ELDERCARE IN CONTEXT: NARRATIVE, GENDER, AND ETHNICITY

by

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ABSTRACT

This study is an investigation of informal elder caregiving among Canadians of Italian, Japanese, and Anglo ancestry who have links to the Vancouver area of British Columbia, Canada.

In this study, I explore the meanings attached to eldercare in the specific contexts of narrative, gender and ethnicity. In order to conduct the study, I analyzed transcripts generated in qualitative, in-depth interviews with 30 caregivers (24 women and 6 men). In addition, I employed interactive and observational techniques in care facilities, at support group meetings, during a course for caregivers, and in various community settings. I also wrote extensive fieldnotes and garnered information from academic sources, media reports, and popular culture.

The collected information is used to show how personal meanings are expressed through mixed-genre, co-constructed, dialogical (in the Bakhtinian sense) eldercare narratives that generally focus on a senior care-recipient who is a parent or spouse, his/her need for care, and the caregiving experience itself.

I argue that both differences and similarities occur in the meanings given to caregiving. Eldercare narratives are different yet similar. Each caregiver, care-recipient, and caregiving situation is unique, and each eldercare narrative reflects these unique differences. Yet there are also parallels and differences attributable to other factors. These other factors include caregivers' situated involvements with a problem-fraught health
care system, the social constructions of caregiving, ageing, gender, ethnicity, and class, and the character of narrative itself.

My findings have policy and practice implications. They are particularly valuable for alerting us to how we should listen to and interpret what caregivers are telling us about their emotionally-charged, and often physically-draining, unpaid work.
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PREFACE

My dissertation focuses on 30 people each of whom is looking after an elderly spouse or parent. Individual caregivers are mainly women and each is a Canadian of Anglo, Japanese, or Italian ancestry (See Appendix I). All have ties to Vancouver or other nearby locations in the British Columbia Lower Mainland.

Many qualitative studies address eldercare and gender (see Angus, 1994; Aronson, 1998; Kaden and McDaniel, 1990). Others address caregiving and ethnicity (see Gelfand, 1994; Rosenthal, 1986). In contrast, few studies examine caregiving and the intersection of gender and ethnicity. My dissertation aims to help fill this knowledge gap. But to me, filling the gap does not just mean compiling empirical facts. First and foremost, I want to learn about variations in the meanings that people develop in their narratives about taking care of an older person.

The primary argument of the dissertation is that elder caregiving has been too simply conceptualized. In the following pages, I suggest that if we allow more substantive and theoretical/methodological sophistication into our thinking, various stereotypes can be countered and new understandings can be forged. I advocate, therefore, the following shifts away from traditional studies:

a) Creating a text in which the voices of various individuals are heard;

b) Contextualizing personal narratives to include their dialogical relationships to social structures, cultural representations and public discourses;
c) Taking seriously the role of the researcher in co-producing personal narratives;

d) Disclosing to readers the positions from which authors are writing/speaking;

e) Examining the intersection of factors which influence caregiving experiences, such as gender, race/ethnicity, class, age, and so forth.

The elaboration of caregiving should render policy-making and professional and lay practices less--rather than more--difficult. This is because rich descriptions provide decision-makers with more nuanced and experience-near information from which to unravel perplexities, reveal pitfalls and, thereby, guide successful action.

As researchers, our access to the actual experiences of participants is circumscribed. In part, this is because language, power and theory mediate our experiences. Our realities are constructed using all these tools. Therefore, I focus on the representation of caregiving in narratives. That is, I begin my analysis in actual experiences as narrated. And to the extent possible, I retain the original words of the caregivers, although I have altered specific details for the sake of anonymity, confidentiality, and readability.

I think of personal narratives as responses to current discourses. Mikhail Bakhtin's work (Bakhtin, 1981, 1986, 1993) has been invaluable in helping me to realize that language is complex and dialogical, and that individual narratives are only monologues in a narrow sense. To understand their social nature,
and their social meanings, we must view them in the contexts in which they are produced and used.

I also use the work of Dorothy Smith. With women's standpoint methodology, Dorothy Smith (1996:171) has developed "a sociology for people" or "a sociology committed to inquiry into the actualities of the social as people live them." Smith (1996:172) writes that:

Women's standpoint means beginning in the actualities of people's lives as they experience them and a sociology for people developed from this point d'appui orients to the social as it organizes people's everyday/evernight living. It proposes to create a knowledge of the social grounded in people's experience of their own lives. It does not treat experience as knowledge, but as a place to begin inquiry. Speaking from experience speaks from the only site of consciousness—in an individual's own living, and hence as it is, and must be, embedded and active in social relations and organization that are not contained in what people can speak of directly.

I implement this methodology by beginning with the actualities of caregivers' lives as experienced and transformed into the language of personal narratives. Because I recognize that social analysis inevitably involves interpretation and expansion, I also go beyond the understandings and explanations of the caregivers—all the while trying to keep their concerns foremost.

I began my investigation of the problem of meaning by engaging caregivers in directed, semi-structured interviews. In comfortable settings, I asked individuals to tell me about their lives and caregiving experiences, while I simultaneously tape-recorded these conversations. I then looked for narratives or narrative fragments within the interview transcripts, and called these eldercare narratives.
Next I examined the texts of eldercare narratives and the processes by which they were created. My goal here was two-fold: to identify ideas and their expressions, and to explore my own role in co-creation. Afterwards I expanded my focus through critical personal narrative analysis in order to investigate how various ethnographical, geographical, and historical contexts could help account for the specifics of the eldercare narratives.

