waiting for things to happen. The value of “time” is not translated into the policies. Yet, time, so limited for these frail seniors, is distorted by the incongruity of the experience between being rushed through personal care and left waiting for it. The ambiguity of time is translated into the role of passive actor by these seniors. They seem resigned to the fate of “hanging around and waiting” all day for life to happen to them. Their choice seems to be either an exhausting battle to demand more time with staff or resign themselves to waiting patiently for care.

There seems to be no minimum or exacting ratio of care staff to residents in the Act only that there be a “…sufficient number of employees on duty at all times to meet the needs of the residents and to provide a safe standard of care for the residents.” (Sect. 6.8 (a)) does not indicate whether this “safe” care should be “holistic”. These informants raised the issue of the inverse relationship between a decrease in functional ability and an increase in reliance on a limited number of professional caregivers. Many of them noted the rushed atmosphere of the staff during personal care activities.

The Community Care Act, “Adult Care Regulations” states, “A licensee must develop and implement written policies to guide staff actions in all matters relating to the care of residents.” (Sect. 9) and while the Act does provide some guidance around the specifics of care, “A licensee must ensure that staff develop and implement an individualized care plan for a resident who remains in an adult
care facility for two or more weeks.” (Appendix A) it does not clarify how these policies are created or whether to work within a holistic framework. Institutions are left to develop a caring framework for themselves in which to create and implement policies in the area of personal care. The incongruities seem to exist between the provincial regulations and the organization’s policies in this case. Below we see a carefully outlined text about personal care for these seniors from the *Community Care Act*, “Adult Care Regulations”, Sect.10.3 (See Appendix A);

i) “… A licensee must, to the greatest extent possible while maintaining the health, safety and well-being of all the residents, ensure that (a) the personal privacy of each resident is respected, and (b) the privacy of each resident’s bedroom, locker and storage area is respected.”

ii) “...As with all adults, residents have the right to: a) the basic requirements of life, i.e., food shelter and social contact. b) live their lives as they wish, provided they do not infringe upon the rights and safety of others. c) protection from psychosocial, emotional, financial, sexual and medication abuse; violation of civil/human rights and neglect. d) information about their civil and legal rights. e) participate in making decisions about themselves in accordance with their ability to do so. f) self-determination

iii) one organization’s “Resident’s Rights and Responsibilities” policy states,” that all residents a) be treated respectfully and courteously in a way that fully recognizes dignity and individuality. b) be afforded privacy in all aspects of daily living. c) participate in making decisions which affect daily life d) receive support to be as independent as possible...”
While much is said in the Act and the facilities' mission statements and visions (Appendix G) about "dignity", "privacy", "independence", and "self-determination", rarely, are these concepts translated into the fiber of the facility policies. Organizational policies tended to focus on nursing concerns including accurate charting, completed checklists, and the maintenance of legal records;

"The professional nurse welcomes the resident to the unit, conducts an admission history with the appropriate forms, creates a temporary care plan, completes an admission checklist..." (Sect.2.2 of a Facility Policy and Procedure book)

in addition, the care aide is required to;

"...inform the resident of meal times, location of call bells and the bathroom, label equipment complete admission checklist...complete care plan checklist and routine logs on behaviour, sleeping and bowel movements..." (Sect.3.2 of one of the facility Policy and Procedure books).

Policies may be the link to the dominant social processes shaping the functional, task-oriented and rushed attitudes of health care professionals in institutional settings. If these policies are contradictory negative experiences may be infused into the facility community as a result. The result of ageist shaping in healthcare provider attitudes can have a devastating effect on the care receiver's experience of his or her most intimate of personal care routines. This can lead residents to a negative perception of their self-image and self-worth as care receivers in an institutionalized setting.
However, it is not the only policy that creates a structural oppression among these seniors and their care. Misleading texts such as the participating facilities' policies for nursing services state, "...on admission, Professional Nurses assess the resident's needs and begin to develop a care plan and/or care guide based on a Needs model...the resident is involved as much as possible in the care planning process as are other disciplines...resident's needs are reviewed regularly, plan is evaluated and revised if necessary...". While the text and intent of this policy sounds empowering, at some point, the idea of "self-determination" has been lost and the concept of "care" has been reduced to checklists, charts and logs. This "needs" model neglects to mention anything about residents' rights, only that they be included in the care decision process. There is no mention of the resident directing the decision-making process. As a result, staff may be enabled by policy to dictate what care needs to be completed without taking responsibility for how care needs to happen.

The policies demand accountability for the care of each resident in a long term care facility to ensure that the basic needs of these residents are being met. For example, the organizations all had a similar checklist of events that need to occur to ensure quality of care in their institutions;

"...the Professional Nurse welcomes resident...conducts resident's admission history interview, initiates care plan...completes the Admission Checklist form...the Care Aide informs the resident of meal times, location of call bells, bathroom...labels equipment and completes Admission
Checklist..." (Facility A's *Policy and Procedure* manual, Sect. NG0300, 2.2)

Here we can see how the emphasis on checklists is embedded in the policies, yet the lack of mention regarding how care is provided i.e. holistically, humanely etc. is omitted from this essential text. In contrast, the Resident Handbooks and Mission statements of these facilities stress the concept of “dignity”, “privacy” and “holistic care” in both the *Residents’ Rights and Responsibilities* and the vision of each organization (See Appendix G). This contradiction is experienced at both the resident and frontline staffing level. In order to negotiate through this contradiction, both staff and residents work to devise an approach to care that can be tolerated. This forms a structured approached to care focussing on the functional aspects of providing care. With little training in the area of diplomacy, many care workers are required collect data on extremely intimate issues and provide a very invasive type of care. The lack of staffing, limited time to complete policy-dictated tasks and sparse education in providing care with dignity for frail seniors is only part of the picture.

