

Homecare:  
One Woman's Journey

A Thesis

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Homecare: One Woman's Journey

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### Abstract

Contemporary social policy compels seniors who require assistance with personal or household tasks to obtain help from 'the community'—a term that most often means 'women' family members. Much is written about 'caregiver burden' but little research explores the experiences of older women who are the recipients of home care. Using narrative inquiry methodology and a life history framework, a senior woman home care recipient on Prince Edward Island, Canada, was interviewed over a span of 4 months in 2005 creating a total of 10 hours of audio taped interviews. Interviews were analysed using a critical inquiry approach embodying a feminist and political economy perspective. Data were analysed throughout the interview process and understandings emerged about how care and care needs were negotiated and managed. Exploring Aronson's (2000) 3 images available to older women, this research seeks to expand on the image of 'managing'—resistance to 'being managed'—and extend the notion of 'work' involved in staying in charge of everyday life. Work is examined under 3 concepts, managing, controlling, and raging. Social policy with its reliance on family as care givers is an inadequate response that entraps and marginalizes women both as caregivers and as care recipients. Care recipients engage in work that involves resistance and raging against injustice in their daily practice of negotiating homecare. Rage as resistance is an appropriate response to the experience of marginalization and silencing among older women care recipients. Angry seniors is an image that claims rage as a legitimate force; it is an image of older women that calls for reconstruction and research to uncover its legitimate power in the daily lives of care recipients.

### Acknowledgements

The water is as taut and smooth as I've ever seen it, flowing effortlessly, softly, imperceptibly, past the wharf where I sit under the variegated veil of a willow tree. It is nice to sit here peaceful, alone, knowing the work of writing a thesis is past. This is unlike the tumultuous aloneness when I struggled this past winter with data and literature and ideas that were huge and unwieldy and seemed to constantly resisted my efforts to tame them. Certainly at that time I seemed, to myself, to be alone. But, in the self-centredness of thesis writing, I was like the drop of rain that breaches the surface of the still water beyond the willow tree. I was at the centre but in concentric ripples around me were all the people who supported me in my quest. The first ripple is composed, in ring-around-the-rosy sort of way, of Alexis, the wonderful, generous woman who told me her story in increasing depth of detail and nuance and also of my delightful and insightful academic advisor in this project, the ever patient, Dr. Anne-Louise Brookes. In tight ripples after that are those who supported my effort emotionally and substantively by being there throughout this long process and offering words of encouragement in their myriad forms from 'you can do it' to 'oh, just get it done!'. Here, I think of my husband Richard Baker who both babied and barbed me in my effort to complete the task. Also here are my children, Josie, Katie Colleen, and Jean Begley Baker, who in their own way assisted in seeing this project come to an end. Jean in particular passed a very quiet ten-day March/Easter break with only me for company. Jean provided the comic relief for my work breaks. My community of friends compose another ripple forged by patience this past winter when I asked to be excused from social invitations and offered none. My friends respected my need for time and ensured that I remained connected with my community by dropping over meals and other

family was away. Other ripples are formed by the parish nurse who distributed recruitment letters—her identity will remain concealed in order to protect the identity of my research participant—and by people with whom I work especially Colleen MacQuarrie and Philip Smith who encouraged me to begin this course of study and aided me with encouragement, advice, and contacts throughout the course work and thesis preparation. A colleague, Paul Gray, who is a master at APA style edited my final draft before submission to the thesis committee—any errors are mine. Paul also helped solve computer snarls in preparing my thesis presentation. I would like to recognize Dr. Fiona O'Donoghue who served as the internal examiner, Dr. Ann V. Dean of SUNY who served as the external examiner, and Dr. Elizabeth de Freitas who served as second reader. Their comments and suggestions were greatly appreciated. Finally I would like to mention Marg Kovacs, Joey Edwardh, and Jane Aronson, my mentors in homecare research at McMaster University.

This thesis is dedicated to my parents, Norbert and Kathleen (Cook) Begley, who, even in death continue to aid and inspire me and to my brothers and sister who contributed so much time and resources to the care of my parents.

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## Part I: Introduction and Theoretical Framework

### *Introduction and Rationale*

Homecare, according to the 1999 report by the Federal/Provincial/Territorial Working Group on Home Care is defined as “an array of services which enable clients incapacitated in whole or in part to live at home, often with the effect of preventing, delaying or substituting for long-term care or acute care alternatives” (Anderson & Parent, 1999, p. 8). Homecare takes the form of formal (paid) or informal (unpaid) care and is obtained from public or private sources. Formal homecare is provisioned either as a public service or as care that is privately purchased from the legal or the underground economy. Informal homecare is obtained from family, friends, or neighbours.

My interest in homecare developed from a desire to understand the practice of homecare and what it might mean to be a care recipient. When I began this work I had not yet met ‘Alexis’ and did not know then that my exploration of her life would form the basis of this thesis. As is often the case in qualitative research the process of researching and writing about a topic grew and broadened as I got to know the participant, as I studied the literature on homecare and, as I thought about the research I had completed in the past with respect to homecare and ageing women. When I first met Alexis I intended to interview at least four participants but following our early meetings I decided to conduct a deeper study of Alexis’ life, in part, because of the richness of her life-story and her generosity in sharing it and, in part, because I wanted to construct a thesis that would enable me to understand and connect meaningfully with the complexities of one woman’s life as she lived homecare. In keeping with the work of Cole and

Knowles (2001), this study is “...based on the fundamental assumption about the relationship of the general to the particular, and that the general can best be understood through analysis of the particular” (p.13). From the outset, my goal was to seek data from our interviews and conversations, observe how Alexis and I interacted, and see how the data could be understood in relation to the literature. The stories told to me are rich in detail and emotion and I want to construct a representation of Alexis’ life that will honour her story, while maintaining the ethical standards necessary to the research process. The lenses with which I analyze the stories, are mine.

Research suggests that the trajectory and evolution of women’s stories of becoming a homecare recipient differ from that of men’s (Lochhead & Scott, 2000). My goal was never to prove whether or not this was true. Rather, I wanted to understand first the story of one woman receiving homecare. I elected to study senior women because, in part, that is my future. I am either blessed or cursed with long-lived genes and the perception of this as a blessing is impinged upon by the availability and sufficiency of homecare services. Alexis’ stories tell me implicitly and explicitly that homecare is a women’s story but this does not make it only a women’s issue. Most of the participants in homecare are women as either caregivers or care recipients and most of the care recipients are senior women who suffer from chronic diseases and mobility problems. From talking with Alexis, I realize that her experience of care receiving constitutes work—the work of managing, of resisting the diminishment and devaluation of ‘being managed’, the work of controlling her care, care that at every turn conspired to deprive her of its control, the work of raging against injustices in her prosaic daily practices. The work of rage articulates a protest against being old, being female, and being a homecare recipient in an ageist culture augmented



by the reductive images of old people embedded in the ideologies of globalization. It is this work that I set out to understand. As a feminist researcher, I seek to make visible this work as part of the full range of women's unacknowledged and unvalued work.

In undertaking this research, my aim was to listen carefully to Alexis' life story and to make sense of her experience with homecare in relation to the literature and to some of the biases and assumptions I bring to the research process. Ostensibly, the purpose of the study was to investigate and understand the experience of one recipient who is at the centre of the care relationship. I undertook this research in order to understand what it is like to be in a position of requiring homecare, what needing care involves for one woman, and what is required of a person who needs homecare. In this thesis, I explore assumptions made in the literature about the provision of homecare, and how these assumptions translate—or not—into the fulfilment of the needs of a person receiving homecare.

In theory, homecare is one way that the federal and provincial governments respond to a complex and serious social need, that of providing health care to an ageing population. However, ageing seniors do not comprise a homogeneous population. In reality, homecare and related social policies affect Canadian women and men in different ways. Women over the age of 65 receive homecare at a rate greater than men simply because women live longer, often caring for and outliving a male spouse. Women face other sobering realities that affect their quality of life in later years. Women are paid less for their work (Statistics Canada, 2000), the pension system is tied to labour market earnings, there are gendered patterns of labour force participation, women have primary responsibility for reproductive labour, the majority of elderly women are poorer than are men, and relative to men, women's chances of persistent poverty becomes much

greater with age (Lochhead & Scott, 2000). Lochhead and Scott (2000) state that “...the incidence of persistent poverty among elderly men is the *lowest* of any age group. Among elderly women, it is the *highest* of any age group” [italics in original] (p. 11).

Women also suffer in a disproportionate way, relative to men, from chronic diseases such as hypertension, arthritis, emphysema, (Elliot, Hunt & Hutchison, 1996) and disabling conditions, including fractures, osteoporosis, back problems, osteoarthritis and depression (Murtagh & Hubert, 2004) that incapacitate women for longer periods of time. The issue of homecare when viewed from these points of disadvantage has heightened meaning for women, pointing to the grave reality that significant numbers of elderly women will receive the larger portion of homecare, and for a longer period of time. Homecare policy as a result affects women in a disproportionate way. Facing this reality, for example, my mother in her senior years suffering from chronic disease and with no pension and few investments was fortunate in a sorry sort of way—she died before my father when the true reality of being old, female, widowed, and in need of homecare may have made her final years even sadder.

These realities lead to a number of questions about senior women and homecare. As a result of my ongoing interest in homecare, I approached this study with several questions that changed as the research developed. Initially, I asked the following questions: What does the possibility of receiving homecare mean for women who may also be disadvantaged socially, economically, and politically? What might women who are currently part of the homecare system be able to say of the care they receive, or hope to receive? What is a senior person’s role as a recipient of homecare?

This study was designed to hear the stories of one care recipient and to understand what it

might mean for women generally to receive quality homecare. My aim is two-fold: from a critical feminist perspective, I examine theoretically and practically the social and political underpinnings of homecare; from a narrative perspective, I examine Alexis' life story in an attempt to understand her experience of homecare on Prince Edward Island. Specifically, I examined biographical information about Alexis' life experiences and how these experiences are connected to her present practice of receiving care. My goal was to listen carefully to the stories so that I understand both the context and her personal experience of homecare. At the same time, I hope to make clear my own assumptions about women and homecare. From these various perspectives, my aim is to listen to and explore the experiences of a senior woman as she daily experiences care with a view to examining the links between "personal troubles and public issues, biography and history" (Marshall, 1999, p. 437).

#### Researcher Stories (One, Two, and Three)

For researchers undertaking a life history research project, Cole and Knowles (2001) offer the following suggestion: "one way to unpack our research baggage...is to write what we call a personal history account in which we examine the path taken to a research project" (p. 49). In keeping with this idea I begin this study with a short biography and with three stories of my own; I use these stories to explain my interest in and my bias when exploring the story of a senior woman who is a homecare recipient on Prince Edward Island. Significantly, both of my parents required homecare to enable them to live their final days with deserved quality and dignity at home. My father got this quality care; my mother did not. It is from these personal experiences of the highs and lows of homecare that I became interested in the experience of the homecare of others.

*A little bit about me.*

I was brought up in the 1950's in a traditional family with one sister and four brothers. My mother worked at home in reproductive labour and my father in the paid labour force. I understand from my research with Alexis that our family was one husband/father away from poverty. I am the product of a very traditional Catholic home and education. I learned the lessons of Catholic social teaching and recall the foment of the Second Vatican Council. At university I encountered progressive politics and I'm not sure when I became interested in the struggles of women—always, I think, when I consider my life with four brothers. Later I became interested in liberation theology that was emerging from Latin America and the exciting work being done to bring the issues of social justice and the marginalization of disadvantaged groups onto the main stage. These concepts informed my thinking then and they continue to inform my thinking now. However, now the oppressions of which I am prey because of my gender threaten me with more danger as I become a senior. My years in reproductive labour and in paid labour that offered lower wages relative to men's, with no benefits or pension are closing in on my reality. I remain, as was my mother, one husband away from poverty. Like Alexis, I feel, after a lifetime of work, I should be able to expect more. Poverty and marginalization is not a good enough response to the needs of senior women now, or ever. This research is an effort to 'do something' about this for my future and the future of my daughters who enter a world significantly different from the one in which I grew up. But also much the same.

*Story one.*

As my father tells it, if my mother searched through her purse once, she searched ten times on the half-hour trip to see the specialist. Even now it is not clear what she searched for,

nor whether she found it; I doubt if even she knew. But it was the first inkling that all was not right. It was a routine medical appointment to address her history of high blood pressure and type 2 diabetes. What it turned into was the beginning of a quick slide into dementia. Not the slow insidious comings and goings of Alzheimer's Disease but the speedy disorientation, confusion and memory loss of multi-infarct dementia—the ravages of many small strokes. On the heels of that September 1988 trip came hospitalization, release, and a final re-hospitalization on Christmas Day until her death one month later.

It was clear, that Christmas, that she was not going to recover her mental health, health that was made worse by the disorientation of the unfamiliar hospital environment. Her physical health was not such that she required hospitalization—an experience that was marked by chemical, and physical restraints both in bed and in a geriatric chair. This clearly was not the way to spend one's dying days. My family and I were unable to secure publicly supported homecare resources to augment the family's limited ability to care for my mother as her illness took her further and further from health and reality during those fall and winter months in 1988 and 1989. For my mother the homecare alternative to the acute care ward would have been far preferable to spending the last of her life surrounded by strangers in a strange land.

*Story two.*

Eight months prior to his death on August 24, 2000 my father informed his six children that he had Stage IV prostate cancer. My father was 87 that July when he was rescued from a drugged haze in the small town hospital where he was being treated. Rarely ill throughout his long, active and unmedicated life, he found hospitalization worse than death—the latter a solution he sought to solicit from his doctor. My sister, a school teacher, took him from the hospital after

school closed for the summer to the family home where he had lived for fifty years—eleven of those alone following my mother's death. Under the care of one or other of his six children that spring and summer, and with the support of a mixture of publicly resourced, privately paid and volunteer workers who attended to his needs, he lived out his final days in relative comfort, surrounded by those he loved and those who loved him. This contrasts with the failed attempt to obtain public homecare services to support and ease my mother's life. Her death occurred mid-winter— a time when adult-children were unable to offer sufficient day to day physical presence to support her living out her life at home.

My father's experience with homecare was with end-of-life palliative care where death is seen as imminent or within sight. Stage IV cancer is terminal and palliative care is short-term. It differs from long-term care in that although mentally and physically draining, exhausting and painful, there is an end to it regardless of how wrenching that end. Family members arrived from across the country that spring and summer for spates of final-farewell care giving— possibilities available only for the short term. The mixture of voluntary, public and privately-paid homecare services offered him that summer reflects the lack of standards and the mixed economy of care that is experienced by homecare recipients, not just on Prince Edward Island, but across Canada. Perhaps if his needs had been chronic, and long-term, his experiences with care in the home may not have been so positive either for him or his family, all of whom knew that in the summer of 2000 all that could be done to support his quality of life was being done. Though my father's carers felt satisfied that his needs were met we never inquired of him about his experience of homecare. There was a story we would have benefited from hearing.

From my experience, homecare that relies on primary care giving from family and friends is a hit and miss type of care. Despite the positive experience of my father's homecare it could

have turned out dramatically differently. The key factor? In this case, timing. Because of the time of the year in which my mother's illness and death occurred (fall and winter) her experience of failing health and death differed from that of my father's that occurred over spring and summer. Two of my siblings are school teachers and my father's time of heavy need occurred over the summer break, and because they were able to leave their families for periods of time and move into the family home, hours from their own homes, to provide continuity of care and the constant attention that he required, he was able to live and die at home. My mother's death did not occur at a similarly convenient time so her need for care at home meant that she remained institutionalized until her death.

The image of the care provided, by a functional family to a parent in failing health, is a myth on which social policy relies—care by family and friends. I am one of six children in a family that did not experience violence, abuse, alcohol, or parental absence. Caring for dad at home came without resentment or coercion. Given the convenience of his timing, caring was something that was given willingly. The presence of some publicly provided care did not diminish our desire, as adult-children, to aid and participate in care. The coincidence of his timing and the lucky ability of a family to be able to provide care speaks to the instability of social policy that plays on the myth of traditional family caregiving, and relies on coincidence and luck to provide sufficient resources to satisfy seniors' needs. The comments by the physician, nurses, priest and mortician on the family members' cooperation and participation in his life and death speaks of the unusualness of this story. Yet, this is the uncritiqued fiction on which social policy governing homecare programs and services is marketed to the popular imagination.

*Story three.*

Though I am not by profession a teacher, and while I have worked in social critique for my professional life, I have been drawn to graduate work in education because I am interested in helping others to see and learn about the things I have observed over my career. My interest in and experience with homecare arises from two sources, both the personal stories I relate above and an academic interest that stems from the longevity branch of my father's family tree. At the time my father was still alive and strong at 86; his mother died at age 105; her father, my great grandfather, lived to be age 92. Following from this personal connection I pursued an academic interest obtaining a degree in gerontology at McMaster University in 1999. During that time I observed first hand the interaction of rural homecare recipients with one of the leading case managers in the Hamilton-Wentworth Community Care Access Centre (CCAC). Along with this case manager I was able to note, analyse, and discuss the impact of shrinking budgets on the array of services and service hours that accompanied a move toward the privatization of health care services that hallmarked Ontario's Common Sense Revolution under the Progressive Conservative government of Mike Harris. From a critical perspective, I observed that CCACs were created as an institutional mechanism designed to shift the responsibility of caring for people in need from the state to the community with neither the consent of care recipients or caregivers nor the concomitant resources to maintain these services even at their pre-existing level (Begley, 1999). I was observing, in the daily lives of senior women who were the recipients of homecare, the functioning of the shift toward globalization of the economy and the impact of the neo-liberal and neo-conservative ideologies that came into vogue over the past two decades. I had the luxury of studying a CCAC in detail and was disturbed by the findings of my study. My research worked to uncover the fallacy of the rhetoric about community care, choice in care



receiving, consumer options, and the role in privatization of services the CCACs were established to perform in the guise of improved services.

In my current research I set out to understand how these social practices affect the life and experiences of Alexis, a senior Prince Edward Island woman. According to the literature I reviewed, social location and globalization have an impact on the experience of senior women who are recipients of homecare on Prince Edward Island. In fact, the literature suggests that senior women are disadvantaged because of their sex since their early life. The role of established social location and the tumult of globalization, according to the literature has an impact on how experience is portrayed by women. Very little literature is extant on this topic and because I want to hear the voice of one female participant receiving homecare, I chose to use a narrative approach to this study. Consistently, my aim in this thesis is to understand how specific social practices and organizations affect the woman whose stories I tell. Working from a critical feminist perspective, and using narrative inquiry, I want to shed light on what it is like to be a senior woman receiving homecare on Prince Edward Island.

I have struggled with the appropriate adjective to describe a person of Alexis' age. We live in an ageist culture and the terms available for use all carry serious negative baggage. I have not made an attempt to recover words and work through their negativity. Rather I have chosen to use the term, 'senior' that I feel carries the least amount of cultural negativity. However, the term is ill defined in the popular imagination with shifting boundaries and arbitrary definitions. Sixty-five is an age that is commonly used to demarcate the dividing line between being a senior or not. This age was arbitrarily established and has only the advantage of custom to recommend it. The expanse of years that has come to represent the senior years—age 50 to 100+—is too broad and unhelpful. Alternatively the terms Third Age and Fourth Age provide for some definition

using chronology but more than that provide qualitative distinctions. Chronologically the distinctions represent the ages of 50-75 and 75+ respectively. Qualitatively the distinction between the Third Age and the Fourth Age “is the onset of serious infirmity that marks the point of transition” (Twigg, 2004, p. 64). Alexis, at age 63, is chronologically in the Third Age but qualitatively resides in the Fourth Age.

The most common form of homecare involves seniors with chronic diseases such as arthritis, diabetes, heart disease, kidney disease, mobility problems, or other illnesses that are neither dramatic nor climactic. This kind of long-term care involves struggles with getting out of bed, washing, eating, cleaning, bill paying, transportation, shopping, and home maintenance for example— assistance that may be required for years. The availability and calibre of this kind of care contributes immeasurably to the quality of life of the care recipient.

Over the past two decades the availability of publicly funded homecare, for citizens needing enabling-care that allows senior women and men with chronic diseases, and people with disabilities to remain in their homes, has decreased. The trio of economic restructuring, health care reform, and population ageing has increased pressure on the homecare sector and decreased its availability for its traditional users (Armstrong & Armstrong, 1999; Aronson, 2004). Prior to these changes, homecare services were directed primarily to the needs of the frail elderly, and those with disabilities. Following health care reform, homecare became more commonly directed to the needs of acute care patients rather than to the care of long-term, chronic care recipients. More commonly, too, patients receiving acute care are released ‘quicker and sicker’ from hospitals to alleviate bed shortages in institutions that are strapped economically (Armstrong & Armstrong, 1999). These patients with acute care needs became the new clientele for the restructured homecare sector of the health care organization. According to Aronson (2004),

“...the restructuring of homecare in all provinces is driven by a central concern to relieve acute hospitals, rather than by a central concern to address the ongoing needs of elderly people and people with disabilities” (p.169).

Economic restructuring under the impetus of globalization repositioned the care of people in need from a right of citizenship demanding a public response, to a responsibility of the individual. Homecare or ‘community care’ became the responsibility primarily of families, and within the family, the responsibility of women. The impact is felt by both caregivers and the care recipients whose ‘needs’ were redefined ideologically by the state. The ‘hollowing out’ of social policy made care an individual responsibility by abandoning a collective response to care need.

Because women suffer from the majority of chronic disease, research suggests that seniors in need of care, particularly women, are most affected by this policy change, due in part to globalization. Homecare in Canada has no national standard and provincial governments have adopted a mixture of voluntary, public, and commercial service providers to address the need. Women without the private wealth to purchase homecare services on the market may be at serious risk as they strive to navigate declining health and increased need for care within a framework of declining and inaccessible public resources.

In considering the services that might be available for me as an ageing woman blessed (or cursed) with a genetic history of deep, deep old age, I asked of the research process another set of questions: How did my parents experience a difference in care, and why? How might their experiences inform my research? Working with these questions I developed an interest in the differing experiences of homecare available to women and men, as well as the multitude of ways that personal and gendered biography and social structures shape that care. From this perspective I set out to understand Alexis’ experience, beginning with a brief overview of the setting in

which the study was done

### *Setting*

Background documents prepared for a National Conference on Homecare (Canadian Homecare Association, 1998) described the program of homecare offered on Prince Edward Island in the following way: “Services are provided to support and supplement family and community resources with minimum intervention whenever possible” (Canadian Homecare Association, 1998, p. 1). On Prince Edward Island paid care giving is viewed as a last resort due in large part to the meagre allocation of funds to support homecare through the health budget. Among the provinces, Prince Edward Island allocates the lowest health expenditure per capita to homecare, paying less than half of the national average and a little more than one third of that of the neighbouring province, New Brunswick (Anderson & Parent, 1999). The Statistical Report on the Health of Canadians (Health Canada, 1999) estimates that 12% of Canadians provide unpaid care to people with long-term health problems. In Prince Edward Island however, this percentage more than doubles with a quarter of all residents providing unpaid care to people with long-term health problems, the largest proportion of any province. Unpaid caregivers on Prince Edward Island pick up more of the homecare work than in other provinces. In Prince Edward Island seniors are the most likely to receive this unpaid care.

### *Theoretical Framework*

By design this study used a qualitative approach, one that was infused by narrative and feminist theories to reconstruct and interpret a life story in keeping with the definition set out by Cole and Knowles (2001) that illuminates the dilemma of senior women who receive and need homecare. According to Dorothy Smith (1987), a critical feminist perspective necessarily

includes an emphasis on power relations, economic and social inequalities and the creation of knowledge from the experiences of a person living in the everyday world. A political-economy perspective emphasizes how the experiences of old age are rooted in social structural factors such as political policies governing retirement and pension systems (Twigg, 2004). From the perspective of Cole and Knowles (2001), narrative inquiry also begins from the experiences of the everyday world. Clandinin and Connelly (2000) suggest that experience is best expressed in the lived and told stories of the research participant as well as the researcher. Using a feminist critical perspective, I set out to understand the connection between the experiences of receiving homecare and the social and political context to which these experiences are tied. Through this process, I attempt to make clear my own assumptions about women and homecare. From these various perspectives, as well as my own and the research participant's, my aim is to listen to and explore the stories of one senior woman and her ordinary day to day experience of care with a view to examining the links between "personal troubles and public issues, biography and history" (Marshall, 1999, p. 437).

### *The Research Context*

This life history research is based on the story of one senior woman and her experience of homecare as it occurred amid a dominant rhetoric of globalization, cut backs, restructuring, and crisis demographics. Privatization of social services and reduced expectations for citizenship rights in old age are proclaimed to be the only, the reasonable, and the inevitable solution to these dire demographic indicators. But not everyone thinks so (Denton & Spencer, 1997). In pursuit of the objective of economic restructuring to accommodate the demands of globalization, Canada introduced massive social and economic changes; the impact on national policies is being felt in the lives and homes of Canadians. The accompanying neo-liberal ideology of

smaller governments is “hostile to anything that may impede the ‘natural superiority’ of the market” (Estes, 2004, p. 18). The resulting shift toward individualism, that is the hallmark of neo-liberalism, is accompanied by the transfer of work from public provision to private pay, from paid to unpaid contexts. Homecare has been reorganized on ‘market-modelled’ lines and the care needs of seniors and the disabled are being redefined and shifted from public provision of care to that supplied by informal, voluntary, and purchased care from the corporate sector or the underground economy. Homecare, once a small area of social policy, is now a burgeoning sector as cuts to hospitals and long-term care institutions have relocated the site of care into people’s homes (Neysmith, 2000). Under the shift from collective right to individual responsibility, conceded by governments to the demands of globalization, the redefinition of what seniors ‘need’ to support them as they ‘age in place’ has become narrowed, resisting the broader descriptions of how seniors define their care needs. The provinces responded to Canada’s acceptance of the demands of globalization by ‘hollowing out’ social policies particularly those affecting homecare (Aronson & Neysmith, 2001). One senior characterized the new services offered under restructuring as being ‘just fed and watered’ (Aronson, 2004, p. 167).

Social policy governing homecare in a globalized economy exploits the domestic myths. One of the chief myths is that of the family and of the family’s ability to be a primary caregiver to frail seniors. Homecare policy is built on the basis that publicly provided homecare services act only to support the primary care provided by family and friends. The myth of the family and ‘the community’ that is exploited by social policy serves to marginalize senior women in need of care in the home. As a result of these myths, the mostly women who are required to act as caregivers in the home and the mostly women who are the recipients of homecare are exploited and disadvantaged. Lewis (1993) says that myth is frequently used to subordinate groups to the

will of the benefactor. All oppressed groups, she explains, have

borne the consequences of tales fabricated by those who would wish not to take responsibility for their complicity in practices violent against the Other. Indeed the access we have to myth making is directly proportional to the power we derive from our social, political and economic positions. All subordinate groups have less need for myth making since their interests lie more in uncovering the realities that are the consequence of the myth maker's practices. (pp. 135-136)

Social policy under globalization has reneged on a post-war promise of social welfare as a collective responsibility and right of citizenship. Globalization has insisted on the acceptance of a neo-liberal ideology of individual responsibility of care for those in need. Welfare policies under the post-war welfare state are not unproblematic based as they are on the traditional nuclear family with a male wage earner and women engaged in unpaid reproductive labour in the home. However, under the welfare state the recognition of a collective responsibility opened up the opportunity for the writing of fuller rights. The notion of individual responsibility places the responsibility for care on the community, on the family, on women. The stories composing the research data illustrate the contradictions of care shorn of collective rights and responsibilities.

Seniors are key actors in social policies governing homecare because "it is they— not policy makers—who must live them out" (Aronson, 2000). In the day to day life of a senior woman homecare recipient, social class and gender deeply impact how these policies unfold. The intersection of social class and gender is crucial to the unfolding of the day to day at all stages of life. The experience of sex and social class are experiences of oppression by women and by members of non-privileged social classes. Ovrebo and Minkler (1993) describe the intersection of the twin oppressions of class and gender with the oppressions of age. Gender is "a pivotal

variable influencing the trajectory of growing old by predetermining an individual's location in the social order" (p. 289).

Gender represents a distinct status position in Canadian society (McDonald & Wanner, 1990) and is paramount in an analysis of homecare. Gender shapes the experiences of old age and ageing and, perhaps most crucially, the distribution of resources to senior women. Negative effects of economic and social policy are most harshly felt by senior women who do not conform to the traditional model of family with a male breadwinner (Estes, 2004).

Research in the United States projects a decline in the percentage of women who will be married in old age. Consequently economic hardships for these women are not projected to decline. This contrasts with projections of the rate of senior men's poverty that is expected to decline or disappear over the next several decades (Estes, 2004). The persistent gap between men's and women's incomes, access to pension plans, and the cultural and structural dependence on female family members for care of elderly parents threatens even never-married women with reduced incomes in old age.

McDonald and Wanner (1990) explain the crucial distinctions between women and men's economic opportunities throughout the life cycle:

As in all industrial societies, women in Canada are likely to have very different life chances than are men. Although the labour force participation rate among women has been growing, women are less likely to have a job on a full-time basis; if she has a full-time job, a woman is far more likely to be working in a "woman's" job, in which the majority of other workers are also women and the likelihood of promotion is relatively low; her job is more likely to be in the periphery sector of the economy; she is probably paid less than a man in a



comparable job; and her job is less likely to have a private pension entitlement attached to it. Being a woman thus represents a distinct status position in Canadian society, a status position that restricts access to scarce resources as well as to other desirable positions. Gender is more than an attribute of individuals for purposes of understanding labour force behaviour generally or retirement behaviour specifically. It represents a set of distinct structural positions in society, both in the division of labour and the stratification hierarchy, that has important consequences throughout the life cycle. (p. 115)

In old age women are disadvantaged by their exclusion from public programs and private pensions that are based on a male model of labour force participation that disqualifies women's work in reproductive labour. Within social policy men are the primary clients of contributory social insurance programs while women face means-tested social assistance programs (Quadagno & Reid, 1999; Armstrong & Armstrong, 2004).

Precious little research has examined senior care recipients as the site of class inequalities. Graham (1993) cites the need to focus research on homecare recipients because questions are opened up about the distribution of poor health and disability. "It moves social class and age from the margins to the centre of analysis" (p. 464). Using income as a proxy for social class, Canadian research reports that people with low incomes have poorer health status. Low income is independently predictive of receiving homecare (Statistics Canada, 2001). Many senior people who are the prime users of health care have low incomes (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999). There is an inverse relationship between household income and receiving publicly funded homecare. Just over 1% of those in the highest income category were homecare recipients, compared with about 7% at the lowest level

(Statistics Canada, 2001). Reports suggest that this disparity may reflect the reality that people with higher incomes are better able to afford private home-care services (Federal, Provincial and Territorial Advisory Committee, 1999; Wilkins & Park, 1998; Federal, Provincial and Territorial Advisory Committee on Population Health, 1999). The fractional level of usage of homecare services by high income households suggests that publicly provided homecare services may be substandard and inadequate—those able to make choices in homecare due to a better economic position choose higher quality private care; public homecare may be, by definition, only for people without choice.

Lower income gradients are predictive of early mortality (Adler, Boyce, Chesney, Cohen, Folkman, and Kahn, 1994). Quality as well as quantity of life is related to income. The Health Adjusted Life Expectancy (HALE) figures predict the number of years a person can expect to live in perfect health considering morbidity and mortality conditions. There is a positive correlation between increasing income and the number of years in perfect health that an individual can expect to live (Second Report on Common Health Indicators, 2004).

The impact of social class, is further illustrated by utilizing type of employment as a proxy for class. Social class, defined in this way, affects the receipt and experience of homecare. Although Canada does not collect statistics on the basis of manual and professional employment, research in Britain confirms that women and men in ‘unskilled manual households’ are twice as likely to suffer from limiting long-term conditions than those in professional households. The difference between disability and social class is most pronounced in middle age. The explanation suggests that “the cumulative impact of class disadvantage produces an earlier increase in morbidity among those in manual households while class advantage works to protect the health of those in nonmanual households” (Graham, 1993, p. 464-465).

Armstrong and Kits (2001) state that women were more likely to need care but also were more likely to have those needs unmet. "The lower the income and education, the greater the unmet need" (p. 18).

### *Care Coming Home*

Homecare is frequently referred to as 'community care' and is popularly understood to mean the receipt of care in one's own home. The understanding is that, if a senior requires assistance to remain in her own home then the state provides the help to insure that she can 'age in place'. The misinterpretation of the meaning of community/homecare has served to obscure the reality of this 'service' and to hide the fact that most care giving is being done by unpaid caregivers— and most of these caregivers are women (Medjuck, O'Brien and Tozer, 1991). Barry (1995) explains that the power of these terms is anchored in political reality as the now "taken-for granted double equation of 'community = family = women'" (p. 363). Aronson and Neysmith (1997) argue that:

the rhetoric of community is invoked and put to use in deinstitutionalization and community care policies of all kinds. In LTC [long-term care], this empty invocation means that the costs of frailty and care are simply hidden from public view in the private lives and homes of old people and their families and in the isolated work worlds of paid homecare providers. ( p. 42)

The shift from institutional care to community/homecare has not seen a corresponding shift of resources to ensure that care provided in institutions can be delivered in the home. Aronson and Neysmith argue that "the shift actually signifies the privatization of the costs and work associated with frailty in old age" (1997, p. 38). The assumptions embedded in the dominant political discourse accompanying this policy shift to 'community care', where senior women in

particular remain in their homes or the homes of their children to be cared for by unpaid caregivers, is critiqued in the literature. "The unwritten assumption," says McCann (2002, p. 227), "is that informal [unpaid] care is the alternative and is the highest quality by definition."

According to Barry's (1995) critique of ideological and cultural expectations:

Community care is based on a family model of care as the standard against which all forms of care are judged. If family care, at one polar end, symbolises the best form of care, then, by implication, residential [or paid] care is symbolic of noncare or absence of care by family and society. (p. 363)

As Barry points out, social policy decisions have conveniently implied that seniors who are the recipients of this care prefer their own homes as locations in which to receive the care they require, and that their relatives are their preferred caregivers. McCann's (2002) research into the problem of unpaid homecare in Ireland reports that most caregivers did not have a say in whether they wished to provide care for ailing relatives. "The acceptance of the caring role," she reports, "is often related to a complicated set of social expectations and obligations that influence the individual's propensity to care" (p. 228). Decima (2002) research confirms that half of caregivers in Canada felt they had no choice in giving care. Armstrong and Armstrong (1999) argue that because most of the homecare work falls on the shoulders of the female family members and friends, "Women's choices are ...being fundamentally altered by their conscription into work as unpaid care providers in the home..." (Summary section, ¶ 2).

Little is known about the experience of senior care recipients in the context of care provided by either family and friends or paid caregivers. It is likely that care recipients, receiving care from either conscripted and possibly overtaxed, unpaid caregivers, are in an unenviable situation. Barry suggests that caring be divided into 'caring for' and 'caring about'. 'Caring for',

suggests a relationship involving the labour of looking after a care recipient. The latter, 'caring about', suggests a relationship of love. The care recipient, Barry suggests, may wish that labour and love be obtained from different sources. Research in Britain and Scandinavia points to an evolving trend in which seniors increasingly prefer "public non-stigmatizing care provision rather than family care" (Barry, 1995, p. 363). Seniors in the study, either as current or future care recipients, worried that family caregiving negatively affects the relationship with family members who are also their caregivers. Seniors, the study said, "demonstrated cognitive awareness that the achievement of the goal--"caring for"--may jeopardise achievement of the primary goal--'caring about' by placing undue strain on family relations" (Barry, p. 363). Social policy that relies on unpaid care also deprives the care recipient of choice in who will provide them with the care they require. Care requirements can be intimately personal and who assists with the most personal of bodily experiences matters quite a lot. Care recipients receiving care from an unpaid caregiver who has no choice in the provision of that care may experience issues related to quality of care and may experience a drastic decline in their quality of life. Decima Research says that "choice in taking on this role is a significant factor influencing the degree of stress and disruption they [caregivers] experience" (2002, p .7). Statistics Canada reports that 15% of unpaid caregivers "nearly always felt stressed" and that 3% "nearly always felt angry" when performing caregiving tasks (Cranswick, 1997). The danger of elder abuse in a coercive relationship is very real and may be a constant condition in some relationships where homecare is conscripted care.