The dignity and privacy of these residents is further compromised by the social structure during which they were raised. Most of these informants experienced a patriarchal, capitalistic, conservative, Judeo-Christian social structure. Based on the social histories they provided, most of the informants were raised in small nuclear families, where rugged independence, the trappings of youth, and monetary wealth were highly valued. These seniors were not accustomed to divulging what they believe to be family issues or private
concerns. In addition, the field notes I made during the introduction and profile phase of the interviews revealed that some informants admitted they were comfortable providing care for others, but not receiving care for themselves. There is no indication in the policies that inform staff on the art of diplomacy. Social Workers are not immune to this patronizing speech or the checklist-procedures that invade a frail senior’s life. Organizational policies, if they even exist, often dictate a Social Worker’s duties, as well;

“...prior to admission the Social Worker is responsible for arranging an interview with the applicant and/or his/her family/authorized representative to assess personal care needs, psychosocial and spiritual needs, review policies and complete forms...” (Facility A’s Policy and Procedures manual, Sect. NG0100, 2.1)

Finally, it would seem that the residents who challenge the system for more time and demand a greater effort from the staff like Maggie, Tony, and Marie-Lise reported that their experience their care was, in their own words, “humiliating”, “degrading” and “undignified”. This reinforces their understanding of Nadim, Marie-Lise’s, and Walter’s perceptions of being “burdensome”, “useless” and “difficult” in their institutional structure.

Very Busy Being Bored.

“... on Tuesdays and on uh, Thursdays and Saturdays. Like you know, I go in there [in the weight room] and put on weights. You exercise, you know, different movements, and... I think that we’re pretty lucky to have that over here.”—Walter
At some point during most of my first interviews, I inquired about the informants' family participation in the daily social activities of the residents' lives. Most of the informants indicated that they had little family involvement in their daily activities of living and that if there were involved family members, they only came when necessary or on special occasions. These seniors tended to define their social relationships within the limits of the facility. Contrary to my assumptions, a number of the informants expressed some satisfaction in the social atmosphere of the facility. I noted that the higher functioning residents enjoyed the increased opportunity for socializing, in general, and the opportunity to build relationships with other residents and staff alike. Susan writes about her trip to the mall:

"...off to Sears' to find a shelf for my cottages - friend looking at purses - no shelving to be found. Back to purses, friend still looking - waiting in dept for her - again heard my name paged! - Go to "Clinique" counter! Had to hunt for "Clinique" section - there is friend (with mirror) waiting - She'd hunted & couldn't find me! Off to Zellers for lunch - met another [nursing home staff] worker - joined her for a coffee & chat. "
She notes her excitement in meeting up with both her friend and a staff member and joining them for lunch. There seemed to be fewer disharmonies between policy-intent for increased recreational socializing and the personal experience of comradery among some of these residents. The Community Care Facility Act enables facilities to provide access to social activities in both physical structures and programs by requiring that these facilities have indoor and outdoor recreation areas for the residents (See Appendix A). This is supported by the participating facilities who ensured that there were specific policies on the recreation and socialization for the residents;

"Leisure staff develop and implement programs which address the residents' identified needs, and which improve or maintain the health of as many residents as possible. Programs include, but are not limited to: activities, entertainment outings special projects therapeutic programs, e.g., music, pets, gardening; leisure staff encourage and/or assist residents to attend programs which interest them, are appropriate for their abilities, and meet their needs." (a facility Policy and Procedure manual, Sect. NC0400, 2.1)

Insisting on a variety of physical areas in which to meet encourages residents to socialize outside their rooms. Facility policies echo these sentiments with a variety of programming to accommodate most residents' needs. This challenges my previous incongruencies which discusses the impersonal nature of facility living. The informants recalled that while enjoying the independence of
living at home alone or with a small family, they remember the social isolation from their peers and the community. In a facility, these individuals now had the opportunity to interact with both their peers and the community outside the facility. Some of the participants described very positive experiences with respect to the social aspects of their daily lives;

“From the moment I get up.... I go down to breakfast. A nice breakfast and then the exercises I did the uh, exercises in the diningroom, lots of fun...and then uhmm we were sitti’n around and I was talking to the all the people in the room down there, I don’t know, I got a name for all of them and they always got a name for me! You know, “Oh! There’s Dori!” and we say, “Hey there!” and we’re laughi’n and shaking hands and that’s what I like to do. I get along with people. I like helping people!”-- Doris

Helen giggles when describing her feelings about the Social Worker encouraging her to teach staff and residents the game of Mah Jong;

“...she [the social worker] just come up to me and say,' Helen, teach me Mah Jong and I play with you', next thing I know, line-up of people in the lounge waiting for me to teach them. ‘We all like to win money, Helen!’"

At first this seems a successful story of autonomy achieved under a rule governed system, however I would like bring the reader's attention to the fact that
most of these informants were among the highest functioning seniors in the group interviewed. One informant complained of boredom during the day with nothing to do. Maggie, the frailest of all the residents I interviewed, perceived the facility activities as "stupid" by her definition. She describes winning a bowling contest, with chagrin;

“Oh Yes, there's different activities, I won at bowling, I'm on the bowling team [snorts]. I've been on that ever since they were making up the team several years ago and uh, somebody else, when I was in the room and they just pull me out by the back of the neck and say, "You'll bowl with us" Well, they've got some silly, stupid things that are really pitiful. One of the bowling ones they've got... no of 'em can bowl so they've got a big long traugh, like an eaves traugh, it goes right into the pins with no effort at all... And that's supposed to be "educational" or somethi'n, I don't know, I wouldn't go back to the second one 'cause it makes you look like you're stupid or feel stupid. No way could you miss. I have gone to talk to them; I don't go on a continuous basis because I can't find any sense in it. That's my long answer to it; you should get fun out of it no matter how stupid it is. That seems to be the outcome they're looking for..."
The policies do not describe the appropriateness of the activities to these residents' needs. In Maggie's case, while she is frail and limited by her physical abilities, her mind works very well. Because of her physical limitations, she has been associated with a group of very confused residents. She finds the recreational task "senseless" and demeaning and quickly loses interest in the activities offered to her. On the other hand, a positive social activity that Maggie does enjoy is the relationship she has forged with an Asian resident who sits with her at meals;

"There's an old Chinese lady there, she eats, my God, she eats barrels of stuff! And, uh, and if you help her with it she's so grateful and her first impression is, "I'm a Chinese and how are they gonna eat next to me, do you think they're going to like me?" That's on her mind all the time, she told me lots about the Korean war and things like that. If a man comes and, and, first thing she does is try to help him like a wounded soldier. She treats them like a real wounded soldier, passes them things, and they're probably in worst straights than she is, they don't know what she's doing anyway. It's sad to see it all but, I'd rather see that then this, uh, grabbing for stuff in the mall."