### *Homecare Research*

Beginning over a decade ago, researchers took note of the dearth of literature on women who receive assistance in their homes with daily living activities. Much research was dedicated

to the women who performed these care giving duties in either a paid or an unpaid capacity, but almost no literature looked at the needs and experience of the recipients of this care (Aronson & Neysmith, 2001; Barry, 1995; Graham, 1993; Russell, 1997). Feminist researchers focused almost exclusively on caregivers which contributed to the invisibility of care recipients. British researcher Hilary Graham (1993) explains:

academic feminist research has attended to relationships in which care is being exchanged, describing these relationships through the perspectives of those who provide rather than those who receive care. 'Caring' is a shorthand way of talking about what carers feel and do rather than what care-receivers feel and do. (p. 463)

Worse than simply ignoring the role of the care recipient in the caring relationship, both Arber and Ginn (1991) and Barry (1995) argue that feminist work on the notion of the burden of care, in support of the work and stress of caregivers, has contributed to a diminished, pathological view of seniors.

Arber and Ginn suggested in 1991 that feminist writers exhibited ageist and exclusionary practices and were slow to examine the Fourth Age that encompasses frailty and dependency—the most common age of care recipients. The exclusion, these writers explain, reflected the ageism embedded in the wider culture: "Feminists just as everyone else, have been socialized into our geronto-phobic culture" (Arber & Ginn, 1991, p. 279). And, with flawed prescience, these writers note that this situation had begun to change. Writing in 2004, however, Twigg argued that feminist research has not examined "deep old age" the demographic location of many care recipients. She explains it like this: "here the old remain essentially Other: their lives described from the outside ...." (p. 71). Others have suggested that feminist researchers feared finding their own future selves in their research and shied away from this all-too-harsh reality (Barry, 1995).

Graham offers a more credible explanation for the shortage of care recipients' voices in the literature. In 1993 she wrote about the absence of research on care recipients noting that feminist research on caring developed in the late 1970s and 1980s alongside government policy that was focusing on families and communities as the site of care. The myth, beginning to take form then, was related to de-institutionalization and what later came to be known as 'community-care.' The impact of this restructuring of care on families and on women in particular drew critique from feminists, one of the few voices pointing out the regressive impact this emerging policy shift would have on women. Graham explains:

through a series of empirical and theoretical studies, this body of [feminist] research argued that informal care was resourced by women in ways which reproduced their disadvantaged position within marriage, within the labour market, and within the social security system. ( p. 462)

The renewed focus on 'traditional' care giving practices, resourced through women's unpaid labour, represents a regressive step tying women even more closely to reproductive labour and the home. The rhetoric of 'tradition' conveniently served the state's aim of shifting the locus of care responsibility from the public sphere to individual obligation. Neysmith (2000) explains "a restructuring discourse that eulogizes the traditional family may be less about the particulars of family form than it is about ensuring that dependency remains defined as a private responsibility" (p. 4).

As accurate as this analysis of unpaid homecaregiving is, researchers neglected to examine in a similarly critical way the impact that the emerging de-institutionalization, globalization, and the shift in social policy toward community care had on the other half of the caring dyad—the recipients of this unpaid care. For these (mostly) women care recipients, I see

their position as similarly disadvantaged because of their location "within marriage, within the labour market, and within the social security system" (Graham, p. 462).

In the intervening decade, since Graham wrote, little has changed on the research front. Researchers continue to note the absence of care recipients' voices in the literature and underscore the limited knowledge available regarding the experiences, needs, and vision of this growing group of senior women (Aronson, 2002; McCann, 2002). Aronson (2000) stated that previous research had amassed a body of knowledge, regarding care recipients, but this knowledge focused on those in institutional care. The changing location of the large part of care from institutions to the home renders this knowledge obsolete and creates a vacuum in the caring literature regarding an understanding of care receiving in the home.

Silencing of the voices of senior women and senior women care recipients is not limited to researchers. Another way that senior women, who are the recipients of homecare, are silenced is in privileging caregivers to speak on behalf of the women receiving care. This is a complex concept involving power relations and rights of citizenship. Barry explains that:

knowledge about care is culturally determined so that who has been sanctioned to speak on this topic, and under what conditions, should alert us to the possibility that family-based models of care contribute directly to the silencing of the care-receiver voice and, accordingly, to issues of power and control in care relations. (p. 362)

Twigg (2004), in her research on the body and bathing, echos Barry's concern and addresses the disempowered role of the care recipient and the need to engage in direct research with care recipients regarding their experiences with caring;

It is through [Foucault] that we come to grasp the ways in which power is pervasive, operating through and in the micro processes of social life. This is relevant to care



because it allows us to see how professionals and lower-level workers, whose activities are often neglected in the literature, exercise power in the fine detail and the day to day routines that control and discipline the bodies of patients. This is the level [the frontline of care] at which we need to refocus our analysis if we are to grasp what it is really like to be old and frail. (p. 66)

Dorothy Smith (1987) wrote about the exclusion of women from ‘man’s culture’ and the invisibility of women within cultural texts that are the primary medium of power. Smith argued, convincingly, that words reflect the ideology of the culture as well as the way we think about ourselves in relation to the culture. I find clear parallels between the textually mediated invisibility of women within the culture and the ideological consequences of this invisibility and that of senior women care recipients and their invisibility within the research literature. When voices are not heard, experiences are not reflected and knowledge is not accurately created. Smith (1987) explains:

Being excluded, as women have been, from the making of ideology, of knowledge, and of culture means that our experience, our interests, our ways of knowing the world have not been represented in the organization of our ruling nor in the systematically developed knowledge that has entered into it. (p.17)

By focusing research on caregivers and silencing the other half of the caring dyad, the image of care recipients has been ‘worked up’—using Dorothy Smith’s term—into one of passivity and powerlessness (Aronson, 2000; Barry, 1995; McCann, 2002; Walker, 1992). McCann's research concludes that care recipients are not passive, that, with opportunity, many people needing care are capable of and willing to express their views and should be consulted at every stage regarding their care. Other researchers argue that caring is a reciprocal relationship with

care recipients contributing greatly to their care ( Lewinter, 2003; Russell, 1997; Walker, 1992, ). Aronson (2000) theorized that senior women are active in managing their care and that the image in the dominant discourse of senior women as passive serves to facilitate the diminishing of their rights within the culture. Barry argues that once care recipients are included in the caring vision a more complex situation arises where the issue of control between caregiver and care receiver materialises as a critical part of care.

When researchers and feminist organizations focus predominantly on the struggle of caregivers, the perception is created that caring is a one way street. For reciprocity in a caring relationship to exist there must be resources available on both sides of the relationship for giving. Resources on both sides of the dyad allow for both partners to have a degree of power over the circumstances of their care. Lewinter (2003) and Walker (1992) note the heightened importance, in unpaid caring relationships, of being able to reciprocate. The consequences of seniors as care recipients being unable to reciprocate in a meaningful way stresses and disempowers the recipient within the care relationship. Walker explains; "unbalanced exchange ratios force elderly individuals to exchange compliance for the resources they receive" (p. 82). Seniors who lack resources are forced into the role of passivity in the care relationship--the role that is the prevalent image of elder care recipients. Lewinter explains further that the inability to reciprocate for unpaid care with anything other than gratitude has a dis-empowering effect on the care recipient. Seniors, she said, are required "to reciprocate with deference" (p. 362) to their children in order not to strain relationships with their caregivers. The reliance on elders' gratitude for unpaid caregiving exacts a heavy toll from the care recipient; "gratitude can easily take on a taste of bondage in situations that cannot be quid pro quo" (Lewinter, 2003, p. 359).

Lewis (1993), in her work on women and silence, wrote about the inequalities

experienced by disempowered groups and their refuge in silence. "For the majority of the population--women, racial and ethnic minorities, the working classes, the young and the old ...these inequalities become profound daily experiences, marked fundamentally by disempowerment, the struggle to survive and silencing" (p. 11).

In Canada, in the three decades spanning the post-war years to the mid 1970s a broad array of social programs was introduced that redistributed income, power and resources. Women benefited from these programs but they were not without problems. These programs marked the recognition by the state of the notion of "shared risk and collective rights that meant the state bore overall responsibility for the welfare of citizens and for limiting the negative impact of markets" (Armstrong & Armstrong, 2004, p. 15). Currently, these same responsibilities of caring, in part under the force of Canada's response to global economic restructuring, are being returned to the private, voluntary and unpaid spheres (Aronson & Neysmith, 2001), to the responsibility of the individual.

Social policy affecting homecare disproportionately impacts women and shifts in policy are occurring despite changes in the social organization of women's work over the past thirty years. The reassigning of social responsibility from public resourcing to individual responsibility is driven by both neo-conservative and neo-liberal ideologies (Estes, 2004 ). This return to individual responsibility and toward an increase in the level of unpaid reproductive care demanded of women reduces social spending through the privatization of the costs of reproduction. Aronson and Neysmith (1997) explain that "the shift actually signifies the privatization of costs and work associated with frailty in old age" (p. 38). "Costs," Neysmith (2000) says, "that were ejected from the public world frequently landed in the private world of households where women picked them up with little control over the terms and conditions under

which the resulting additional work would be done” (p. 3) . McDaniel says that women, under policy changes practised in globalization, are serving as the “ambulance attendants for the neo-liberal agenda” (2004, p. 37). She describes women as "picking up the bits and pieces of caring and generational continuity as they tumble out of the transformations occurring in globalizing western democracies" (p. 37).

Cuts to the hospital and institutional sectors have shifted the site of care to people's homes with little reasoned discussion above an uncritical dominant discourse framed in crisis demographics and the demands of a globalizing economy. Aronson (2004) explains:

These rapid changes in homecare are presented in dominant political discourse as the unavoidable consequences of scarce resources and the self-evident imperatives of containing the costs of hospital care. The changes and their justifications are challenged by a wide range of [groups].... These groups voice a number of key concerns. First, they call attention to the particular jeopardies resulting from homecare's physical location—out of public view, in the privacy of people's own homes. "Behind closed doors" (Care Watch Phonenumber 1999), homecare's insufficiencies for care recipients and its strains for care providers are obscured and easier to ignore than, for instance, inadequate or exploitative practices in hospitals, doctors' offices or nursing homes. (p. 168-169)

The repositioning of the site of care into the private arena of a home serves to mask, from the public consciousness, the conditions of oppression experienced by caregivers and care recipients. Barry says that little is known about the receipt of care in the home because of the veil of privacy that bars examination of what is happening in this private space. "Knowledge of care in the domestic setting is limited because these relations lie at the heart of the 'contemporary domestic ideal' and are strongly associated with privacy and intimacy" (p. 366). Estes (2004) expands on

Barry's point by saying that the state's position in social policy has hidden behind this notion of the domestic setting and has been both silent and blind when it comes to addressing issues of inequality arising in the domestic sphere. "The blindness toward (and devaluation of, in public policy) reproductive work historically has justified the treatment of women's and men's family relations (the division of caregiving and household work) as private and beyond scope of state intervention" (Estes, 2004, p.12).

With the relocation of caregiving to the isolation of the home it is easy to feel that the problems created by recent policy shifts are personal. Estes (2004) and Minkler and Cole (1999) say that senior women's individual situations and problems have to be viewed in social structural rather than in individual terms. By privatizing the problems of caring in the lives and homes of the frail elderly, the lives of senior women are further marginalised and making connections to others with like problems is hindered. Lewis (1993) explained that "new subordinations are lived in the context of our experiences which to the extent that they can be made to seem to be private, cannot then offer the ground for collective political practice" (p. 10). The issues associated with care for senior women in the home are practices that are politically and culturally created. The genesis of these issues emerges from the realm of public policy and cultural expectations and acceptances. For Lewis (1993) giving voice to the experiences of individual women whose lives and struggles are given form by the culture allows for the themes of collective experience to emerge as political forces. "...the fusing of the private with the public...help[s] to uncover the politics of personal experience and to give these personal experiences social meaning" (p. 15).

### Research Methodology

#### *Qualitative Research*

In this research, I have undertaken qualitative research and used a feminist perspective to

pursue a critical inquiry and to reconstruct a life history through narrative. Because of the complexity of stories involving the multiple systems of oppression related to sex, class and age it is necessary to use a multi-dimensional theoretical approach to address the layers of oppressions under which this research participant struggles.

Historically, research has been understood as the quantification of data to obtain an objective truth. According to Berg (2001) and Pitney (2004) research cannot meaningfully express certain human experiences by quantifying them. Researchers such as Berg have moved from the position that the quantification of the universe was the sole source of objective knowledge to an understanding that experience and its subjective understanding also creates knowledge. Traditional research methodologies, according to Lewis (1993), refuse to acknowledge “that knowledge is a function of personal experience” ( p. 5). The denial and trivialization of experience as capable of knowledge generation deprives those outside of ideological generating ruling institutions (universities for example) from having their interests and knowledge represented in the organizations of ruling (Smith, 1987). I, too, believe it is the responsibility of researchers to investigate the lived experience of marginalized groups and to reflect these experiences in cultural organization and research.

For a depth of understanding, one that closely reflects lived reality as well as clearly recognizes the biases of the investigator, qualitative research methods are appropriate (Pyette, 2003; Pitney, 2004). Berg explains that qualitative research,

provide[s] a means of accessing unquantifiable facts about the actual people researchers observe and talk to or people represented by their personal traces....As a result, qualitative techniques allow researchers to share in the understandings and perceptions of others and to explore how people structure and give meaning

to their daily lives. Researchers using qualitative techniques examine how people learn about and make sense of themselves and others (p. 7).

From Shank's (2002) perspective, qualitative research allows for multiple interpretations of reality and the recognition that what we often assume as 'natural' are socially constructed dictates and doctrines. Qualitative research is often exploratory research and can be effectively used when little is known about an area of research (Marshall & Rossman, 1999; Pitney, 2004; Shank, 2002). Little research has been undertaken to explore senior women's position as recipients of homecare (Barry, 1995; Graham, 1993; Russell, 1997). This suggests to me that research begin with an exploration of the women's own experiences and in women's own words. "The qualitative approach to research," explains Marshall and Rossman (1999), "is uniquely suited to uncovering the unexpected and exploring new avenues" (p. 38). More specifically, however, my aim is to conduct qualitative research, infused by narrative and feminist theories, to (re)construct and interpret a life history, in keeping with the definition set out by Cole and Knowles (2001). From their perspective,

...the term 'life history' acknowledges not only that personal, social, temporal, and contextual influences facilitate understanding of lives and phenomena being explored, but also that, from conceptualization through to representation and eventual communication of new understandings to others, any research project is an expression of elements of a researcher's life history. (p.10)

In writing this, Cole and Knowles "...challenge any claims of researcher 'objectivity' in the study of human lives" (p.10). In other words, from their perspective, "as in other forms of qualitative research, the life history researcher serves as the central 'instrument,' the prime viewing lens" (p.10).

*Narrative Inquiry and Life History Research*

From the perspective of Cole and Knowles (2001) “life history inquiry is about gaining insights into the broader human condition by coming to know and understand the experiences of other humans....It is about understanding the relationship, the complex interaction, between life and context, self and place” (p. 11). From their perspective, life history inquiry and “...narrative method in research is based on the assumption that human experience is episodically ordered and best understood through a reconstruction of the natural narrative order in which it is lived” (p.19). According to Cole and Knowles, life history research is designed to invoke relationality, mutuality, empathy, care, sensitivity, and respect for all involved in the process.

Within education, Clandinin and Connelly (2000) are well known for their extensive work on the use of narrative method. As a researcher interested in story, I use a narrative life history approach to (re)construct Alexis’ life history and involvement with homecare. According to Clandinin and Connelly (2000), rather than being generalizeable, narrative inquiry offers “readers a place to imagine their own uses and applications” (p. 42). From their perspective, people embodied in their stories, are creating lives that shape and are shaped by social and cultural norms. Researchers are part of the world and also live within their own stories, they suggest. Researchers enter the inquiry field with their own stories and work with both participants and with ourselves. As Clandinin and Connelly explain “our principal interest is the growth and transformation in the life story that we as researchers and our participant’s author” (p.71). The story, they suggest, is the unit of analysis. It is making sense of lived experience and “trying to find out the taken for grantedness” (p.78) in our stories. Narrative inquiry, from this perspective, is aimed at understanding and making meaning of our experience. “Being in this world,” Clandinin and Connelly say, “...we need to remake ourselves as well as



offer up research understandings that could lead to a better world” (p.61).

Teachers of research methods frequently repeat the statement that the research question determines the research method (Brookes, A.L., personal communication, January 29, 2004). The aim of this study is to investigate the experiences of a senior woman who receives homecare and to explore ways that these individual experiences are shaped by cultural forces and public policies. Key to this question and the methodology appropriate to its investigation is the research participant—a senior woman—a population of which little is known (Aronson, 2002; Barry, 1995; Graham, 1993; Pitney 2004; Russell, 1997). In keeping with these authors, I suggest that qualitative research methods are a fruitful way to investigate this area of study.

In keeping with the qualitative approach used by Cole and Knowles in this thesis, I am interested in the relationship

- ▶ of researcher to the topic or focus of study;
- ▶ of research to research participants;
- ▶ of research to the research representation;
- ▶ of research topic or focus to pertinent literature; and
- ▶ of participant’s lives in the contexts in within which they are situated. (p.9-10)

Being aware of these relationship connections are, I suggest, key to any kind of qualitative research that involves narrative and life history approaches. These relationships, I suggest, also inform how I think about critical inquiry and feminist theoretical perspectives.

### *Critical Inquiry*

Critical inquiry examines relationships between events in a person’s life and the social, cultural and historical structures to which they are connected. Carspecken (1996) explains

researchers use of critical methodologies in this way:

Those of us who openly call ourselves ‘criticalists’ definitely share a value orientation. We are all concerned about social inequalities, and we direct our work toward positive social change....We use our research...to refine social theory rather than merely to describe social life. (p. 3)

Critical inquiry aims to do more than describe social life, it seeks to transform it. It aims to transform social, economic and political structures that “constrain and exploit people, particularly those marginalized as a result of their race, class or gender” (Stevenson, 2004, p. 45). Critical inquiry is motivated by the immorality of social structures that exploit and marginalize vulnerable people and seeks to compel human emancipation and social justice. Critical inquiry is built on the idea that democratic ideals are not reflected in our social institutions; critical inquiry methodology sees social justice and greater respect for human potential as the goal of the research. “Critical or emancipatory methodologies are explicitly concerned with questioning underlying human interests and ideologies, illuminating the historical and political antecedents of contemporary practices and empowering individuals to identify alternative possibilities that provide greater social justice and enhance human potential” (Stevenson, 2004, p. 261).

Cusack (1999) outlines the components of critical inquiry. These include “challenging assumptions, recognizing the importance of context; imagining and exploring alternative beliefs; and maintaining an attitude of reflective scepticism” (p. 32). Critical inquiry, he explains, is an on-going process of questioning the assumptions that underlie the taken-for-granted ways of acting and thinking. As well, this reflective practice requires that we then must be “ready to think and act differently” (p. 32). Unlike participatory action research this investigation, using the tools of critical inquiry, does not seek to mobilize participants or to work in collaboration for change.

However this critical inquiry does involve the emancipatory potential of consciousness raising among participants receiving homecare.

In this investigation I aim to understand the connection between the experience of receiving homecare for a senior Prince Edward Island woman and her personal history, the connection between her private troubles and public issues. To understand these questions I examine a range of literature focusing on homecare, women, and the relationship of women to that care. I examine themes arising from the review of the caring literature especially that related to the image of senior women and their care needs, the social location of care recipients and their reaction to care receiving, the personal/private domestic/public sphere, the role of biography, and the experience of care recipients. To investigate this area I examine from a critical feminist perspective the social and political underpinnings of homecare; using narrative inquiry and a life history methodology I examine a detailed account of a senior woman's stories about how she understands and experiences homecare on Prince Edward Island.

### *Feminist Perspectives*

According to Wilkins and Park (1998), Armstrong and Armstrong (1999), and Aronson (2004), homecare is a field that is dominated by women, not only as professionals such as case managers, nurses and physiotherapists, as non-professional paid and unpaid homecaregivers but also, as the focus of homecare, as the care recipient. I use a feminist perspective to examine the issue of homecare in the literature and on Prince Edward Island not because of the preponderance of women in this arena of study but because I understand both age (Hazan, 1994) and gender as socially constructed phenomena, a dynamic force that directly affects the life chances of women and men (Calastani, 2004). Ageing as an active force develops throughout the life cycle. In my opinion, and in keeping with Twigg (2004), a feminist perspective also includes

an emphasis on power relations, economic and social inequalities and the creation of knowledge from the experiences of the everyday world.

Lewis (1993) describes feminism as “a politics of active social transformation achieved through the shared conceptualizations and meanings of our exploitation as women” (p. 4). The investigation of experience in feminist politics, Lewis explains, is seen as the ground for social transformation. “It is here in our experiences not some abstraction of it that we find our subordination and our strength” (p. 5). The challenge is not just to describe the situation and experiences of senior women with homecare but to understand how homecare troubles are interpreted as private problems and to consider how these ‘private’ troubles are connected to public issues.

To understand and reconstruct the context experienced by a woman receiving homecare, I conducted in-depth interviews (see Appendix A) to understand significant moments in Alexis’ life. I began the interviews by asking her to tell me about her life from birth to the present.

Questions included:

1) Biography

- Please tell me about your life. What would you describe as the most significant moments in your life?
- When you were younger what work did you most enjoy and was it paid or unpaid?
- If you could live your life over, what would you change? What would stay the same?

2) Homecare Experience

- What do you do over the course of a day?
- What care are you receiving and from whom?
- What is good about your homecare experience and what would improve it?

- How does your experience with homecare differ from your expectations of life as a senior?

### *Essential Points of Design*

- This is a qualitative study exploring one woman's experience of homecare.
- The population of interest is women over age 60 who receive homecare.
- Possible participants received an information letter (see Appendix B) inviting their participation in the research. An informed consent form (see Appendix C) was signed by the participant prior to the first interview taking place. A non-dementing, senior Prince Edward Island woman who is a homecare recipient was selected on the basis of being the first respondent to the invitation to participate.
- Recruitment utilized the office of the parish nurse (see Appendix D) and personal contacts. Six in-depth interviews were held with the study participant of approximately two hours each. These interviews were audiotaped and transcribed.
- The participant reviewed the transcription of her interview with a view to clarification or addition to the text. Because of difficulties with vision the tape transcripts were read aloud and points were expanded, confirmed or clarified. Questions arising from earlier interviews informed the development of the interview guide for later interviews. Emerging themes and topics were explored and revisited throughout the data collection period.
- Two types of written records were created, transcripts of interviews and field notes. The latter, recording the investigator's observations and impressions, were created following each interview or telephone contact. Thoughts between interviews were also recorded as were possible questions arising from the transcripts.

- Connections between participants' biography and experiences and a feminist and critical inquiry perspective were developed drawing on my observations as a feminist and as a caregiver located within a specific political, social and economic portrait.

### *Validity and Criteria for Evaluation*

Three key qualifiers of quality quantitative research are the concepts of generalizeability, reliability and validity. These are inapplicable to qualitative research but the concepts are sometimes stretched to make qualitative research conform to these traditional terms. Familiarity with qualitative research is not as widespread in the research arena as is quantitative research so this explanation is offered to those unfamiliar with the genre. I will address these concepts from a qualitative perspective.

#### *Generalizability*

Generalizeability is not a precondition for qualitative research. Some qualitative researchers use the term 'transferability' to explain that the findings are relevant to similar contexts. The stories emerging from this research are generalizeable to the participant and to readers who discover in these stories elements that reflect their own lives, experiences and understandings (Berg 2001; Ellis & Bochner 2000; Marshall & Rossman 1999; Pitney 2004; Pyette 2003; Shank 2002). Rich descriptive information about a context is provided to readers 'so they can determine for themselves whether the results speak to their situation or experience' (Pitney, p. 27).

Shank explains that "generalizability is most often a push toward breadth, and qualitative research is much more concerned with depth" (p. 94). Qualitative researchers are interested in both the typical as well as "samples that are more fertile than typical ones" (Shank, 2002, p.94). Typical samples simplify our understanding. Qualitative research believes our understandings

are currently too simple; in simplification, key aspects for understanding situations or stories are lost. *Validity*

The qualitative research equivalent term is ‘credibility.’ Pitney explains: “producing findings that are regarded as applicable and meaningful by readers and practitioners is considered perhaps the most useful indicator of the credibility of any qualitative study” (p. 28). According to Shank validity in all research deals with the notion of truth. In qualitative research it addresses the truth of the observational, spoken or written record. For this research project the concept of truth deals with the grounding of truth in the context and personal experience of the participant. To assure validity of the data and the analysis Pyette (2003) argues that the most important research instrument in qualitative research is the researcher. The acceptance of research methods and findings “entail[s] a degree of trust in the diligence and integrity of the researcher” (As quoted in Pyette, p.1171). But, reports of qualitative research data should be able to be critiqued by the reader. Sufficient detail, context, and reflexivity has to be provided for the reader to assess our interpretation and our trustworthiness to assess whether the findings are valid (Pyette, 2003).

Validity of the data are assured in the stories by member check. The research participant was involved in a series of six face-to-face interviews. The validity of the research participant’s story was confirmed by a personal review of the interview data; she was read, at her request, a transcript of all interviews. This opportunity allowed the participant to explain or expand on the transcript data.

### *Reliability*

In quantitative research this term relates to the reproducibility of the study findings. In qualitative research, the concept of reliability is replaced by the term ‘dependability’. Qualitative research delves into the meaning that people place on their experiences, a meaning that may

change over time as new experiences and cultural understandings evolve—“human behaviour is rarely, if ever, static in nature” (Pitney, 2004, p. 27). Dependability assumes the research findings reasonably can be based on the data informing the study.

Pitney (2004) states that the dependability of a study can be verified using member checks that allow the participants to clarify for the researcher that either the transcript information or the analysis are accurate based on the data. Further dependability safeguards are the documentation of the data-collection and analysis decisions taken while the study is in progress. Multiple interviews also allowed for the researcher to establish the dependability of the stories as the research participant's stories were re-investigated for greater details in repeated telling.

The use of triangulation, which takes many forms, involves collecting data from: multiple and varying sources and using multiple analysts or even multiple data-collection strategies (i.e., both interviews and observations). The fundamental idea of using triangulation is to cross check information or findings to ensure that a full and accurate understanding of a phenomenon is obtained. (Pitney, p. 26)

Triangulation was used by the collection of data through both personal interviews and by documentation of observations in the form of field notes written as soon as possible following the completion of each interview. Triangulation established both credibility and reliability by the co-analysis or inter-rater reliability provided by the thesis supervisor who had access to both the primary data and the analysis arising from the data.

### *Methods*

This research studied the experiences of a woman over age 60 who is the recipient of homecare on Prince Edward Island.



*Participant*

This research studied the everyday lived experiences of a senior woman who is the recipient of homecare on Prince Edward Island.

The participant is an English speaking resident of Prince Edward Island. She is a women over 60 years of age who requires assistance with both the activities of daily living and the instrumental activities of daily living. Activities of daily living and instrumental activities of daily living are described as basic self-care tasks such as eating, bathing toileting, walking, or dressing, or activities such as making telephone calls, shopping, transportation, taking medications appropriately and keeping appointments (Cavanaugh & Blanchard-Fields, 2002).

The research participant was not diagnosed with a dementing condition by a physician, and had sufficient physical strength to participate in a series of six interviews of approximately 2-hours each and a sufficiently strong voice to be audio tape recorded utilizing a lapel-type microphone.

*Recruitment*

The research participant was recruited through third person personal contacts. Her participation was voluntary and no coercive methods were used in her recruitment. The researcher is not an authority figure but is aware of concerns of power that age, education, or social class may bestow. It was important that recruitment was not undertaken by either supervisors, caregivers or others in positions of authority who may have been perceived by the research participant to have power over her participation. Participation was perceived to be completely voluntary.

*Study methods.*

In addition to a review of the literature, the research was carried out through a series of

face to face interviews with a senior woman who receives care in her home.

Personal, in-depth, face-to-face interviews with a senior, female, care-recipient were conducted to discuss her experiences as a recipient of homecare. An open ended interview format was used to conduct six indepth interviews with the research participant over a four month time span, January to April, 2005. Interviews took place in a private area in her home where conversational privacy was assured and at a mutually agreeable time. The personal interviews used a semi-structured interview guide and an open ended discussion format. Interviews were audio taped, the tapes transcribed, and the transcriptions read back, at her request, to the participant for clarification or additions. This allowed for confirmation of earlier details, clarification of understandings, and fuller discussion of previous stories.

The interview guide for subsequent interviews was created from an analysis of issues that arose in previous interviews or by reflection on the text and a return to the literature by the investigator. The participant was offered a \$50 honorarium. This was paid following the second in the series of interviews.

In addition to the tapes and transcripts that form the main data of this study, the investigator also maintained field notes that recorded observations and impressions arising from and between the interviews. These latter were created both during and as soon after the interview was completed as possible and before proceeding to the next interview. Field note journals were also utilized to record possible areas of questioning or non-interview investigation.

### *Informed Consent*

Free and informed consent was voluntarily given, without manipulation, undue influence or coercion and could have been withdrawn at any time. According to the Tri-Council Policy Statement (2003) "undue influence may take the form of inducement, deprivation or the

exercise of control, or authority over prospective subjects” (Section 2). Participation in the interviews was voluntary with no element of coercion from the interviewer or any person seen to be in a position of power in relation to the care recipient. No risk to participants, deception or partial disclosure of the true purpose of the research was involved in this study. The research participant was asked to freely read, understand and sign an informed consent form. In this research process the informed consent form was read to the study participant. The study participant is over the age of 60 and has not been diagnosed with any form of dementia.

#### *Anonymity and Confidentiality*

The Tri-Council Policy Statement (2003) says that: “Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity” (p. i.5). Every effort was made to maintain anonymity and confidentiality throughout. The study participant was assured of researcher confidentiality in all interviews. According to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans “the values underlying the respect and protection of privacy and confidentiality are not absolute, however. Compelling and specifically identified public interests, for example, the protection of health, life and safety, may justify infringement of privacy and confidentiality” ( Section 3.1). The disclosure of actions or practices that threaten health, life and safety of participants may result in breaking of assurances of confidentiality and anonymity. However the study participant will be protected from harm caused by the unauthorized use of personal information in this circumstance. No disclosure took place.

The study participant’s real name is not used either in the written thesis or attached to tapes or transcripts. All transcripts and tapes are kept in a locked filing cabinet in my home study

during the period of the thesis preparation and for two years following the acceptance of the thesis. At that time all tapes will be destroyed.

Computer files are secured to the researcher as part of a password protected entry. Backup copies of data are kept in a locked filing cabinet in my home study. The study participant was read a copy of her transcribed interviews and was asked to verify the contents. The study participant was unable to personally review the transcripts due to a visual impairment and requested that the researcher read the transcript to her in person. The study participant was informed that a copy of the final thesis will be available for review at the Education Resource Centres in the Department of Education at the University of Prince Edward Island.

The researcher believes the risks to the study participant are minimal. Assurances of confidentiality and anonymity and considerations of sufficient mental and physical health and non-coercive participation were addressed. Benefits to the study participant involve the opportunity to tell her story to an interested listener, appreciate that her story possesses personal, historic, and investigative value, the investigator's interpretation may lead to insights that aid the participant or the community, and the participant can enjoy the social aspect of home visits and the development of the relationship that implies.

## Part II Data Collection: Stories Told

### *Relationship of Researcher to Researched*

The data for these stories were collected during ten hours of interviews translated into 120 pages of single spaced interview transcripts collected over four months spanning January to April, 2005. The data support a life history of a woman over 60 who was a recipient of homecare and who lived on Prince Edward Island at the time of the study. While conversations between myself and the research participant are largely the source of information for this study I do not

present her words as though she were speaking for herself. This process has not been one of collaboration between the research participant and myself. I chose to make my own sense of these stories from the information that the study participant shared with me. I have shared with her the understanding I have of how her stories fit into and conflict with social forces but it is an understanding that I composed. She concurs with and heartily endorses my analysis.

What I know from this research process is that more of the story, larger, more detailed pieces of the jigsaw that is our lives, were revealed at each telling and supported my decision that a life history was the appropriate approach for this subject matter. I shared with her pieces of my story where it appeared validation for her position or experience, or the need to establish safe, common ground before entering dangerous territory was required. I am aware that she enjoyed the research process after some initial hesitation in revisiting old and, she thought, buried memories in her life.

*A: I thought it would kind of bring up old bad memories. It did for a while. And then I thought, well I'm one of the lucky ones, I got out. And like I say a lot of women get badly broken up and killed and so, I got off easy. [The research process] wasn't that bad. ...I thought I'd feel worse than I did. But I've kind of overlooked everything and forgiven everything, with the kids. ...We all get along good now....*

The guidance of qualitative research using feminist principles of sharing histories made the process of talking about a difficult life easier. Though Alexis attributes this to me as the researcher I feel her ease lies with practices associated with the theory of feminist research.

*Lorraine: Could you talk about telling your stories to a stranger, to me?*

*Alexis: Well, you're so nice. You're easy to talk to. I didn't mind, Probably somebody else. I would have minded. I didn't mind telling it to you.*

Alexis, I assume, enjoyed the social aspect of the interview process and the opportunity to share and have valued her story of pain, struggle, and being a woman in a world that devalues women. This story is not exhaustive; ideas, thoughts, and experiences that were not relevant to the topic of investigation or that she chose not to tell me also inform and limit her responses to my inquiry. What she said is what she chose for me to know. This is the basis of this story as constructed by this life history participant and as analysed by me using a feminist and a critical inquiry framework.

While the stories I relate here are those of the study participant, a senior woman who generously shared her story, I would like to use what I learned to reflect on her condition by examining the story of her younger life and how its story is marred by male privilege then and now. Male privilege within the traditional family and the role male privilege and the traditional family play, in myth and structure, dominate social policy. I wish to make explicit how the myth of the family has served the dominant discourse in burying senior women alive in their homes under a shroud of unworthiness, passivity and powerlessness. This myth, this dominant image and the language of its purveyors, is fed by a quarter century of crisis demographics that portrays an ageing population in negative terms and link it up to a crisis of unaffordable health care and social programs (Denton, 1997). For senior women needing care in their homes this dominant myth, this image of seniors being unaffordable, justifies “shifts from relatively expensive institutional care provision to relatively cheap in-home provision, [emphasizing] market models of service organization and delivery, and, cumulatively, the diminishment of elderly citizen’s entitlements to health and social security” (Aronson, 2000, p. 55).

The passive and powerless image of senior women receiving homecare created by the dominant discourse has been supported by the research community. Senior women who receive

care in their homes are all but invisible and their voices largely silent in the research literature; few voices were heard and few contested images were forwarded. This is an attempt toward correcting that vacuum.

The experience of marginalization on the basis of old age is well documented in the literature among women living independent lives in the community (Marshall, 1987). The experience of women who once were warehoused in publicly accessible seniors' institutions at least had their experiences of marginalization exposed for social critique (Baum, 1977). Women in need of care, under the forces and myths of globalizing economies, are less studied since being relocated from the institution to the private space of the home. The research need is not to count the number of women receiving care, the number of hours of care provided or even to number the women who report problems with the "quality" of their care. These are all thin definitions of what it means to be old, to be a woman, and to need care in her home. The research need is to understand the experience of women in their daily lives and to document, case by case, the reductive image and diminished value senior women live day by day. It is also to document the ways women resist being marginalised and act to manage their own care and health needs. It is to create a growing body of situated knowledge defined and elucidated by senior women. It is to enable the linking of women's experiences and understandings to the social forces that create and demand both the reality and the mythology of senior women as passive and undeserving of the rights inherent in a just citizenship. Lewis (1993) explained the importance of reading and understanding the situated knowledge available to women through the experience of the prosaic life.