In this case, Maggie is able to provide assistance to another resident and observes other similarly frail residents providing assistance, too. This activity she
can make sense of. She experiences the feeling of being useful and needed in a world that otherwise has defined her as "useless" and "disabled". This restores Maggie's sense of meaning in her world and her pride in her independence and ability to give back something to her community.

Mealtimes also seem to be of great meaning to the residents. The dining room experience differed with each informant, but they all noted that this time of day was one of the most significant events they experienced during the day. All of the informants mentioned dining room experiences without any prompting in our interviews. Generally, they understood that the nursing staff provides medications to the residents during this time, which makes it a significant "medical" moment for them. However, the informants all agreed that mealtimes provided the greatest opportunity for socializing with other residents and staff. Most of the care aides are in attendance assisting residents with eating. Often, administration staff will eat with the residents during lunch hour. Families sometimes, even visit at this time.

The policies reflect the significance of the dining experience with pages of rules, policies and procedures with respect to space required per person, dietary concerns, quality of food, quantity of food, the serving of food and the residents' involvement with food but, did not refer to the significant experience of relationships building conducted at each table. Walter relies on the social relationships he builds at his table and works hard to establish them. When these relationships change, it can be highly disruptive to the resident as Walter found out;
“Yah, they uh, they have changed the whole thing [seating arrangement]...I’m the only one left at my table because they changed floors etc. and uh, so uh, it’s uh, like I just finished saying, getting used to new people is uh, I don’t know, maybe, I often think about maybe, they have to get used to me too! So,...Well...uh, eh, eh, I related to you that uh, you can’t socialize uh, with everybody and uh, I also found out in the past that if you...even at a table if you uh, uh, get too attached to one person the other people feel like you know left out and etc. Another thing is I found that uh, I don’t know maybe it’s me but, if you start certain topics sometimes it might offend them...Oh, but I’m nice to them! I say “Hi” and “Want something?” and that whatever they particularly need but, there’s no uh, control over who sits with me...I guess everybody has their own mental capacities and uh, it’s good enough that they’re able to come to the table and eat.”

Walter finds it very difficult to create social bonds with new people and experiences great loss that his tablemates are no longer with him. He copes with this loss of control over his environment by attempting to forge new bonds with his new tablemates despite their cognitive differences. He does this by assisting those residents who need help with eating. According to three of the informants in this study, everyone’s table had moved without any resident consultation. Apparently, they were told only that the nurses had decided to arrange the tables, by floors, so they could administer the medications more effectively. In this instance, the nursing staff attempts to simplify the medication administration policy guidelines by dividing the dining room into sections “A” and “B” and
splitting the units accordingly. This dramatic change was a strong reminder to these seniors that this was not their home and that the decision-making about their environment and with whom they will be friends was out of their control. This reinforces the experience of oppression among these residents. Forced to accept the changes that had already occurred they turn their attention to surviving yet, another loss in their world. To cope with this loss they work to focus their energy on forging guarded relationships with their new tablemates without investing too much emotion. Walter admits that this has led to increased loneliness in his environment because he is reluctant to work at any new relationship for fear it will be terminated without notice;

"...I suppose that's why I feel so lonely sometimes, they keep moving my friends away from me...oh, and they don't do it on purpose, of course..."

What the reader should take away from this incongruence is that these informants have devised their own coping mechanism for creating meaningful social relationships despite an imposing large and mixed population and an ever-changing environment with inappropriate recreation and social programming. Though they are inundated by the daily experiences of loss on many levels, they continue to work at forging bonds between each other to survive their institutional experiences. They draw their most meaningful and valuable experiences from those which enable them to reciprocate for the care they receive. Whether they help by feeding their fellow residents, assisting them in getting help for their care needs or spending time together in a social atmosphere, these experiences seemed most memorable and most valued by these informants. Despite the
medicalized nature of their environment which tends to limit their discussions to bodily functions, mealtimes, medications and toileting routines, they work to find meaning in activities of reciprocity to balance-out the nursing environment. If these programs lack meaning, a danger particularly experienced by the most frail residents, then boredom ensues and the resident's self-esteem and self-worth becomes diminished. The data indicates that a number of the informants' negative social and recreational experiences were the result of facility safety issues overriding issues of autonomy. This leads me to the next incongruence about safety vs. autonomy. These informants describe the frustration they experience when attempting to build relationships and participate in programming only to be sabotaged by issues of "safety" that concern the organization.

*Safe, But Silenced.*

"Let's put it this way, I think I got wiser..."-- Walter discusses his lesson in challenging the organization's authority.

Many of the informants discussed their experiences when defending their autonomy and challenging the authority of their facilities. These experiences appeared to have negative results i.e. Maggie states firmly, "I'm a 'no-gooder'; I'm widely known as a 'no-gooder". When she describes an incident where she tried to maintain her independence by transferring alone and refusing assistance from any staff. It would seem that the policies indicate that the responsibility of safety and care rests on the staff and administration. Safety issues are noted to override all other concerns in almost every area of these residents' activities of daily living. The informants indicated, below, that
they were often defeated in their quest of autonomy on the basis of "safety issues". In most cases, they tried to rationalize why their demands could not be met by the staff. They often referred to the issue of "safety" as the reason for their defeat. Most surprising was the willingness of these informants to blame themselves for the gaps in their care. I was struck by the practice of self-deprecation that they participated in when attempting to justify these gaps.

In the raw data, the textual contents of their experiences reflect policies that shift the blame for these gaps squarely on the shoulders of these frail seniors. For example, both Marie-Lise and Maggie use the terms "trouble maker" and "no-gooder" to define themselves within the context of their institutional setting:

"...it [bathing routine] was done very nicely outside of the delay and they explained that and that was good enough. If they explain they're actions, why not, I mean, I'm not trying to make trouble, just trying to get along. Often, I speak, as if I'm a trouble maker."—Marie-Lise

While these informants' current perceptions included their experiences as challenging residents, Walter and Doris tried to eradicate their reputations as "difficult" or "demanding". Walter impresses upon me that, while he used to challenge the facility, he has changed his ways for the better:

"So, although now, uh, like when I came in here some might say I was "rambunctious" but, now uh, I've, quieted down and, not being on that many
mediations etc. so I guess, I'm not so "jumpy"! [laughs]... my ability over here to be with the staff has really improved, I guess an...mind you, I still have fears and all that but, I don't have the negativeness anymore... I've been here now, a long enough time to learn that it's OK if Management tells me something like that but, on the other hand, what right have they [the staff] got to tell me different from my opinion and all that! Let's put it this way, I think I got wiser. [shrugs and laughs nervously] I guess if you learn once you learn all over."

Walter has learned that when he challenges the rules in his "home", he is told he is "rambunctious" and "jumpy", worse – there is a threat that he might need a medication adjustment. Walter's negative experiences with authority leads him to believe, that he is not the decision-maker in this home.

Nadim and Helen reassure me, in earlier statements that they try not to be a "burden" or "troublesome" to the staff. This reinforces the perception of a depreciated life of less worth. Nadim elaborates on this sentiment when he states that, "I can't do much and I am a lot of trouble for the nurses, I'm afraid..." Both Walter, Helen and Nadim receive the undeniable message that they are responsible for their own unhappiness and dissatisfaction and that if they "behaved" and complied with the rules of the facility they would have a more positive experience. These three informants made a point of informing me that they were pleasant and compliant residents who were cooperative with care.

However, when Walter states that he “got wiser” he deliberately neglects articulating the institutional teachings that self-advocacy, illustrated by Maggie and Marie-Lise, is not welcomed in any part of his daily life when it conflicts with
organizational policy. He works to survive in his environment by playing by the rules of the facility, even if he disagrees with them. Thus Policy, itself, becomes a shield that the staff and administration can hide behind when they resist changes in their environment. For a frail elder, this shield proves too difficult to penetrate. It is easier to blame themselves and to assimilate into the silent majority then fight a losing battle with what little energy they have left.

Doris learns this lesson when she attempts to complete a "complaint form" regarding several missing items that she believes have been stolen and has no response from the nursing staff since her report one week prior to the incident;

"Well, I reported it to the nurse, but I got so angry after so much of it gone...and just, it happened again! And so I said, 'Well what the hell...?', I really got furious, I said, 'What 's the sense of me telli'n you girls if you don't do nuthi’n 'bout it...', I says, 'well she’ll [the care aide] take me down to the nurse's station again.', I says, 'Well what's the sense of doing that?'

She says, 'Well we always got to sign...' I says, 'OK, but, ' I says, 'I think I'm gonna to do better than that [states Care Aid's name] I 'm goin' up to see', uh, the lady's name, now what is it?...'the Director of Care', Yah. I says, 'I'm goin' up to speak to her and see what can be done.' And then she [the Director of Care] wants me to fill out this here form [waves a form in my face]. Not that I can write with my crippled hands and I'm practically blind but, WHO THE HELL CAN READ IT?! [Doris raises her voice in frustration]. You know, it's an awful feeling. This is my home and I consider it so. But, it gives me the feeling that I'm not home...and it's not
the fault of this place, not the fault of any place....I believe it's the

Government's rules. "

Doris has identified the "government" as the origin of the disharmony in her experience. This could be interpreted to mean the policies dictated by the
government. When I reviewed the Community Care Act in the "Adult Care
Regulations" sections for direction on self-advocacy I noted that no where, in the
Act, is the notion of "advocacy" mentioned at all. In fact, sections 10 and 11 in the
Act, on dispute resolution and the establishment of resident/family councils, are
the closest we get to any concept of self-advocacy (See appendix A).

These two sections of the Act allude to an idea of self-advocacy, but do not
overtly mention it. This neglect to mention such a critical concept in the Act has
resulted in the continued oppression of the frail, institutionalized senior. All the
informants experienced this significant omission in their activities of daily living.
Such a prominent textual omission of this essential concept forces them to
reshape their self-image and the way they experience their participation in the
world around them.

Thus, a strong skill set in self-advocacy is often mistaken for "trouble making".
Residents working to empower themselves are often labelled as "demanding"
and "difficult" by staff. They are often told that their expectations are too high.
Contrary to this message, is that of the facility policies which raise the issue of
advocacy and the residents' rights;

"Residents are protected under the Canadian Charter of Rights and
Freedoms. In an effort to improve a resident's quality of life, staff support
the resident's efforts in voicing his/her needs and concerns in a safe and empowering environment when appropriate staff advocate on behalf of the client to ensure the client's needs are met within reason." (a facility Policy and Procedure manual, Sect. NE0600, 1)

It further states;

"self-advocacy is the most important form of advocacy, the advocate's role [often the Social Worker] is to strengthen the resident's ability to solve problems and to promote the development of self-confidence and independence" (a facility Policy and Procedure manual, Sect. NE0600, 2).

However, disharmony arises when this sentiment is drowned-out by the many other rules of safety that the facility has. Policy Manuals never suggest that one particular policy should take priority over all others. The interpretation of these texts is then left to the individuals who have access to these policies as to the prioritization of the rules that govern these seniors. Access to the complicated text of policies is rarely offered to residents.