The importance of the feminist focus on experience is...to emphasize the political meaning of our personal reality: that subordinate groups live subordination and

marginality through our subjectivity. We live it precisely in the context of the details of our individual experiences which to the extent that they can be made to seem private cannot then offer the ground for a collective political practice....the politics of feminism confirms for me that understanding can begin only from where we are. (p. 101)

My interest in this topic arises from my desire to link the personal with the political and to contribute this research toward building a knowledge that can then 'offer the ground for a collective political practice.'

Within the context of Prince Edward Island, public homecare is provided through the provincial Department of Health and Social Services. The impact of the off-loading of responsibility for the overall welfare of its citizens and the shift away from the notion of collective rights and responsibilities and toward market infused strategies is clearly visible on the government's homecare website. Homecare services are provided as either medical care largely related to early discharge from acute care facilities or as *supplemental* care for those who need assistance living in their own homes. The supplemental care supports the care of the primary caregiver assumed or required to be drawn from family and friends. Here, the provincial Homecare Program describes its homecare and support services as "provided to individuals based on assessed need and are intended to...supplement the care and support available from family and friends"(Homecare and Support, 2005). A second type of formal (paid) homecare on Prince Edward Island is privately purchased corporate care and the contact information and the web links to private care giving organizations (two of the three are for-profit corporations) are posted on the provincial government website under "Services For Seniors".

Another source of privately purchased services are those available within the



underground economy. In the underground economy of homecare, caregivers are mostly women working irregular hours, at low wages, enduring exploitation, and receiving no benefits or pensions. These caregivers are frequently untrained and unbonded. The ability to have needs sufficiently met through the private purchase of services implies a level of disposable income to which many senior women do not have access.

The experience of homecare is not dissociable or confined to acts associated with receiving a specific service in the home. Being ‘incapacitated in whole or in part’ is a position connected to a whole array of other implications outside of the satisfaction of a single care need by social services. Senior women in need of care in their homes experience care needs that are broader and deeper than those identified by social policy. The satisfaction of those broadly defined care needs requires continual negotiation, redefinition, and creativity on the part of the care recipient. In short, being a senior woman in need of care is a lot of work. This work requires the expenditure of considerable energy to ensure these needs are satisfied, anger at the frustration of having a care need go unsatisfied, or, it requires the reduction of the care recipient’s self definition to fit into the reductive vision of senior women in need of care established by current social policy.

When the federal and provincial governments began shifting the collective right into individual responsibility for homecare, they utilized the myth of the community and the myth of the traditional ‘model’ family structure. The policy governing the Prince Edward Island Homecare Program—“Homecare and support services are provided to...supplement the care and support available from family and friends”(Homecare and Support, 2005). -- is based on a number of myths about this care that are exploded by the experience detailed in this life history. With the telling of two stories of family care giving comes an illustration of several dimensions

of the fallacy of the myth of which social policy takes advantage. My story is of a family that closely proximates that of the popular myth of a loving, giving and cohesive family unit with deep roots in the community. The second story, that of Alexis', is of a family whose bonds are shattered by the oppressions of culturally engrained sexism and likewise shatters the myth of family and 'the community'. Both stories expose the same soft underbelly of social policy that exploits the myth of the traditional family and 'the community'. Both stories tell of homecare policy whose bridgework is constructed of luck and coincidence, or not—neither are sufficient responses to the needs of seniors requiring care in their homes.

One myth is the image of a functional family with a loving, willing, available and supportive spouse and children, a universal image of which the existence of battered women's shelters exposes only one of the fallacies. The contrasting images of my father's care needs and their satisfaction with those of my mother's exposes another fallacy about the availability and reliability of family care giving. The policy mythologizes an image of a care recipient located in a pie-in-the-sky functional family composed of parents and children in close proximity. It is socially constructed and manipulated image that turns a blind eye to the reality that most senior women are widowed, single, or divorced. It is also an image of a traditional family with children that speaks of supportive heterosexual relationships and ignores women in non-traditional relationships and single women without children. The contrasting images of my father's care needs and their satisfaction and the care needs of this life history participant wherein both families are originally composed along the lines of tradition evidences dramatically different results. The vision of sufficient publicly provisioned homecare allows for seniors in need to thrive in security, not to suffer their needs without satisfaction in a system that depends on coincidence, luck, and the hit and miss care of a traditional family—even one with the best of

intentions. Neysmith (2000) explains the convenient role the mythical family image plays in the shifts taking place under globalization: “a restructuring discourse that eulogizes the traditional family may be less about the particulars of family form than it is about ensuring that dependency remains defined as a private responsibility” (p. 4).

So too, a social policy that names family and friends as primary care providers paints an image of a situated-ness in a community of people that is born of rootedness and long-term reciprocal relationships. It portrays a person in need of care as having a deeply embedded support network that can be called on for long-term assistance, a portrait that, as evidenced by this life history, is fallacious. Women without those embedded networks and family resources must constantly strive to negotiate care with a succession of ever changing social contacts, and/or go without.

If social policy was built on authentic valuing of the family relationship, it would recognize and address the stress this social policy of private responsibility places on care recipients and family caregivers. Research argues that caring by family and friends does not decrease with the presence of services from public policy. Current social policy threatens to damage the relationships of family that it relies on so heavily for primary homecare giving. The caregiver ‘Zarit Burden Inventory’ included in the PEI Seniors Assessment Screening Tool (PEI Health and Social Services, 2003) used by the Department of Health and Social Services recognizes the damage this policy can have on relationships. In this life history, it is a policy that threatens to sever or undo the meticulous labour of pain and patience that is the ongoing work involved in healing a family rift, work undertaken by the care recipient with at least one of her children. This rift was facilitated, even anticipated, by inadequate social policy 30 years ago that is constructed within an economy and a society that supports multiple systems of oppression

specifically gender and class. Alexis was born into a situation of domestic violence and a society that supported an affirmative action program of male privilege including a gendered control of material resources; she saw these same social acceptances reproduced in her marriage. It appears that she is now being disciplined by social policy for her escape from the violence of her husband within a traditional family. Because she acted to defend herself, the structures binding women in place now deny her adequate care and demand that she obtain care from this fractured family.

For Alexis 'the family' serves as the site where the contradictions and the myths governing women's and senior women's lives meet in a Catch 22 conundrum. Women in a society that is governed by the privileges of sex and class are bound to participate in their own oppression by the multiple ties that secure them in place and the absence of a sustained cultural critique of these privileges. I note the role of the family in maintaining social control in creating and maintaining social and economic inequalities and unjust power relations between men and women. The myth of the family has failed this life history participant previously at three momentous times, in childhood, in her marriage, and in her enforced distance from her children. Now as a frail senior she is expected to look to the family to satisfy her care giving needs. If she has learned one thing over her lifetime it is that families can be dangerous to her well-being, health, and safety. She does not allow the social myth to influence her decisions as she struggles to control her care and have her care needs met. She knows better.

### *Meeting Alexis*

The senior woman that is the focus of this life history was asked to choose a pseudonym for herself and to explain why she chose that name. The name she selected, following some thought, is 'Alexis' and honours a television soap opera character who is witty, attractive, and *doesn't take any shit from anybody*. Her choice is an image that is independent, powerful, edgy,

outspoken, and attractive and she recognises herself in this television representation. The popular portrayal of a senior woman homecare recipient is undemanding, passive, and accepting. These competing portraits are difficult to reconcile but are not static and Alexis moves into and out of these contested visions of TV-Alexis and the passive image alive in the dominant discourse.

Alexis is 62 when we begin our interviews and is 63 when the series ends. She lives in an accessible-design, seniors apartment complex in a rural Prince Edward Island community. She does not own a car and no system of public transportation is available to her. Taxi service is located 30 kilometres away making it unusable. Alexis has a myriad of health and mobility issues and dwells slightly above the low income cutoff level for a single person in a rural area. She is below the official age of 65 so none of the \$200 a month she pays for prescription drugs is covered under the seniors' plan. She rarely leaves her apartment building except for doctors' appointments, infrequent trips to an urban centre with a friend, a short trip with me to point out locations from her stories, and to her daughter's home, ten miles away, only at Christmas. She has lived here for six years and her days are filled with basic routine.

*Alexis' story.*

Last night I hung my least worn and most grownup looking dress on the hook on the back of the door of the bedroom that I share with two of my sisters. My two youngest sisters sleep in a bedroom down the hall with mom and my two little brothers share a room downstairs. The creaky, uneven wooden stairs seem to screech this morning just when I don't want to wake anyone. But, all remain asleep and I tiptoe down the last steps. I don't have to be up this early but today I start my first 'real' job. I want to dress leisurely and enjoy this pleasure without the noise of my brothers and sisters. I didn't mind having my mom up because I didn't often get to see her alone. She's usually up first preparing that same dreadful oatmeal porridge for the seven of us

who rise shortly after she leaves for work in the dark of the morning. I usually hear her stirring the coals in the wood stove trying to coax a little heat against the doomed intrusion of the cold into this drafty old barn of a house. One end we don't even use in the winter; in that end the rats run riot and launch nighttime raids on our end of the house. Well, it isn't really 'our' end because it isn't really 'our' house. But today, that doesn't matter. I am starting a real job today. I only work until 9 pm on school nights but I can work longer on the weekends. It's probably the first time for a long time that someone at school will be jealous of me.

A nice man from the community came around to offer mom a job for one of her girls. He had been around all my life and knew the story, our story, and knew what was most needed—another income earner. As the second oldest I couldn't believe my good luck, something that didn't often come our way. I knew that most of what I earned would go to help pay for food and rent but that didn't matter—I had a real job. This wasn't at the poultry plant picking soggy feathers off scalded chickens, or at the pea plant folding cardboard boxes like I did the summer I was nine, or even picking potatoes that I had worked at since I was seven. This was a real job and, one where I wouldn't get my dress stained or torn.

I step off the lurching back step into the spring mud in my worn black shoes with the frayed laces. I wish that I had a pair of smooth black and white saddle shoes like Rosalie at school; but that's not even worth dreaming about. Right now, if I tuck in my bobby socks right you can't tell that there is a hole where my heels wore through. I pay attention to holding my dress up and to keep from splashing mud as I plough through the mire that is our lawn and driveway. Because of the distance, I kind of wish I could take the fenderless bike propped against the step but that would just mean mud streaked from my bum to my hair by the time I arrived. Besides, it's a large boy's bike and I would have to ride with one leg under the crossbar.

Altogether, that won't do today because now I have a real job.

Before mom leaves for the poultry plant she kisses me and tells me she's proud of me. I follow her now, waving, to the edge of the step and a little later down the clay road toward the village. In the spring, the dirt track that is our road becomes like a ploughed undulating gash cutting through brown grass and dropping over the hill past the next farm. Even now, I'm really early for work as I walk along the road's grassy edge, away from the dangerous mud. Partway there I pick up a stick with a little 'y' at the end and push a clump of mud into the red rivulets coursing down the road like blood and divert their path into a broader vein flowing over the edge into the ditch. I want to be a nurse and this spring run off looks to me like a raw wound open in the landscape. Leaving the stick by the new e-lec-tric-it-y pole pushing up into the blue, blue sky I promise myself to look for it when I return, even then I'll have to be careful with my clothes; wash day happens just once a week unless I want to dab something out in the wash basin.

If this were yesterday I would meet myself leaving school an hour earlier than everyone else to prepare dinner for the kids when they get home a few minutes after 12 noon. Yesterday was my turn and Monday will be one of my sisters' turns. It is a bit difficult keeping up with school work missing this hour a couple of times a week but the teacher helps by putting aside important work to be done later. Besides I'm almost finished school, just two more years to graduation. That will be as exciting as when I moved from the room with the little kids into the other classroom where the big kids sit in big desks and a coloured wall map of the world has pictures of Nielsen Jersey Milk chocolate bars in the corners. I know that in some places kids can go to school for another three years—until they're almost 17. But, that's just like the saddle shoes, no use in dreaming.

Today there's not much traffic as I cross the paved road into the village. Today I'll try not

to think about the white shingled house with the mechanics garage that I pass on my right and wonder if the people in there now are happy. I remember being in the driveway of this house when my dad brought home two brand new red tricycles and a wagon for my sister, brother and myself. He had them in the cab of the truck and they looked like jewels when the sun hit the red and silver as he handed them down to us in turn. We were the oldest--and biggest, you had to be big to drive a tricycle-- and couldn't believe our good fortune--a new trike! We must be rich. My youngest sister wasn't even born then. We drove the trikes next door to show grammy and grampie. Mom called grammy and grampie 'mom and dad' and always sent us to get her mom when the contractions started. By the time she came home from the hospital with the seventh new baby we knew there would be a young woman housekeeper there for a short time to help with the work of a household of many kids and a new baby. A few months later my dad disappeared, and, so did the housekeeper. I only saw him a few times after that when he came home from away to sell the house we lived in and move us 10 miles distant into a strange community and the first of many rented houses in other strange communities. He never gives mom one cent to help out; it was a hard old life she had. ...But, today, I'm happy; I'm not thinking of that. ...The bugger!!

I wave at my mother who glances out the window of the chicken plant, she now works as a bookkeeper. She took a course in town every evening from 7 to 10 pm after picking chickens all day. She and my sister graduated at the same time. That brings in a bit more money, and she smells better too, not so much like blood, and fear, and death. She asked the welfare people for help a lot of time but they always refused. But my fifty cents an hour will help us too. I worry that I won't be able to do this job and make my mother proud, just like she said she was. I'm as nervous as an anxious duck shooter and I don't even want a chocolate bar from the store in the



centre of town. I turn right and walk right past it as I head up the street where my uncle lives, where my relatives are buried, and where we go to Sunday school too. Just past my uncle's driveway I walk carefully across the soggy lawn of a neat looking house. I use the front door to go directly to the front room that has the equipment setup along one long wall. The nice man is there to show me how the equipment works. I twirl the chair down and down and down. I step on the foot rest and hoist myself onto the seat. I put the adult size set of headphones over my 12 year old brown curls and speak nervously into the mouthpiece in a whisper: number please?

I can do it! I make no mistakes on the little tickets I have to fill out for long distance phone calls and my voice becomes more assured. My mother is proud of me, I buy a few things for myself—not saddle shoes—and always give most of my pay to help with the household of eight mouths and growing bodies.

#### Two Years Later

I graduate from grade nine today and fly down the three plank steps of the school in one leap. I say goodbye to some friends before turning up the road to walk the distance to my house. My mother comes through the kitchen door soon after I get home and tells me to pack my stuff because my aunt who has four young children has a brain aneurism and I am needed to keep house. Two years later and what's left of the five dollars a week and the dental repairs I have done is the total of my wealth.

There is a boy I kind of like who is two years older than me and has a good job with the government. He spends a lot of it on liquor and likes to go to parties. I like to go too, at least that's how I get out of the house. But I don't like when he drinks so much; he hits me, says scary things, and gets really mean. When I tell my mother about my pregnancy she doesn't want me to marry him. She thinks he is like my father, drinking and hitting and doesn't want that for me. But

she and I talk it over and know that there is no room at the table for even one more mouth. I marry him knowing he hits me. I marry him knowing that I don't have an option. Within four years I have four children. When I'm twenty a couple comes to visit and mistakes us for youthful babysitters rather than parents of a family of three sons and a daughter.

Some nights I wait until he drinks himself into a stupor before taking money from his wallet to get food for the kids. Some Saturday nights the kids and I wait until he passes out before going to the stock car races—they're a lot more fun without an abusive drunk around. Some paydays I threaten him with the police if he doesn't bring home some money for food. How can I put the baby in bed without giving him milk? Sometimes when he is out of booze and money he goes to the village store and steals that green aftershave lotion and drinks it—straight. Ha. At least he smells nice. I hate it when he drinks. He gets so angry at me, breaks my jaw and threatens to kill me. It's me he wants to hurt because I hide his car keys or take the wire off the coil so the car won't go and he won't be able to harm someone else. I can't leave because I have grade nine education and four little kids. Where can we go? How can we escape?

Today I have a plan. I have been married for 18 years and the kids are now old enough to look after themselves. I have met a friend, a man who is more like a companion or a brother than anything. He tells me he is leaving the province and going out west to look for work. I see a way out. My baby is 14 years old and his sister is 16. The other two have already left home. Their father would never hurt the kids, it's me he's after. When their father leaves for the evening shift I pack my belongings in plastic bags and put them in the back of my car. I kiss my baby goodbye and tell him I love him and will call him soon. I meet my friend and we leave in his car, through the island's 'back door', and I don't contact my kids directly for fear he will find out where I am. I call my sister instead.

I'm 2000 miles from home and have just gotten a prescription for a tranquillizer. I miss my kids and my family so much it hurts in my heart. I find out that he has sold my car by getting our daughter to forge my name. She always was daddy's girl and when I eventually speak to her by telephone I find that she blames me for breaking up the family. My three boys come out to see me and one settles down near me and is still there, but my daughter never comes. I miss all of their weddings, I miss my mother's death and my sister's death. I miss the birth of my grandchildren except for the son's that live near me. I miss everything.

I work here at a call centre but hate the work and have been pestering this woman in the personnel department of a large nursing home to hire me as a nurse's aide. I lie and tell her I have grade 12 education and I'm really scared, just like I was when I started at the switchboard, in case I can't do it or they find out that I lied. I get hired because of my personality, she tells me. It's almost all women here, staff and residents. The first five years I work on an on-call basis—I have no benefits or pension. I take on-the-job training and become a 'Nursing Assistant'—my greatest achievement! That's as close as I'm going to come to being a nurse and it's better than saddle shoes—I get to dress like a nurse. I get hired permanently with wages and benefits! But, no pension. Sharing the household expenses with my friend makes this the first time in my life I have not struggled to get by. I like my work, I like my friends, I like my life. I miss my family.