Further, frail seniors may be unable to read the print size or understand the technical language of this text and are thereby, alienated from the policy process. This reduces their effectiveness as self-advocates as they lack essential knowledge of the organizational rules of the institution. Self-advocacy has clearly taken a back seat to a multitude of other policies that seem to precede it as a result of this technical language and pages of safety precautions. As a result, self-advocacy is often experienced in failure.
These informants experience the failures of their endeavours while attempting to make sense of this paradoxical world. These incongruous conditions may present a challenge too difficult for frail seniors to overcome. The experience of these defeats and confusion lead to feelings of low self-esteem, worthlessness and hopelessness. Thus, these informants succumb to the ranks of the defeated majority of their silenced peers. The tragedy here is that the facility means to provide an improved model of care where the client is the central focus, but only serve to marginalize these seniors even further as their experience of “good care” becomes defined by budgetary cut-backs and safety regulations. As they raise their voice in question or protest, they are uniformly silenced by the texts that govern their daily lives.

Summary

Looking at the textual elements of policies may explain the disharmonious cultural phenomenon experienced by frail seniors living in long term care facilities. Policies guide organizations when designing the physical layout of a facility and the décor and contents within. Policy also provides a foundation for developing controls around the possessions seniors bring with including the pet companions. In addition, seniors are injected into a large and diverse communal setting, which creates barriers in which to build meaningful relationships. No textual attention is given to the challenges of adapting to cognitively diverse populations. The unintended consequence of these policies or lack there of, help to shape residents’ perceptions of their physical world. The resulting effect is the message that this is “not quite home”.

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Policies guide organizations in approaches to care, but fall short of providing language which empowers the resident to control when and how they receive this care. With shrinking budgets and increasing demands of frail seniors, approaches to care are reduced to a task-oriented focus with attention primarily on the functional abilities of a senior. Seniors seek to survive this environment by using the coping tools of self-blame and self-deprecation. This is exacerbated by the limits that their physical environment places on their abilities to function independently. The result is the residents' understanding that unconditional caring has its limits.

Facility policies shape the social relationships of residents and their perceptions of what is a valuable relationship. The most valuable relationship experiences involved opportunities of reciprocity where a frail resident could assist another resident in a formal program or an activity of daily living. While this is the most successful area of policy-intent, the frailest of seniors remain marginalized by the texts as it seems only to apply to higher functioning individuals. Thus, as a resident's physical abilities deteriorated so did the meaningful programming that was provided. It was found that residents also invest little in their social relationships as they learn how to survive the constant social changes in their environment when their peers deteriorate, move and/or die. Thus, the frailest residents experience a busy atmosphere of institutional programming, but remain bored in their environment.

Policy can undermine a resident's self confidence in his or her ability to make independently sound choices in his or her daily life by placing self-
advocacy very low on its list of priorities. On the other hand, these seniors experienced the issue of "safety" in their environment as being paramount to the organization. This was reinforced by a vast number of policies related to safety in the facility. Residents learned that, in order to survive in their institutional "home" they must silence any voice of opposition to the policies that govern them. Thus, they are safe, but silenced.

Finally, these incongruences between the policies and personal experiences have a direct effect on the self-image of a resident. Policies are linked to influencing the way in which institutionalized seniors perceive themselves as defined by the rules that govern them. Upon reflection, these informants realized that they were left to find their own meaning in a rule governed environment that focused on an objectified "self". The irony of these discoveries was the effort to which facility mission statements and visions insisted on a new client-centred model of care while continuing to push the "client" beyond the margins of society.
CHAPTER 5

THE DISCUSSION

In this final chapter I will discuss the three main points I draw from the discovery section as a result of the data. The first section of this chapter, *The Sins of Omission*, will discuss the impact of what is not included in the policy language. What is missing from the policies appears to be as important in shaping resident perceptions and experiences as what is overtly inscribed. The second section, *The Irony of Institutionalized Aging*, will focus on a discourse in ageism and the factors that create a demoralized sense of institutional aging. Here I discuss the absurdity of our intent to create facilities specifically designed to accept and celebrate the frailest of our seniors and the continued process of marginalization we impose on them as they become increasingly dependent. Finally, the third section, *Realizing Genuine Holistic Care*, invites the reader to a discussion of how care is interpreted, implemented and perceived by the care giver and care receiver. In this section I propose several initiatives for health care workers, particularly social workers, to assist residents in re-storying their experiences through empowering language, a shift in the client-centred paradigm to a resident-directed model of care, and re-visioning policy development as an avenue for creating meaningful and resident-empowering change in the current institutional structure of facility care.
The Sins of Omission

One of the most surprising results of this study was the unique insight that these informants provided on the experience of policies by omission, not by commission. It seems the most influential experiences these seniors had emerged through an instinctive understanding of what is not written in the texts and regulations. The assumptions and interpretations these seniors made, as a result of missing language from the policies, support the current dominant social structure and perpetuates the oppression felt by institutionalized seniors. This process may best be described as a lack of codification.

A codification is a representation of the learner's day-to-day situations. It can be a photograph, a drawing, or even a word. As a representation, the photograph or word is an abstraction which permits dialogue leading to an analysis of the concrete reality represented. Codifications mediate between reality and its theoretical context, as well as between educators and learners who together seek to unveil the meanings of their existence (Friere, 1970). When this codification is missing a dialogue cannot be established and reality becomes distorted. For these seniors, the language omitted from the policies becomes an effective oppressor as it cannot easily be identified by those subordinated by it. These seniors are effectively silenced by what is not stated in the regulations.

Friere (1970) refers to this a "culture of silence". Alienated and oppressed people are not heard by the dominant members of their society. The dominant members prescribe the words to be spoken by the oppressed through control of
institutions for example, we here from one informant, “I sit next to a bunch of feeders”, a word only used in the institutional setting. This imposed language and the institutional process effectively silences these seniors. This imposed silence does not signify an absence of response, but rather a response which lacks a critical quality. Oppressed people internalize negative images of themselves (images created and imposed by the oppressor) and feel incapable of self-governance. Dialogue and self-government are impossible under such conditions (Friere, 1970).

Further examples of the influence these covert policies have can be seen when informants described the ambiguity in the facilities’ pet and furniture policy. One informant surrenders his pet companion and all his furniture as a result of his interpretation of this ambiguity, “…I’ve lost everything, my bed, my desk, my sofa… I don’t even have my own bureau… I miss my cat, ‘Vindi’, the neighbours took her when I came here.”. Similarly, another informant assumes she is no longer wanted in the facility due to a lack of rehabilitative programming that may prevent her transfer. In both circumstances the policies are ambiguous. As a result, they are interpreted negatively. Mullaly (1996) describes the adoption of dominant values and beliefs by oppressed groups as internal dominance. This internalized oppression can caused oppressed groups to act in ways that continue to perpetuate the dominant group's view of them as subordinate. This leads to a process whereby subordinate individuals reproduce their own oppression (Mullaly, 1996). The informants assumptions about ambiguous policies
contributed to the inability transform their institutional surroundings into a home experience.

Finally, the lack of critical and progressive language in the policies continued to perpetuate a subdominant response within the oppressed group creating a caste system among them. Informants perceived cognitively mixed populations negatively and were provided with little or no guidance from the facility, “They’re getting sicker and crazier these days, they wander into my room...” No mention of the issues related to this caste system is address in the texts. Left to their own survival strategies, “I have to admit...uhm...when they come down for a program...uhm...well...I steer clear, if you know what I mean”, these informants uniformly responded to their current state of oppression by mimicking the behaviours and attitudes of the dominant group towards and even further marginalized group in an attempt to gain a slightly more privileged status (Mullaly, 1996). In Bowker’s Humanizing Institutions for the Aged (1982) he describes a perceived “contamination” among frail seniors in cognitively mixed populations.

The burning question then becomes, why is the language ambiguous in the policies? Perhaps the answer lies with the dominant group’s determination to maintain and support their values and beliefs. Left unchecked, these subtle, intangible omissions can be extremely effective in maintaining control over subordinate groups. Social workers and policy-makers need to critically attend to the current geriatric lexicon when developing policies through anti-oppressive practices (Fook, 1993; Laws, 1995; O’Connor, 2003). A language that is
empowering for these seniors needs to be established, implemented and impressed upon both health care workers and institutionalized seniors. Eradicating oppressive medical jargon when establishing a senior's new home setting or when providing personal care is essential to the empowerment process (Lather, 1991). Further research into the link between policies by omission and institutionalized seniors' experiences is critical in ascertaining the extent to which this lack of appropriate and clear language is impacting on them and their perceived quality of life. Social worker and social advocates can be instrumental in providing education in empowering language and anti-oppressive practices with both older adults and health care providers.

The Irony of Institutionalized Aging

One of the most prevalent discourses from this study appears to focus on ageist social constructions that link residual ageist policies to these seniors' experiences. The informants experiencing the highest levels of dependency and disability reflected a very negative perception of their own personal self-worth against the back drop of the institution. The informants' comments such as, "...I'm no good to anyone anymore", "good for nothing...", or "...just take me out back and shoot me if I ever get like that...Just shoot me, I say..." and "well, it's dehumanizing wanting... want'n to go to a meal after being in bed all night and being towelled off...[It's] very sad to have to be wiped, your hands wiped with a wet face cloth and the towel flicked by it to dry it.", are clear in their intent to express
the process of humiliation, degradation and rejection that they experience as they grow more dependent on others for their care.

The tragic irony of this study demonstrates that seniors enter these facilities with the expectation that their limitations and needs will be gladly met by the organizations designed to cater to them. They are shocked and deeply disappointed by the perpetuated experience of discrimination based on their physical and cognitive demands. Instead of celebrating their courage to ask for help, we punish them for being old, frail, and a burden, worthless and demanding. This leads these seniors to fear the concept of disability, wishing for death before dependency.

Ageism is a dynamic term that has evolved since Robert Butler coined this term in 1968, "...a systematic stereotyping of and discrimination against people because they are old." (Achenbaum, 1985: 129). Ageism exists on many levels in contemporary society. There exists discriminatory attitudes toward older adults by their own peer group (Goodstein, R.K.; 1985). All the informants expressed some level of discrimination towards the more confused residents living among them, "Who wants to live with so many sick people?!" and, "I have to admit...uhm...when they come down for a program...uhm...well...I steer clear, if you know what I mean" or, "...that crazy bastard keeps walking into my room and tries to sleep on my bed!...he's the animal! He eats with his fingers, he shits on the floor...we got into a fist fight a while ago...I'll punch him if he comes near me again." These informants make it clear to health care professionals that stronger research is
required with cognitively frail seniors suffering from a variety of dementias. Clearly the needs of both these residents and those with dementia are not being met or supported in the foundation of organizational and institutional policies.

Ageist discrimination can be observed in the behaviour against these seniors by individuals i.e. prejudicial comments and poor treatment by service providers (Braithwaite, 1986). We see this reflected by these seniors perceptions of themselves in an institutional setting, "I'm a 'no-gooder', I'm widely known as a 'no-gooder'" and, "Often, I speak, as if I'm a trouble maker" or, "I am a lot of trouble for the nurses, I'm afraid". These seniors reflect the sentiments they feel embedded in the policies that govern them and practiced by the caregivers that provide services for them.

Finally, discrimination of seniors can be observed by institutional practices and policies i.e. mandatory retirement, aged-based promotions, means tested eligibility requirements for government assisted care and needs-based criteria for placement which focuses on emergency cases that tend to service acute care agendas rather then community-based needs (Cavanaugh, 1993). Long term care facilities continue to perpetuate the custodial medical model of care, a system that has been under attack over the past decade (Chappell, Strain, Blandford, 1986).