Today I have been working as a nursing assistant for ten years. I am in the bathroom with a frail resident who uses a wheelchair. I hear my back give out under the strain, click, click, click, as I struggle to transfer her successfully from toilet to wheelchair. The physiotherapist that day tells me to see a doctor, the doctor tells me to see a surgeon, the surgeon tells me he can relieve my back pain but I'll probably never walk again. I'd be useless! Like most events in my life, there's not much of a choice. I opt for the pain. I visit pain clinics on the west coast and see

a physiotherapist daily who puts me back together each afternoon so I can work another half day the next morning. Eventually I am dismissed from worker's compensation onto disability insurance.

I've fought cancer three times and with this latest bout of lung cancer, with the loss of my job and my workmates, with the death of my now ex-husband, I think I'll move home to PEI. I go home for a month every year to be near the kids, I hardly know my grandkids on the Island. But if I move home I can see more of the kids and maybe get to know them better and get to know my grandchildren too. I'll just go slow and carefully build bridges, especially with my only daughter.

Today I move into a provincial senior citizen's apartment building, an accessible building that has no stairs, wide hallways and laundry facilities. I can be independent and the community is familiar because I used to work here a long time ago though I don't know many people well, anymore. There is a grocery store and pharmacy with delivery service, a bank, a doctor's office, and a post office. Though I don't have a car and there is no public transportation system I should be able to get along on my own. My daughter lives about 10 miles away.

My apartment has a nice view out the patio doors of a bridge and a stream banked by colourful leaves in the fall and embroidered with frogs calling in the spring. It's a good thing to have such a nice view when you're older because I don't get out much but I look out a lot. I watch television to pass the time and when I lift my eyes I see right out the patio doors. They keep this building very nice and installed new patio doors just a few years ago. I'm not very keen on my furniture though, it's all used stuff and it's not my taste. I'd love to have new drapes and furniture. You'd think that after working for a lifetime a person would have something to show for it. My workers' compensation is deducted from my disability insurance so I only get a little

bit a month to live on and my drugs cost me \$200 a month—I can't get any help to pay for my drugs from the government or anywhere. Out west I only had to pay 10% but here when I need medicine I have to pay it all. Since I've been home, I lost 100 pounds because my esophagus was damaged during radiation treatments for my lung cancer. It keeps shrinking and I have a hard time eating, even swallowing water is a problem. I have to go in and get it stretched sometimes. That's an awful procedure. I take a nerve pill so I can be calm enough to eat and not worry about choking. If I stood up now you'd see that the crotch of my pants is down around my knees. I need some new clothes but don't have the money to get them. My sister died ten years ago and I asked my brother-in-law for her clothes. He brought them the other day and they fit perfectly. An old friend who also has back problems from working on the farm—we're both just wore out—is taking me to Value Village some day so I can get a 'new' wardrobe. When I lost all that weight my dentures didn't fit either. They could put a bag of cement in there and they'd still be rattling around. These new ones cost \$1,000 and my brother paid half. I'm still paying on the rest. It's really hard living on your own without another income. Yes. Out west was the only time in my life that I haven't struggled. My house there sold but by the time the realtor took his fees there was nothing left to split with my friend who owned half of it. My youngest son, says: "Mom, you've gone from riches to rags."

I didn't think I would like it here in this seniors' complex because everybody is so much older than I am but they are good to me. I'm only 57 but I now have serious health and mobility issues related to my back injury, cancer complications, weight, heart and circulation. A few years after I move in here I begin falling, and I can't get up. Three times I frighten the life out of my neighbours as they call an ambulance to take me to the hospital—maybe it's a stroke, maybe it's a brain tumour. I spend most of one summer in the hospital, including one long bumping and

banging ambulance trip to St. John for tests—my back was just going creak, creak, creak--while they figure out what is going on. In the end it's found that tranquillizers and cholesterol drugs create an interaction that just buckles my legs. Even now I go down on my knees but now I can get up, if I can get to a chair.

The girls that come out to help me are very good, I'd say they're perfect. They don't stay very long, I wish they'd stay longer but they're very busy. I hate waiting for them to arrive especially the physiotherapist. Sometimes my shoulder is so sore that I can't think of anything else but when will she arrive and work on my shoulder. She stays such a short time and then she's gone. The nurse comes and checks on my medications even though I see my doctor almost weekly and the same pharmacists fill my prescriptions. There's a girl that advises me on what to eat. That's a bit of a drop having to have someone tell you what to eat! The first thing I'm going to do when I get more money is to buy better food. Now I often eat weiners, potatoes and turnip—when I can find someone to cut the turnip for me. My favourite of the homecare people is Marg who's a social worker or case manager or something. Her and I talk real good. We tell stories and laugh. Something like you and I but she doesn't have a tape recorder. She's smooth too, getting around to asking me things. I really enjoy her visits but they're getting shorter and shorter, too. We used to talk several times a week on the telephone. Sometimes I'd phone her or she'd phone me. I really like when she comes, same as with you.

I really need someone to clean up my place. I can't vacuum or clean the bathroom or make the bed—I have that walker there by the sink because I might fall, though I try to go without it. Mostly I use the walker to help me when I shower. I have three grab bars in the bathtub and my uncle gave me a shower chair he didn't need. It takes me a long time but I really like my daily showers. The homecare people wanted to have someone come out and bath me. I didn't

want that. They only come once a week!; that might be okay for someone who's old but not someone young like me. 'I shower daily, dear,' I told them. I didn't mind having someone with me in the tubroom when I was in the hospital but I don't want it here. I don't know I guess I'm modest or something. I am really scared to shower at home alone and I thought I'd ask a neighbour or my old friend to just stay in my apartment when I was showering but I never did that. I just take my time. I don't want help with a bath, I'd like some help with housework. Doing laundry, cleaning, and making the bed are really dangerous and painful for me. It takes me a long time to recover from doing the laundry. I just sit here in my maroon recliner with my trusty green flannelette heating pad on my shoulder, or my hip, or my leg for the rest of the day, until the pain subsides. I hire a cleaner girl for an hour twice a month. Sometimes she comes with her granddaughter. Sometimes she can't come because she has to look after her family. She's different from the other homecare people because she'll stay afterward and talk with me—chat time. I really like that. I pay her for her cleaning time but she doesn't charge me when we just chat. Boy can she do a lot of work in an hour. I tell her not to go so hard but she does anyway.

When I was in the hospital the homecare people asked me about my family so I told them I had a daughter and a son living on the Island. They were really interested in my daughter and wanted to give us counselling because I told them we didn't get along so well— It's only now that I'm her mother, again. I turned them down. I was afraid that they wanted her to come out and keep me. She said that if I couldn't get along on my own that I should go to a nursing home. I said, no way am I going to a nursing home! I'm only 60, or 62! I was afraid that if I fell in the shower too that she would put me in a home.

I have beautiful grandchildren. They are in their teens now and very handsome looking. My daughter is very busy driving them here and there. Sometimes I phone her on a Sunday and

say, 'why don't you just drop out today.' And she'll say she has to drive my granddaughter to work for ten and pick her up at two and then my grandson has to go to play shinny or something. They are very busy and I understand. She sometimes calls me on her way home from work on her cell phone. I just say to call when you can. My son in Charlottetown is just like his father; he prefers his own company. I saw him and my grandson at Christmas; I see him two or three times a year.

Today I will do what I do every day, I get up and come out here to watch television and then I have my breakfast. I go to visit one of my four neighbours and then I come back and make some dinner. Then I visit some more and watch television and make supper. I have trouble cutting up the turnip that I usually have for supper. I ask a neighbour man down the hall who is twenty years older than me for help. He helped me make the bed one time—how do you get all four corners of a fitted sheet on when you have to do it one corner at a time, it doesn't work-- and it was really funny having a neighbour in my bedroom. I said we might start a rumour. But I never have my corners tucked in tight like I used to make beds when I was working. Now I just lay the top sheet on top. Another neighbour man helps me too and they both give me rides to the doctors or the bank if they're going. When I do the laundry one of them put a rope on the basket so I can tow a little load up the hall with my good arm. I have to use my sore arm to reach into the dryer to get my things out and a pair of panties always sticks to the back of the dryer. I stop at my neighbour's apartment to have a rest before I continue. Sometimes he carries the basket down the hall, home, for me. Then I'm done in for the day; it's just me and the heating pad in the recliner. One of my neighbours changed the outside light when it broke. But it still didn't work. I had to get on a chair and fix it myself but I didn't get the globe back on. I just can't. You know, everybody helps me. The milkman cashes cheques for me and you bring me things from the



store. I always try to have the apartment aired out when I know you are coming to visit. I just open the patio doors until the smoke clears out; I know you don't like it. It's not bothering you, is it?

I don't know what I'd do if I had transportation like they have out west—the 'bunny bus' helps people in wheel chairs and who can't get around very well to get to where they want to go. You just phone ahead and it picks you up. I'd go into town, look around, eat a hamburger in a restaurant—I haven't had one in years—visit the kids, and come home in the evening. I'd just get out. I hope some old friends will take me out on a Friday night when the weather gets warm—I don't want to fall and break a hip—and we could go someplace and have a beer and look at the guys. I can't play darts but I can look, alright. Today, I'm only 63!

### Part III: Analysis

#### *Retelling the Story in Broader Detail: a Researcher Perspective*

Life history research places lives within contexts such as cultural, political, familial, educational and religious spheres (Cole & Knowles, 2001). The implications of the critical feminist/political economy perspective point to an established trajectory that Alexis' life was set on from her birth. Born a female into a society that maintains apartheid-like discriminations against women and establishes political and economic structures that favour and support the advancement of people on the basis of sex and social class Alexis' options were predefined. Her life follows a script engraved by violence, alcohol, poverty, limited educational opportunity and underwritten by gender. As a woman with minimum schooling she finds employment as a Nursing Assistant, a position requiring a large component of physical labour. As predicted by the statistics on social class and employment Alexis is injured on the job and in like manner becomes a statistically predictable homecare recipient because of her gender, and social class. The same

forces of oppression that delivered her to this door also work to limit her ability to satisfy her needs either by providing adequate care as a public service or by privately purchasing sufficient care. Following a lifetime of work, that spans the decades from the spring she turned 12 to when she was dismissed from work as a Third Age woman, her options are limited. Each step along her history has been shadowed by forces that control, diminish and delimit her ability to escape the trajectory. For example, within her adult life she witnesses her abusive, alcoholic husband, with similar education immediately obtain permanent employment, easily construct an uninterrupted, stable life-long work-history on the basis of her uncompensated reproductive labour, and have access to male employment pattern pension and benefits. No similar options were available to Alexis.

For Alexis, the vector was set; she did not even have to open her eyes to follow its path, straight and true it was to the social, political and economic structures that repeatedly construct that scenario in women's lives. Now as a woman who entered a seniors' apartment complex at age 57 the pattern of being a senior woman in need of care is repeated. Alexis enters a world of homecare where the reductive image of senior women and their care needs is narrowly defined to align with the demands of a globalizing economy.

Alexis' options for responding to these diminishments are circumscribed. According to Aronson's theorizing on the cultural images available to senior women needing care there is only one model available to her in the popular imagination. This is one drawn in the dominant discourse of media and policy documents and imagines senior women care recipients as bundles of care needs that require 'being managed.' The image uses a market model applied to public services to identify low cost, standardized services that concentrate on the accomplishment of a narrow definition of needs—this is 'managed care'. This managerial template concentrates on

inputs and outcomes and requires that senior women in need of care adjust their needs to suit the standardized services identified by the architects of social policy. This managerial framing of senior women as passive and powerless leads to meagre allocations of resources and service practices. Aronson (2004) explains the situation in Ontario in the mid 1990s when the Progressive Conservative government of Mike Harris introduced a market-model system of managed care to shift responsibility for care away from the public sector. Using this market approach, the government of Ontario intended to reduce social spending and "to frame health and social issues as individual, not collective concerns requiring private, not public solutions" (p.170). This market model has been reproduced in most provinces in Canada.

This study of a senior woman acknowledges and recognizes the power of the dominant discourse and how Alexis is situated within this image and her acceptance of the diminishment inherent in the narrow services provided by social policy. The robustness of this unidimensional image is underscored by Alexis' repeated assertions that 'homecare is perfect.' Aronson identifies two other images but both are outside the popular imagination and both allow for imaging senior women care recipients as resisting and protesting the reductive image of senior women. The images are not static but women move in and out of them depending on shifting experiences during her senior years. One of these images is of seniors as co-actors in a collective movement for political change. In Alexis' life this image is undeveloped. The final image Aronson theorizes in this description is that of senior women 'managing'.

For this research I draw on Aronson's work on this latter image of senior women 'managing'. She describes 'managing' as "captur[ing] the possibilities of older women sustaining active senses of selfhood and of striving to stay in charge of everyday life and its challenges" (p. 54). I augment Aronson's labour on this image by describing the 'work' performed by Alexis in

her efforts to sustain an active sense of selfhood in a climate where declining rights of citizenship are replaced by the rights of the marketplace. Feminists, says Armstrong and Armstrong (2004), “have long struggled to make the full spectrum of women’s work both visible and valued...” (p.6). The notion that care recipients actively work at achieving care makes an image of passivity difficult to sustain. Recognizing senior women as active citizens exerting the right to selfhood moves their needs and rights into the public spotlight. Dissecting Alexis’ stories of the work involved in her daily life uses her story “as a window into broader social and societal conditions” (Coles & Knowles, 2001, p. 12).

I have chosen to examine the work of being ‘incapacitated in whole or in part’ and receiving homecare, in all its guises, under three concepts of work: managing, controlling, and raging. Alexis’ work of ‘managing’ ensures that her self-defined needs are met, often by creativity, negotiation, and persistence. Alexis’ work of ‘controlling’ addresses the work in which she engages in an effort to maintain and retain control of her home and her health care. Alexis’ work ‘raging’ uncovers an emotion usually not open to senior women in the popular imagination. The work of rage is called forth when the narrow services and yawned response from an ageist culture serves to diminish the life of a senior woman whose work managing and controlling has gone unheeded. All three of these serve as platforms for protest and resistance, the latter, rage, carries it in the back pocket.

#### *Work I: Rage*

Investigating rage as work that senior women invest in to manage their care is an area that clearly creates space for resistance and protest because it embodies both. It is an area that also shatters a stereotype of seniors and especially of the diminishing and destructive passivity embedded in the popular image of senior women who are the recipients of care. It is an area that

opens up a space for a transformative symbol to emerge. Woodward (2003) calls for the recognition of a 'noble anger' at the multiple diminishments of ageism that regularly and uncritically are reproduced in our culture. A righteous anger, she says, is not associated with old age in the popular imagination but evidence of the existence of anger are pervasive. The image of old people angry at the humiliation of their diminished human dignity has not yet been formalized. Because there is no parallel word to 'feminist' to oppose the ageism of the dominant discourse and find practice in social policy affecting senior women, Woodward suggests we are very far from "recognizing and honouring the emotional experience—the anger—associated with ageism" (p. 66).

Woodward (2003) argues that the traditional notion of wisdom as the special strength of the old is counterproductive and feeds into a culture of ageism. The true position of the aged should be rage. She quotes Germaine Greer, at age 60, reflecting dismay at the dismal progress in women's issues across the life span. In *The Whole Woman* Greer writes "It's time to get angry again" (Woodward, p. 55) and evokes anger as a powerful cohesive force drawing in all women and, this time, including senior women in an image of a coalition of women. Greer's anger, Woodward argues, is the foundation of the articulation of a political viewpoint. It is in the ability to experience rage and to value that rage that senior women can recognize, articulate, and analyse their needs for care that are unmet by their current homecare services or efforts to manage. At the same time the dominant discourse's efforts to draw reductive images of senior women and sketch them/us as objects of care that are 'being managed' is resisted.

Woodward (2003) writes, "the emotions are one of the important building blocks that our society draws upon to construct meaning and value" (p.57) and to attempt to ban or control behaviour according to age. Typically, rage is not associated with old age, especially senior

women. Rage has been pathologized in relation to both of these oppressions. Woodward explains the difficulty of viewing rage in old women as positive and of reclaiming the value of rage in old age.

In terms of a social politics of the emotions, angry women have long been labelled irrational or hysterical. The strategy is to demean those women. Analogously, anger in the old is outlawed. Such anger is what the philosopher Alison Jaggar (1989) has called an “outlaw emotion,” “conventionally unacceptable” (p. 160). But angry challenges to ageism by those older should not be dismissed. Anger can be a sign of moral outrage at social injustice, at being denied the right to participate fully in society. Such anger is a judgment, or more strongly, an indictment. (p. 63-64)

Rage may be the voice and the image Aronson argues is required to articulate the position of senior women protesting and resisting. Woodward draws on the experience of black rage from the 1960s as a way of marshalling resistance to the oppressions of racism: “Rage meant outrage at racial injustice” (p. 61).

Alexis’ image as a senior woman making public demands as part of a collective is undeveloped. But the image of a senior woman angry at the diminishments in the minutiae of everyday life also forms a political statement. It is in understanding the significance of the ordinary and the day to day that women re-write faulty scripts of our lives. One of these has to do with senior women and rage.

In Alexis’ experiences of being a homecare recipient she has expressed anger on a number of occasions sometimes over, from my perspective, seemingly small issues. I felt the importance of her rage but was originally unable to understand its significance. Alexis rages at

and protested her inability to “sustain the preferences and small pleasures of a lifetime” (Aronson, 2000, p. 59) when the only grocery store to which she had access through home delivery of goods and where she had purchased it for half a decade sent her a brand of toilet paper she had not specified. She does not notice it until the delivery person has departed, she has no way to return it, and no avenue to obtain the brand she prefers.

*I figure they'd know. I've bought it for five years. Oh, I get so mad sometimes.*

The diminishment of not having her carefully crafted grocery list filled appropriately and respectfully was not an expression of the fussiness stereotypical of old age but of a thwarted attempt to control her life and her care.

Alexis rages at the injustice of having spent two decades of her life in marriage to a brutal man, of having to leave her job, her home, her children, and her possessions to preserve her life, and of receiving no recognition of this indenture in his pension benefits.