Key concepts such as, infantilization, depersonalization, dehumanization and victimization described by Kayser-Jones (1981) continue to be voiced by seniors in institutional settings. NACA (1999) continues to advocate for changes
to combat ageist constructs that create these experiences through policies mediated by the dominant group.

These informants discussed how ageism has affected their daily experiences of living through the neglect to provide meaningful programming, a lack of funding for rehabilitative therapy and our continued efforts to ignore the work that seniors do in their daily activities of living. While much attention is given to the efforts of caregivers and care providers, the language, itself implies care receiving on the part of these seniors, reducing their roles to passive actors in their own existence (O'Connor, 2003). Social workers and Social advocates need to increase public sector education raising awareness about the work that seniors do to survive their institutional habitats. A new language is needed to re-story the experiences of these seniors to include the work that they do and recognize the skill and expertise they have in managing their institutional setting.

Further research focussing on policies being translated into practice is desperately needed to increase our understanding of seniors' continued negative experiences despite resident-centre care models. Social workers play a key role in re-storying the experiences and understandings of both health care providers and institutionalized seniors in an effort to eradicate the pervasive ageist construct that continues to plague these seniors.

**Realizing Genuine Holistic Care**

I would like to close this study by discussing a final discourse, which emerged from the data, on the failure to achieve a genuine holistic care or whole body medicine model (Levin, 1999). These informants, throughout the data,
articulate the need for a change in approach to the language we use in the care they receive. Bowker (1982:14) describes the need for replacing resident-staff dependency relationships with helping relationships as one factor in establishing a holistic care model. The Organization for Economic Co-operation and Development, OECD, (1996) confirms that the need for long term care facilities will continue and the goal to turn them into livable habitats is an important component of policy concerning older people. Considering residents as "clientele" and "consumers" that health care providers service may provide a springboard from which to re-story the institutional setting into a genuine holistic experience (OECD, 1996:93).

When the language and phrasing of policies are structured to consider the "citizens" of these facilities, first and foremost, the balance of power within a facility setting may equal-out. Reshaping our current thinking begins with changing the language we use in our practice. Empowerment cannot be established if the very language we use is exclusive and compartmentalized rather than holistic. Removing the academic and medical technobabble from our research, our laws and our policies and replacing these words with holistic, client-inclusive terminology will help to provide greater accessibility and understanding, to these seniors, of their rights and responsibilities as citizens of a facility.

Here I would challenge social workers/advocates to consider a radical move towards from resident-centred care to resident-directed care. The two concepts are quite different. The first suggests that health care teams consider the resident as the focus of their care planning. This still seems to allow for a
differential power structure where the team may fall into their residual medical model habits of deconstructing the individual into a multidisciplinary approach. Often this approach divides the resident into disciplines, if not body parts, with similar results. Rather than all disciplines considering all aspects of this resident as a whole person, the team “reports” on each disciplines area of expertise, effectively partitioning the resident into departments, quite like body parts. Social workers/advocates need to recognize that this is not a genuine holistic approach. As a result, we need to reconsider what genuine holistic care needs. In order to do this, more qualitative research involving test groups of institutionalized seniors is needed to understand what they believe to be holistic care. This might provide insight into what a resident-directed approach genuinely looks like and how it may work in practice. Policy makers would be forced to re-vision their understanding of the regulations from a resident-directed framework. The change in language and focus in these policies may lead to a genuine holistic model of care. Until this is attempted, we will continue to repeat the history of institutionalized seniors experiences.

In closing, I would like to challenge my peers to question and re-visualize existing policies for their use of language and their focus to ensure they cease to marginalize these population groups. It is my hope that by improving the language and spirit of these texts, we may provide more choices to these citizens and reshape their daily lived experiences as positive, meaningful and a life worth living.
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APPENDIXES

Appendix—A

Community Care Facility Act
ADULT CARE REGULATIONS
[includes amendments up to B.C. Reg. 141/2002]

Lounges and recreation areas in residential care facilities (Section 5):

The licensee of a residential care facility must provide

(a) one or more readily accessible and comfortably furnished lounges, containing, in total, not less than 1.50 m$^2$ of floor area for each resident,

(b) one or more readily accessible, suitably equipped and furnished areas where recreational activities may be carried out containing, in total, not less than 1.00 m$^2$ of floor area for each resident.

Lounges and recreation areas in residential care homes:

The licensee of a residential care home must provide one or more comfortably furnished lounges or living rooms containing, in total, not less than 2.00 m$^2$ of floor area for each resident.

Outside activity area

(1) A licensee must provide one or more readily accessible outside activity areas

(a) including, in total, not less than 1.50 m$^2$ in area for each resident, and

(b) including a surfaced patio area and comfortable and safe seating.

(2) A reasonable portion of the areas described in subsection (1) must provide shelter from the sun and inclement weather.

(3) If a resident who uses a walker, wheelchair or other mobility aid is accommodated,

(a) the licensee must provide access by a ramp to the outside activity area, and,

(b) a ramp described in paragraph (a) must comply, except for width, with the requirements for ramps for persons with disabilities as described in the British Columbia Building Code.

Care plans (Section 9)
9.3  (1) A licensee must ensure that staff develop and implement an individualized care plan for a resident who remains in an adult care facility for two or more weeks.

(2) A care plan must include

(a) a plan for the resident's health care, including any self-medication plans,
(b) a plan for the resident's oral health care,
(c) a nutrition care plan, and
(d) a plan for the resident's recreation and leisure activities.

(3) A care plan must take into consideration the abilities, the physical, social and emotional needs and the cultural and spiritual preferences of the resident.

(4) A care plan must be

(a) completed within six weeks of the resident's admission to the facility,
(b) reviewed on a regular basis and modified according to the current needs and abilities of the resident, and
(c) accessible at all times to staff who provide direct care to the resident.

(5) A licensee must encourage a resident to participate in the development and review of his or her care plan.

[en. B.C. Reg. 329/97.]

Dispute resolution (Section 10):

The licensee must ensure that

(a) a fair, prompt and effective process is established for residents and their families or substitute decision maker to express a concern, make a complaint or resolve a dispute,
(b) there is no retaliation as a result of a resident, family member or substitute decision maker expressing a concern or making a complaint,
(c) all complaints, concerns and disputes are responded to promptly, and
(d) a record of all complaints and concerns, and the responses to them, is maintained by the licensee and, on request, is made available to the medical health officer. (Sect. 10.14) and,

Resident or resident/family councils (Section 11):
(1) A licensee must facilitate a forum for residents and for family members and substitute decision makers, to meet in order to promote the collective and individual interests of residents and the involvement of residents in decision making on matters and concerns which affect their day to day living.

(2) The forum referred to in subsection (1) may consist of a resident council or a resident/family council.

(3) If no resident council or resident/family council is established, a licensee must provide an opportunity, at least annually, for residents, family members or contact persons, or all of them together, to establish a council or similar organization." (Sect. 11.3)
### RESIDENTS' RIGHTS AND RESPONSIBILITIES—FACILITY "A"

<table>
<thead>
<tr>
<th>Every Resident Has the Right To:</th>
<th>Every Resident Has the Responsibility to:</th>
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</thead>
<tbody>
<tr>
<td>• Be treated respectfully and courteously in a way that fully recognizes dignity and individuality</td>
<td>• Treat other Residents, staff and volunteers respectfully and courteously and accept them as individuals</td>
</tr>
<tr>
<td>• Be afforded privacy in all aspects of daily living</td>
<td>• Respect others’ privacy</td>
</tr>
<tr>
<td>• Participate in making decisions which affect daily life</td>
<td>• Participate in making decisions which affect daily life</td>
</tr>
<tr>
<td>• Have access to Leisure and Recreational Programs</td>
<td>• Make leisure and recreation requests known to staff</td>
</tr>
<tr>
<td>• Receive support to be as independent as possible</td>
<td>• Participate in one’s own care as much as possible</td>
</tr>
<tr>
<td>• Have one’s own religious and cultural preferences respected</td>
<td>• Respect the religious and cultural preferences of others</td>
</tr>
<tr>
<td>• Openly express any concern without fear of repercussion</td>
<td>• Communicate concerns until the issue is resolved</td>
</tr>
<tr>
<td>• Have care and treatment explained in words that are easy to understand in order to make informed decisions</td>
<td>• Seek out information when one does not understand care and treatment</td>
</tr>
<tr>
<td>• Receive palliative care and make funeral arrangements according to one’s wishes</td>
<td>• Inform the care Team of preferences regarding one’s own death and to make funeral arrangements</td>
</tr>
<tr>
<td>• Refuse medical treatment except when the safety of others is at risk</td>
<td>• Accept medical treatment when others are at risk</td>
</tr>
<tr>
<td>• Receive confidential accounting of financial transactions</td>
<td>• Budget one’s own funds and pay accounts in timely fashion</td>
</tr>
<tr>
<td>• Receive mail unopened unless otherwise indicated</td>
<td>• Respect the privacy of others’ correspondence</td>
</tr>
<tr>
<td>• Live in a safe and clean living environment</td>
<td>• Keep the facility clean and free from litter</td>
</tr>
<tr>
<td>• Have access to the outdoors</td>
<td>• Notify staff if one chooses to leave the facility for a period of time</td>
</tr>
<tr>
<td>• Display personal possessions, pictures, and furnishings in keeping with space and safety regulations</td>
<td>• Respect the property of other residents</td>
</tr>
<tr>
<td>• Meet privately with a partner in a room that assures privacy and, where both partners are residents in share rooms</td>
<td>• Respect the privacy of other residents</td>
</tr>
<tr>
<td>• Choose a Family Physician to assume primary responsibility for medical care</td>
<td>• Communicate one’s choice for medical services and make the necessary arrangements</td>
</tr>
<tr>
<td>• Be informed of pertinent policies and procedures</td>
<td>• Observe policies and procedures</td>
</tr>
<tr>
<td>• Expect staff to know about the process of aging and care of the older adult</td>
<td>• Acknowledge that staff know about aging and the care of the older adult</td>
</tr>
<tr>
<td>• Expect staff to be knowledgeable of the Residents’ Rights and Responsibilities and to implement them</td>
<td>• Accept accountability for these rights and responsibilities</td>
</tr>
</tbody>
</table>
Appendix -- F

The 10 Principles
The Heart of the Eden Alternative™

1. The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering in a human community.

2. Life in a truly human community revolves around close and continuing contact with children, plants, and animals. These ancient relationships provide young and old alike with a pathway to a life worth living.

3. Loving companionship is the antidote to loneliness. In a human community, we must provide easy access to human and animal companionship.

4. To give care to another makes us stronger. To receive care gracefully is a pleasure and an art. A healthy human community promotes both of these virtues in its daily life, seeking always to balance one with the other.

5. Trust in each other allows us the pleasure of answering the needs of the moment. When we fill our lives with variety and spontaneity, we honor the world and our place in it.

6. Meaning is the food and water that nourishes the human spirit. It strengthens us. The counterfeits of meaning tempt us with hollow promises. In the end, they always leave us empty and alone.

7. Medical treatment should be the servant of genuine human caring, never its master.

8. In a human community, the wisdom of the elders grows in direct proportion to the honour and respect accorded to them.

9. Human growth must never be separated from human life.

10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

(Source: www.acqi.org.au)
Appendix -- G

FACILITY “A” AND “B” MISSION STATEMENT AND VISION

Vision:

“An integrated health care delivery continuum which includes support of person in their own home, a congregate support network and multi-level care within which people may move freely with degrees of support according to their needs”

Mission:

“[Facility “A”/ “B”] provides homes for people who are functionally dependent at the Intermediate and Extended Care levels. We continuously strive to provide caring and supportive living and working environments for residents, family, staff and volunteers in a thoughtful, collaborative and professional way.