*Alexis: Yes, and [husband] got a big pension. And because him and I were divorced the kids got all the money. Yeah. I done twenty years of my life and I had to go without it. Wasn't fair.*

*Lorraine: Did twenty years of your life?*

*Alexis: With [husband]. So I should have got a share of my pension, [husband's] pension. But I wouldn't take it from the kids. I was working then...*

The province expects family and friends to supply the primary homecare for people in need of care but the negotiation of that care is a site of conflict and disarray. Alexis rages against obtaining a short ride to the doctor's office with a relative (her ex-husband's cousin) who was going anyway and then being expected to pay him from her limited resources. She felt exploited by the caregiving support the province identifies as appropriate for senior women needing care.

*Alexis: See out here, we've got none [public transportation]. Everywhere I go I've got to pay. A*

*fellow up the hill took me to Dr. [family doctor] which is over the hill there. Five dollars! A relative!*

*Lorraine: A relative of yours? He took you over and back for \$5.*

*Alexis: Yeah. I mean that's a lot of money. And he was probably going over to get his B12 shot anyway. But it's money. Every time you turn around you have to pay somebody to do something for you. Yeah.*

The frustration of failing to have her care needs satisfactorily addressed despite the work entailed in the attempt produced a justified rage in Alexis.

Alexis is angered at the thought that her daughter—the province's solution to her care need—would place her in a nursing home. In this story Alexis is inspired by her anger and maintains control of a dangerous situation.

*When I was in the hospital, [daughter] thought that I should go into a nursing home. Cause I couldn't walk. And I said, no, by god! I'll walk supposing it kills me! I'm not going to no nursing home! Fifty, sixty year old woman going to the nursing home! That just floored me!*

Alexis sometimes gets angry with me when she feels I fail to understand what it is like to be a senior woman in need of care and the constant work of maintaining control and resisting diminishment.

*Alexis: YOU FEEL HELPLESS, Lorraine, when you have to get somebody to bath you. To me that's the last resort. If you can't bath yourself you're pretty well finished.*

*Lorraine: Finished in what way?*

*Alexis: In looking after yourself. Do you see my point?!*

Alexis strives to maintain a calm demeanor when she is angry. She feels that the pain resulting from her physical condition causes her to be angry but she manages to hide it.



*Yeah. I'm very grouchy when I don't feel well. I think I am. Everybody says I'm not. I just feel grumpy.*

Woodward (2003) writes that the rage of old women can be understood as both a protest against injustice and as the intellectual work of the historical understanding of the roots of ageism against women. From this perspective, anger does not only provide the energy for work. It is the work. When one is angry, one must continually confront others and one must be on one's guard. (p. 65)

If anger is work, Alexis' experience of care receiving constitutes work. The work of managing, of resisting the diminishment and devaluation of 'being managed', the work of controlling her anger, the work of controlling her care, care that at every turn conspired to deprive her of its control, the work of raging against injustices in her prosaic daily practices articulates a protest against being old, being female, and being a homecare recipient in an ageist culture, driven by market assessment of value.

### *Work II: Managing*

Managing, "captures the possibilities of older women sustaining an active sense of selfhood and striving to stay in charge of everyday life and its challenges" (Aronson 2000, p.54).

My first understanding of Alexis managing her care needs is a story of how I became a caregiver and of the work involved in planning my participation. It is a common story made interesting only by the fact that I spend my paid labour hours working in the field of tobacco research on smoking cessation and harm reduction in the office of the Socio-behavioural Cancer Research Network at the University of Prince Edward Island. My home phone rang as I prepared to leave for my second interview with Alexis. Her gravelly voice rattled from the receiver and I expected to hear that she was cancelling our meeting because she was not feeling well. "Could

you pick me up a package of ‘Players Filter’ at the pharmacy on your way here this afternoon?” was the message. Following a moment of conflicted thoughts, of a vision of me buying cigarettes at my local pharmacy –“Oh, they’re not for me!”– I agreed to her request and made the purchase before arriving for the interview. She paid me and we continued with the interview. Alexis does not smoke when I am there and, as already stated, she airs out her apartment prior to my arrival. The work, planning, and negotiation involved in having her self-identified needs met and ensuring that I had a pleasant visit, and would return, is work that is overlooked in an analysis of homecare.

Another time before beginning an interview Alexis requested that I purchase some non-prescription pain medication and Juicy Fruit gum to ease her discomfort and to keep her mouth moist during our conversation. I left for the pharmacy a little concerned about my role as errand girl and only later understood the deeper significance of how I fit into Alexis’ coordination and management of her care needs and the work involved with this. I am a social contact; I am an unwitting caregiver; I am part of how Alexis manages to have her care needs satisfied.

During an evening interview our conversation is broken by the milkman making a delivery. I turned off the tape recorder not wanting to waste time or tape listening or transcribing a conversation that I thought was extraneous. The home delivery service assists Alexis in satisfying her needs for milk, butter and cheese but, to my surprise, the milkman also serves as banker and he agreed to cash a personal check for Alexis from his money pouch. I understood from their interchange that this was not the first time he acted in this capacity. Like me, the milkman too is a social contact and like me was assumed into Alexis circle to assist in her struggle to meet her care needs. Alexis is continually working to sustain a sense of capability and selfhood.

The level and complexity of constantly negotiating care needs with an ever changing cast of social contacts represents considerable work for Alexis as we move into and out of her life for short periods. For care recipients, like Alexis, whose roots in the community and connections with family do not run deep, ever recurring work is required to constantly discover new ways to have needs satisfied and avoid diminishment. New social contacts offer new opportunities for Alexis to negotiate the satisfaction of her care needs. Alexis telephoned me at income tax time inquiring whether I knew how to complete her tax form. She later told me that she was able to find assistance from a young niece who did the job.

Alexis is a personable woman and is currently capable of negotiating the constant work and the goodwill required of people to assist her as she asserts her needs. Aronson explains that negotiations like these could have ended differently and are not equally available to all care recipients.

Such solutions require home-care workers [or social contacts] to have goodwill, time, and skill and elderly home-care recipients to present themselves as engaging and deserving. In the absence of these conditions, a very different scenario could result. Instead of being perceived as tenacious and creative and therefore deserving, an older woman with similar needs and strategies could easily be deemed manipulative, fussy, difficult, and therefore undeserving. (Aronson, 2000, p.63)

Alexis' experience in having other care needs met involves her older neighbours who live in her seniors' apartment building. Her methods are both creative and physically taxing, require advance planning, cooperation, and constant negotiation with co-residents. Alexis achieves with great difficulty the requirements of everyday functioning, she does her laundry, makes her meals,

makes her bed, changes a light bulb, and goes to the doctor all with the assistance of her co-residents. Bed making is usually done by a private-pay homemaker that Alexis hires from the underground economy for an hour every two weeks. Sometimes this woman is not available or else Alexis elects to save the \$10 an hour she pays for this care.

Her laundry regime is instructive of how she manages with help.

*Alexis: Well, I load it [laundry basket] down here, not much stuff. Enough to make a little load. And I drag it up the hall with a string on it; [#1 neighbour] put on it. Put it in the washer, then I come back here. In a half an hour I go back up, put it in the dryer. Then I come home again. And when that's dry I go back up, put it in the laundry basket and get it as far as [#2 neighbour]'s door.*

*Lorraine: So that process has exhausted you, then, has it?*

*Alexis: Yes. Well my back is paining, my shoulder's hurting. Everything hurts, Lorraine, when I have to do my laundry.... Yeah. And this is the arm [sore right arm on which she currently positions the heating pad ] I put into the dryer to pull out stuff.*

*Lorraine: Oh, your right arm.*

*Alexis: Right arm. That's the one that's got the cracked rotation cuff-cup or cuff-what ever you call it. And naturally a pair of panties always sticks on the back of the dryer. So you have to reach in. So I'm in pain when I'm done the laundry, bad pain. And see I don't take no pain pills any more so I have to sit with the heating blanket on [as a remedy for pain]*

Her doctor does not want her to carry a laundry basket because of the stress on her outstretched arms. Rather than succumb to the alternative of not doing laundry or paying from her inadequate budget for a homemaker to do it, she has devised a method whereby her laundry gets done. In the aftermath of this taxing exercise Alexis retreats to the recliner and the pain controlling comfort of

the green flannelette heating pad.

In her years as a Nursing Assistant Alexis had made thousands of beds with sheets securely tucked into hospital corners; Alexis' own sheets are often simply laid on top of the mattress, corners untucked. When her private pay homemaker is not available and the bed requires changing, Alexis has involved her 82 year old neighbour in helping her get the fitted sheet over all four corners at once, something she cannot achieve by herself. She feels odd having this man twenty years her senior helping her with this activity but resists letting her need to change bed linens go unsatisfied and the diminishment that this entails.

*Alexis: [Neighbour] came in last night and helped me make the bed. I had taken the sheets off and washed them and he brought them down out of the dryer. Of course I phoned and asked him. And then I said, 'You wouldn't help me put the bottom sheet on? I can do the rest myself.' That darn bottom sheet, I can't get it on. Yeah, sure he [said].*

*Lorraine: You mean the elastic corners?*

*Alexis: Yeah. So him and I made the bed. I said 'we could almost cause gossip, [neighbour]'. He's only 30 years older than I am—20 years. ....Yeah. We laughed. ...It just seems I don't have enough strength in my arms to pull them on. I can do one side and then go over and do the other, the other side goes off.*

*Lorraine: You have to crawl across.*

*Alexis: Yeah, but I can't.*

Alexis tells me that, although she cannot vacuum or clean the bathroom because of her disability she can prepare her own meals, not baking, she tells me, but preparing and cooking meals. Later she tells me that she engages a neighbour to assist her in preparing vegetables because she cannot cut one of her main-stay vegetables, a turnip, by herself. The work in

negotiating these points of assistance and the struggle to complete daily tasks she knows are required is significant.

One afternoon in late winter when I arrived for an interview the globe from Alexis' exterior light sits on the tv inside her patio door. The work required in this story is of negotiating with a neighbour to satisfy her need but when it remains unfulfilled--the bulb still does not light-- Alexis is unwilling to accept the situation. Alexis assess the situation and feels she should not overtax her neighbour, by asking him again for help. She does it herself, with great difficulty, suffers the consequences of her action, and the job remains unfinished-- the globe has not been replaced.

*Alexis: Well, [male neighbour] put the outside light in for me, here a couple of nights ago on the deck. And it never worked. So today I thought, well I can't be always asking the man to do things for me I've got to do them myself. So I went out there in my slippers and no gloves and that globe sitting there by the tv, I couldn't figure out how to get the damn thing off. So finally I got it off, put in a new bulb and it works. So now it works.*

*Lorraine: But you haven't got the globe back on.*

*Alexis: I'm not going to.*

*Lorraine: You're not going to. How come?*

*Alexis: It's too hard, Lorraine. My hands are just stinging and burning. But that's from the Raynauds. Yeah.*

In retrospect I recognize that I was being asked, in a diplomatic way, to complete this task, but the negotiation was lost on me and I left without replacing the globe. More planning and negotiation with someone will have to go on to see that the globe is replaced on its exterior mount. Clearly, social contacts make unreliable caregivers and negotiating help has to be done

with great tact. Changing a lightbulb for most people is not a difficult job. For Alexis it required work, negotiations, and creativity to have the need filled in a way that would protect Alexis from harm. When that failed, she refused the diminishment of being without an outside light and fixed the bulb herself. But now her body retaliates.

Finally, Alexis attends to her medical needs by going to the doctor about once a week. She arranges her need for medical attention by planning to see the doctor whenever one of her neighbours is going. She plans her life and negotiates with neighbours to provide transportation to the doctor's office. On a recent occasion she was unable to arrange her medical needs at a time that was convenient for one or other of her neighbours. She searched further afield for transportation and located a cousin of her former husband who lives in a house at the end of her driveway. When he picks her up for the short drive up the lane to the doctor's office she discovers that he expected to be paid even though she has accommodated his schedule as he was going to the doctor's office anyway. She pays him reluctantly knowing all the effort she has already exerted in having her care needs satisfied and now more is expected.

Alexis also 'manages' by resisting 'being managed'. On at least two occasions Alexis refused the offer of formal services suggested by the provincial homecare representative. In refusing both of these services Alexis avoids the diminishment of 'being managed' by being a compliant body and uncritical receiver of care. Because of the refusal of these services Alexis increases the work required for negotiating and planning the fulfilment of her care needs because she knows she both needs an attendant for personal care and someone to assist her with her day to day needs.

### *Work III: Control*

Maintaining control over her home and health care are significant areas of work for

Alexis and she exerts considerable energy in ensuring these are achieved in a way with which she is comfortable. Alexis controls her need for homecare by identifying and locating an apartment where, with mobility impairments, she could navigate her daily life with minimum assistance with her day to day needs. Safety is a major consideration as injuries could increase her disability, her pain, as well as her need for care. She limits her domestic and social activities to avoid accidents that she fears may limit her independence and increase her care needs or, worse, lead to institutionalization.

It is not in the public services that Alexis receives where her control over her care is observed. It is the services that Alexis refuses that clearly show the work involved in maintaining control of her life and the damaging reductionist view of senior women embedded in social policy governing homecare. These narrowly drawn services represent great danger to Alexis and to the direction in which she desires her life to go. She refuses two services and 'chooses' to maintain control of her homecare: first, Alexis is offered the services of a counsellor to mend the estrangement that separates her from her daughter, a condition Alexis would dearly like to see righted. Alexis refuses the counselling service offer. Second, Alexis refuses the offer of assistance when she showers, attention that she feels she needs, but only on her terms. This offer too is refused.

The counselling service was offered to Alexis while she was hospitalized as a result of polypharmacy. The hospitalization left her fragile body with greatly reduced mobility and it was clear that she could not return to her apartment without assistance. Social policy governing homecare supports the primary caregiving of family and friends. The knowledge of both a son and daughter on the Island focussed on the daughter as the caregiver social services sought. Alexis explained the estrangement between herself and her daughter; no consideration was given



to identifying her son as a caregiver. Alexis' only daughter is the most estranged of all of her children and was the only one not to visit her during the two decades Alexis spent in her western sanctuary. Social service's offer of counselling to bridge the gulf that separated them was designed to fill the needs of social policy rather than of Alexis'. Alexis' need was clear: for assistance in her home, and for the opportunity to rekindle a love-relationship that is very dear to her—that between herself and her daughter.

*[It's] just now getting that I'm her mother again.*

If her daughter was required to serve as caregiver to her estranged mother this relationship would be endangered.

*She'd resent me.*

Researchers have shown that recipients of homecare wish to separate the labour of 'caring about' from that of 'caring for'. Seniors in need of care prefer public non-stigmatized care rather than care from family and friends. Allowing the state to intervene in this fragile and intimate matter would devalue and diminish Alexis in the eyes of her family if counselling means grooming family members to 'care for' Alexis; she would rather be 'cared about' by her family. In Alexis' case she felt that the service offered to her would have served to separate her even further from her daughter. The danger was very real and Alexis refused the service without consulting her daughter.

Alexis' refusal of the service was further built on her fear that if her daughter were pressed into care giving service as social policy mandated her to be that Alexis would lose her daughter, lose her home, and lose control over her life. If Alexis had accepted the offer of counselling and looked to her daughter for care giving service she felt that her daughter would have refused the role and pursued instead the route that would have seen Alexis placed in a long-

term care seniors' institution.

*She'd resent me. And put me in a nursing home.*

This option clearly was not what Alexis wanted. She felt that she was too young when she began living in a seniors' apartment complex and she now felt she was too young to be placed in an institution like the one in which she spent most of her work life. The danger embedded in this narrowly defined social policy threatened to diminish Alexis and to loosen the control she maintained over her care. She rejected the counselling service choosing to retain control over her homecare and retain the possibility of a positive and healing relationship with her daughter. Alexis resisted the mandate of social policy governing homecare and refused to involve her children in her care.

Alexis also worked to protect her daughter from the demands of social policy that family and friends serve as the primary caregiver. She refused to allow social services to groom her daughter as her caregiver and protected her daughter from the pressure to accept this role that social policy had identified as hers to perform. Alexis offered protection for the important relationship she wished to develop.

*That's right. We're just getting it on track.*

Alexis also refused another service that threatened to loosen the control she carefully maintained over her life. The homecare social worker was concerned about Alexis' frail condition when Alexis returned to her apartment following her hospitalization. Both she and Alexis feared an accidental fall while Alexis attempted to bath. The services of an assistant to help her bath were prescribed. A complicated set of images and implications lay at the heart of Alexis' refusal of the prescribed bathing service.

Alexis refused the diminishment embedded in the narrow definition of this care need.

Alexis admits that she was “*so damn scared I was going to fall*” while in the shower yet she refused the service. Her refusal was based on two significant issues both of which, if the narrowly defined care service was accepted, spelled diminishment and loss of control over her care. Although Alexis recognized the danger inherent in her refusal she chose to accept the consequences of her refusal and to retain control over her life. Also interwoven in the story is the way she sought to manage her care and reduce the negative effects of the narrow service offer by substituting informal care for the demeaning/inadequate social policy care allocation. Alexis declined the bathing service opting instead for a complicated procedure that was exhausting and time consuming.

*Alexis: I take the walker in, stand it by the bathtub. My uncle bought me a bath chair. And I have three rails to hang on to. So there's no way I can fall in there. And then coming out of the bathtub I hold on to my walker. And my legs are kind of weak from standing so long so I take two towels, go in the bedroom, sit down and dry. That's how I work that.... It's very easy when you have the tool, equipment.*

*Lorraine: And why would they have offered you that?*

*Alexis: Well they thought I was too shaking to get in the bathtub at first. And I said, no. I wouldn't like somebody here when I'm showering.*

Declining the bath is a complex issue related to ageism, power, perception, and staying in control of her care. Alexis was offered the services of a caregiver to assist her with her bath because her physical condition made bathing a safety issue. Alexis herself recognized the danger. Nonetheless she declined the offer of this homecare service. Her explanation spans the concerns from modesty to loss of power, to the diminishment of seniors using this service. Alexis did not feel helpless or overly modest while bathing with the assistance of a nurse in the hospital. The

relocation of the bathing ritual to home represented to Alexis a loss of power over her care and possibly her living situation. She explains her acceptance of hospital routine and by implication her rejection of at-home bathing services as an issue of maintaining control at home.

*Because you know [in the hospital] that's how it's got to be. I'm not in charge [there].*

Alexis resistance to the bathing service is resistance to the diminishment that the homecare bathing service offers on two levels. Alexis says she would feel 'helpless' having assistance to bath at home, a diminishment of her view of her own capability. This loss of power over her personal care at home, Alexis feels, also gives credence to the notion that she should not be living at home. If her daughter perceived her need for personal care her daughter would feel: *I should be in the nursing home where I'll get looked after....If mom has to have all that help she should be in a place where she'll get it.*

She is not willing to surrender this power over her personal care and chooses instead to retain control and follow her labourious bathing ritual instead. At home, she is in charge. Alexis recognizes the danger inherent in this decision. Rather than accept the services of someone to bath her, she considers how to retain control over this perilous task, minimize the danger, and fulfill her need to perform this ritual herself. Alexis considers enlisting the services of her female neighbours and a friend who lives 10 kilometres away to be within earshot when she performs this daily ritual. This, she feels, would be an acceptable solution to the risk associated with bathing without assistance.

*Alexis: At first for a few times, I thought if somebody would come, just sit here while I had a shower, just in case. But then \_\_\_\_\_, my uncle, gave me the chair, bathtub chair, I was fine.*

*Lorraine: Did you suggest that to the homecare people?*

*Alexis: No.*

*Lorraine: That if you just had somebody.*

*Alexis: I was just going to get one of the girls here. \_\_\_\_\_ or, not \_\_\_\_\_. but \_\_\_\_\_. or.*

*Lorraine: Somebody just to ...*

*Alexis: Pop in. Sit here while I'm having a shower. I was so damn scared I was going to fall and [daughter] would put me in a nursing home. Break my hip or something. You never know,*

*Lorraine. Those things happen.*

Alexis recognizes the unfeasibility of negotiating this and the responsibility on others of this solution and so she daily accepts the jeopardy and bathes alone.

Alexis showers rather than baths and enjoys the experience tremendously taking long, warm showers while standing on shaky legs except when her back causes her too much pain to permit this taxing ritual. She has obtained from her uncle a bath chair that remains in her bath tub and which she uses when her legs are weak or fail her. The homecare service offer for assistance was for bathing, not showering, and is offered to Alexis on a once a week basis. Alexis showers daily and finds this response to a care need as inadequate and demeaning.

*Alexis: They offered to come out and bath me once a week. Now who wants a bath once a week?*

*[laughs] I said, 'dear I bath every day, shower.*

*Lorraine: What'd they say?*

*Alexis: No....*

*Lorraine: They'd come once a week? What'd you think of that?...*

*Alexis: I didn't think too much of it. I said, my god, I shower every day—just about every day.*

*Some days I miss a day. If my back's very sore, I don't. Well, \_\_\_\_\_next door, she has one [bath attendant/homemaker] comes out every Tuesday and does her bath. I COULDN'T GO ALL WEEK WITH ONE BATH. I'D GO NUTS.*

She feels that level of service may be appropriate for someone else but not for someone like her.

*Lorraine: What does [care receiving neighbour] think if it?*

*Alexis: Well, she's [three decades older]. They only bathed once a week years ago anyway.*

If the bathing service offered to Alexis were accepted, she would be placed, she feels, in the devalued category of someone else--old people. This is an image that she strongly resists. When I innocently referred to her as a 'senior' in our initial conversation her response was both visual as her head jerks back and oral. "*What do you mean, dear? I don't understand.*" Alexis perceives differences between 'seniors' and herself. When we discuss the one bath per week service provided by homecare Alexis feels that this is acceptable for old people but not for someone younger, someone her age.

While working in the seniors' home Alexis was charged with bathing 13 women each day--residents were provided with two whirlpool baths a week. This procedure involved strapping naked residents into a harness, lifting them using an hydraulic lift mechanism, and lowering them into the water. Researchers argue that this process objectifies and devalues seniors but Alexis sees no power imbalance between her position as a younger, clothed, capable Nursing Assistant and the older, naked, culturally devalued bodies she was charged with bathing (Twigg, 2000). Alexis replied with some difficulty in excluding her own age group that this may have been an issue if the residents were young but they were older and so *not as sharp*. (Some residents suffered from dementia.)

*Alexis: ... Well it would be different if we were bathing young-er like middle aged women all the time. But we had old women, 80 and 60-no-75, 80, 90.*

*Lorraine: What would be the difference between an older woman and a--*

*Alexis: Well, I don't think their senses are as sharp.*

*Lorraine: In what way?*

*Alexis: Well, to know what we were doing.*

*Lorraine: Oh, so did most of them have some sort of impairment, mental impairment?*

*Alexis: Yes. Like a lot of people with Alzheimers—not a lot of them, but with mental impairments.*

Bathing with assistance at home for Alexis placed her in a category in which she resists membership because of the objectification and devaluation of persons located within the group called 'seniors'. Alexis struggles to maintain control of an image of herself that does not fit the objectified, disempowered, devalued, passive image of the senior female homecare recipient that she describes using the image of senior women care recipients portrayed by the dominant discourse.

*Alexis: Well I'd sooner do it [bathe] myself! It don't symbolize nothing, it's just that I feel helpless. And that's an awful feeling.... I just would feel, god if I can't bath myself, I shouldn't be here.... It means I'm helpless. And I'm one, I done everything for myself. And now when it comes to the point you can't, where does that leave you.*

*Lorraine: I don't know. Where does that leave you?*

*Alexis: In a bind.*

Her rejection of this diminishing service provided once a week allows her to maintain control of the image she constructs for herself about herself and about her position as deserving better than homecare offers seniors.

A second feature of Alexis' rejection of the bath service is that accepting the bathing service and the embedded image of helplessness it portrayed may confirm in her daughter's mind the perception that her mother should be institutionalized.

*I'd be in the nursing home, that's where I'd be, if she thought that.*

Alexis worked extremely hard to return to her apartment with the aid of a walker because she feared her daughter would press to have her placed in a nursing home. Now she resisted the image of helplessness that accompanied the bathing service and retained control of her self-image, preserved an image of resilience in her daughter's mind, and directed her homecare to serve her self-defined needs.

### Conclusion

I first met Alexis when I arrived at her apartment to commence the data gathering for this research. I knew very little about her except that she was over age 60, receiving homecare, a friend of a friend's mother, and she agreed to participate in my study. Alexis was to be the first of four women I was to interview twice for two hours each time. I was interested in understanding the effect of being a senior woman in need of homecare on the daily life of these women. I thought I might find common threads among their stories and the chance to share with them the anonymous experiences of other women that I interviewed. I thought that this might break down some of the isolation experienced by women who require care in their homes. And I still think this a worthy undertaking. But it is too early for that. The state of research with recipients of care has for the most part ignored these voices; in concentrating on the experience of caregivers, research has inadvertently silenced the recipients. Too much is not known about women who receive homecare outside of the quantitative numbers of service delivery. I learned it is not possible to understand much about the real experience of homecare from two interviews. This is not a comment on the inadequacy of my interviewing but rather a comment on the inadequacy of what we already know about the experience. I had to be educated from the bottom up by Alexis because of the paucity of literature available. We know too little to investigate so shallowly.



Alexis' story was revealed layer by more trusting layer as we delved deeper into and revisited in more privileged detail events and issues in her life story. At the end of the second interview, which would have been the end of my research with Alexis if I followed my original research plan, few of the important details were revealed. I had an outline of her life and her daily routine, and her assessment of the formal homecare she was receiving. I had questions about the silent spaces I knew existed in her story. But her trust in me and the research process barely had time to develop before it would end. I had to prove to Alexis that I would do as I said I would. It was not until I read back to Alexis the transcript of the second interview that she allowed me into her life as an abused women. This revelation of course opened up whole expanses of questioning and mulling over the impact of what was, for her, an experience of exile. The impact of this exile on herself, her children, her family, and her community has a direct impact on her experience of homecare when she returned to PEI a disabled and poor woman. With this knowledge I became aware that I knew very little about my research participant and that she was now willing to share more deeply her story. We had reached a new level of trust that held open a door into her life. Turning away from this opportunity to do similar 'research lite' with three other women appeared inappropriate and disingenuous to the intent of the research initiative. There is so much to learn.

Of course Alexis' story is filtered through me as the research instrument. My stories and experiences affect how I understand those of Alexis'. My experiences of homecare with my parents has proven both a juxtaposition and a parallel to those of Alexis'. Understanding my own history in relation to Alexis has clarified for me the frailty of the opportunity we had to support and sustain my father's end of life journey and to be present with and participate in his death. I understand, now, how useful is the myth of the traditional family and how its valuing in the

dominant discourse and representation in social policy serves to trap and enslave women as caregivers and as care recipients. I understand from my own story how tenuous and unreliable is the care provided by families, even those without overt scars of abuse and abandonment. I understand more clearly about the myth making that backs up social policy and the need to expose it as a sham. Someone wins from the success of this myth-based social policy and it is not women, it is not the economically disadvantaged, and it is not the care recipient.

I began this thesis with a definition of homecare. I end with a description of homecare that elevates the rights of citizenship above those of the market. Ungerson describes it like this:

...carers and the people they care for have a joint project: to campaign for the development of support services that allow all of us who wish to remain in our own homes to do so. If such support services are of high enough quality and reliable enough, then the private aspects of care—the parts that contain the love and watchfulness—can flourish within a public framework, underwritten by the collectively guaranteed provision of caring services by the state. (As quoted in Aronson, 2000, p.62)

This life history research is important because it opens “a window into broader social and societal conditions” (Coles and Knowles, 2001, p.12) regarding senior women and their experience of homecare as it is currently constituted. The literature regarding homecare tells me that, in the Canadian context, senior women who dwell on the margins, economically, under the conditions of the welfare state are even further marginalized under the conditions of globalization. The ascendancy of the market has further diminished the value that the culture places on seniors; senior women, in particular, experience this devaluation most frequently. Under the conditions of globalization the state offloads public responsibilities and costs onto the

private lives of women in homes where care giving is expected to be performed as unpaid service. For homecare recipients this family care giving can be experienced as a number of negative effects including trading compliance for care and doing without needed care. Alexis' life history tells of decades in exile because of violence endemic in her families. Alexis' relationship with her children is damaged because of this violence and her escape to protect herself from it. It appears she is now being punished by the state for leaving this abusive relationship because it expects a caregiver to emerge from among her disaffected children. The state's narrowed definition of care needs, in this life history, translates into dangerous possibilities if accepted and potentially dangerous possibilities if not accepted.

The state exploits the myth of the family as favoured caregiver in the popular imagination, a myth that, as this research suggests, is deeply flawed. Both my stories of a family that is emotionally capable of providing care and Alexis' stories of a family emotionally damaged by social structures show the yawning canyon that divides the myth of family care giving from the reality. As Neysmith (2000) suggests, the myth of the family as caregiver has proven a useful tool to a state that is shifting toward a neo-liberal ideology of individualism and market supremacy. At the same time the myth serves the forces of regression by returning women to the home in the service of greater levels of unpaid reproductive care; neo-conservative ideology is served by this myth of family care giving, 'family' as a euphemism for 'women'.

How social policy translates into the private life of a woman in need of care in the home, how the personal is political, is the focus of this research. For Alexis, the meager services offered under social policy to serve her needs pose a threat to a woman who lives with fragile health and few care options. Because of the apartheid-like policies towards women inherent in social structures throughout her life Alexis now lives on the brink of poverty without money for needed

clothes, dentures, and appropriate food; she has no private pension and few economic reserves. Social policy forces her to spend much of her energy negotiating her care needs with social contacts who are recruited as stop gap caregivers to satisfy immediate needs. The work and energy required to engage with a constantly changing set of social contacts and to negotiate from them a level of care is not available to all care recipients. And, it is not available to Alexis when her health makes her feel out of sorts.

The work that Alexis engages in to negotiate her care is significant and the anger she feels at having her work thwarted is evident. The image of angry senior women resisting diminishment in their daily lives is an image that demands a larger response than that made under current social policy. Angry senior women is a model that needs visibility and voice through ongoing research and communicating to the popular imagination the image of what it is like to be a senior woman in need of care in the home. Like previous movements that claimed rage as a legitimate and active force in their protests, senior women's anger needs to be freed from the prohibitions and misconceptions that currently surround it. It is not a cantankerous or crotchety anger that is currently associated with senior women. Rather, it is, as Woodward says, a noble anger against the discriminations and diminishments of being a senior woman in need of care in her home. It is also the anger of women who see that their lives in old age reproduce the disadvantages and discriminations visited on women by social structures that lay out the design of our lives in this way. It is an anger that needs to erupt as a public testament to refute the silence of marginalization which senior women currently experience in this culture. If Alexis' life history can teach us anything, it is that structures that support sex and class oppression will not easily yield to demands made by senior women most of whom are poor. It demands a loud and long social critique that incorporates rage as its central concept and form of protest. This

may be the symbolic image that sustains it in the popular imagination.

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## Appendix

### Appendix A: Interview Guide

*Thank you for meeting with me. The purpose of these interviews is to explore what it is like to be an older woman who is receiving homecare on Prince Edward Island. We will have a conversation rather than a formal 'interview' about your life and your experiences as an older woman. I wish to know your experiences, your thoughts, your perceptions, and your assessment of homecare from your perspective as a recipient. As claimed in the informed consent form I will do everything I can to maintain the confidentiality and anonymity of this interview.*

#### 1) Biography

Please tell me about your life. I wish to know your route from birth to today including:

- where you were brought up,
- what did your parent's work at
- what are the ages of your brothers and sisters,
- where do they currently live,
- where and when you went to school,
- your work career,
- where did you live most of your adult life,
- if you married, what was your husband's work,
- do you have children,
- where do your children live?

## 2) Home Care Experience

1. What do you do over the course of a day?
2. What care are you receiving and from whom?
3. What is good about your home care experience and what would improve it?
4. How does your experience with homecare differ from your expectations of life as a senior?



## Appendix B: Information for Participants

Winter 2005

Dear Home Care Recipient,

In fulfilment of the thesis requirement toward a Master of Education degree from the University of Prince Edward Island I am conducting a research project aimed at understanding the experiences of older women receiving home care on Prince Edward Island.

I am interested in speaking with women over age 60 who receive care in the home either from a friend or relative or from a paid caregiver. Very little has been written about home care from the perspective and the experiences of the recipients. This unique research will add to knowledge about what it is like to receive care at home and what women care recipients feel they need in order to have the quality of life to which senior women are entitled. I would like to understand how your personal experiences with home care may have been affected by influences in earlier in your life.

Rather than a formal interview I am hoping we can have a conversation. There are no right or wrong answers. I am asking you just to talk about your experiences and your story as a senior women on Prince Edward Island. I will have a number of questions to begin our conversation but I expect to move away from these as our conversation follows your story. I will be asking questions about your biography and your home care experiences such as where you were brought up, what your parent's work was, what are the ages of your brothers and sisters, where do they currently live, where and when you went to school, your work career, where did you live most of your adult life, if you married, what was your husband's work, do you have children, where do



they life. Examples of questions about home care that I will be asking concern why you are receiving home care, what care are you receiving and from whom, is the care you are receiving sufficient, what other care do you require, what do you need in order to have the quality of life you wish, how do you describe being elderly and receiving care from others, how and where would you like to be living and what do you do over the course of a day?

You may benefit from the knowledge arising through the interview process and from the stories of other women who are in a similar homecare situation to your own.

If you agree to take part in this study, you will be asked to participate in two private interviews of less than two hours each at a convenient time and location--your home is a possibility. Another convenient location can also be arranged. The interviews will take place between 1 December 2004 and 1 February 2005. I will be audio taping the conversations with your permission and the tapes of our conversation will be typed out, word-for-word, to create a transcription of what we said. The transcription will be returned for you to check what was said and to make any changes or clear up errors or oversights on my part. When I return the transcript to you I will arrange for a second interview to ask new questions that have arisen from our earlier conversation. Once the transcriptions are completed, I will analyse what you and three other senior Prince Edward Island said about the experience of receiving home care. Only myself and my advisor at UPEI will have access to the transcripts.

Your participation in this study is entirely up to you. You are free to refuse to participate, to not answer any questions or withdraw from the study at any time without negative consequences to you. You have the freedom to not answer any question. I will ask that any information gathered up until that time be used for the final report. If you do not permit me to use the information, it will be destroyed immediately. It will simply be noted that a participant did not

5. Your real name will not be used at any point of information collection, or in the written thesis. Instead, your and other persons and place names involved will be given pseudonyms that will be used in all verbal and written records and reports.
6. If you grant permission for audiotaping, no audiotapes will be used for any other purpose than to do this thesis and will be destroyed or returned to you (at your discretion) three years after the completion of the thesis process.
7. Your participation in this research is voluntary; you have the right to withdraw at any point from the study, for any reason, and without any prejudice, and the information collected and records and reports written will be destroyed at your discretion.
8. You will receive a copy of the transcript to review for clarification or amendment of information.
9. You will have access to the final thesis from the Faculty of Education Resource Room at UPEI or may request a thesis summary.
10. You will receive a \$50 dollar honorarium following the second interview.

Do you grant permission to be audiotaped for this study? Yes\_\_\_\_\_ No\_\_\_\_\_

Do you grant permission to be quoted directly? Yes\_\_\_\_\_ No\_\_\_\_\_

I understand the statements in this letter and agree to participate in this research.

Participant's Signature:\_\_\_\_\_ Date:\_\_\_\_\_

Thank you for considering my request to participate in my study. You will be provided with a copy of the information letter and consent form.

### Appendix D: Script: Parish Nurse

Mrs./Ms.\_\_\_\_\_, a mature student studying in the Masters of Education program at UPEI is interested in speaking with older women who receive homecare about their experiences. She would like to talk to Island women about their lives and their experiences with aging.

I have an information letter that explains more about the research and what would be expected if you chose to participate. Participants will be awarded \$50 after the second interview.

Would you be interested in finding out more about this study?