During my dissertation work, it also became apparent that I had a personal stake in what I was writing. This was apart from anything to do with formal education, work, and career. What I was learning about was my own history, society, and culture, and how the personal (my own as well as that of others) relates to the political. In other words, this is more than just a study of local caregivers. It is a study about self, others, difference, connection, suffering, silence, and power. It is about how gender, ethnicity, class and other putative differences keep all of us apart and disempowered, how individuals variously respond to and participate in cultural practices, and how we can use each others' contextualized narrative accounts to clarify our own predicaments.

I want to draw attention to how creative and clever the people are whom I interviewed, to emphasize the extent to which they can speak directly--frequently with insight and irony--about the positions they occupy. They seem able to recognize and analyze how their experiences and stories are socioculturally
embedded in time and space and shaped by "webs of mystification as well as significance" (Good, 1994:57).

This study also illustrates Gramsci's notion that hegemonies are fluid. Always occurring is a "moving balance" between mystification and demystification. Some individual caregivers may be perplexed by how caregiving is being constructed and dealt with, but many are aware that injustices are occurring which increasingly pose hardships on caregivers and the elderly in terms of their treatment by health care and social service systems.

In the dissertation I present data in the form of excerpts from eldercare narratives to query simple but controversial statements such as the following:

**Ethnic groups** expect to take care of their own.
**They live in extended families.**
To them, caregiving is natural and based on honour and filial piety.
**Ethnic women** are subservient.
**Ethnic family members** cooperate to provide care for elderly members.

Such formulations tend to: a) elide intra-group differences, thereby representing individuals as members of homogenized ethnocultural units; b) hide the very real moral and emotional dilemmas all caregivers (and often their families) experience; c) construct certain people as ethnic and inferior Others in contrast to so-called mainstream groups which are non-ethnic, and, therefore, Self, Canadian, superior, normal, logical, respectable, and so forth; d) gloss over the extent to which women are the main caregivers; and e) reproduce stereotypes of
ethnic women and their putative subservience in contrast to implied liberated Anglo women.

There are two ways of ordering our views of people in the world. One way is to seek out essential differences and to build conceptual, linguistic, and political schemes which reflect these sorting procedures. Kay Anderson provides a good example of this process regarding perceived, putative racial differences (from British Columbia in the late 1800s). Anderson (1991:46) states:

In the hands of British Columbia's early provincial politicians, the race idea was a useful idiom around which to forge a regional consciousness. Race was an influential language with which to cement the collective sense of an in-group, in part because it enabled politicians to concentrate into a 'counter-idea' everything that was thought to be in conflict with the building of an ideal community.

The second way of viewing people seeks out similarities and connections, considers differences between people as merely superficial or skin deep, and universalizes by averring that we share a universal human nature, and furthermore that this human nature is rational (Schor 1995:3).

What I want to suggest, however, is that both of these are untenable positions. On the one hand, underscoring difference hides deep connections between people, pits individuals and groups against one another, and forces false affirmation of dissimilarities—in cognition, morality, and emotionality. It provides the groundwork for exclusion, ethnocentrism, discrimination, and racism, classism, sexism, and ageism.

On the other hand, declaring that we share a homogeneous, rational human nature robs us of our individual humanity, strips
away cultural processes, and interferes with our ability to understand local situations and practices. Stressing our sameness allows us to develop hegemonic laws and institutions which apply to everyone everywhere without regard for the particularities of individual circumstances. For example, such a view underpins Western biomedicine with its insistence on universally-valid diagnostic categories, theories of disease causation, prognoses, and curing procedures.

To change this binary view, one must first recognize that there are complex relationships between people. There are both differences and connections between individuals and groups of individuals. But it is insufficient to investigate the ways in which we are the same and different. Rather we need to develop in-depth understandings of "the politics of difference" (Cornel West, 1993), that is, the multivalent meanings of similarities and differences, and why particular categorizations are emphasized. In other words, in the Canadian context of nation-building and global restructuring we need to ask how identifications of similarity/dissimilarity bestow privilege--and simultaneously exclude.

What the dissertation tries to demonstrate is how complex all cases of caregiving are and that they can be viewed as dialogical responses to hegemonic meanings (which have been attached to caregiving and the intersecting processes of race/ethnicity, gender, class, and age identification).
I also try to show how my research has wide significance. My findings have implications for theory and methodology, as well as policy and practice. Furthermore, my work makes women's issues prominent and it demystifies the glossing of women's work as family care.

Eldercare is not an isolated example of the disregard for women's work. Women's caring work of all kinds, in and outside the family--caring for children, the sick and disabled (of every age), the elderly, friends, and neighbours--remains largely unpaid, undervalued and invisible (Angus, 1994; Aronson, 1998; Canada, 1993). So, although my dissertation is about eldercare, I want it firmly understood that my larger goal is to render more visible the extent to which all women's free physical and emotional labour underwrites societal health and well-being.
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I would also like to acknowledge the help, encouragement and understanding given to me by caregivers, care-recipients, and staff members of various facilities and programs (none of whom, for reasons of confidentiality, I am able to mention by name), family, friends, colleagues and, in particular, my husband and colleague, Sam Migliore; friend and colleague, Rita Stern; and friends, Bill and Elaine Merrell.

Finally, I would not have been able to continue my studies without the support of the British Columbia Health Research Foundation which thankfully awarded me studentships for the academic years 1996-1997; 1997-1998; and 1998-1999.
We are educated to think of the world, and our lives, as being divided into separate and distinct compartments, each of which can be studied and understood in isolation from the other. We describe our physical environment as 'geography'; our past as 'history'; our customs, attitudes and beliefs as 'culture.' We divide our present into 'personal life,' 'family life,' 'working life,' 'political life.' Yet each day, as each of us goes about the business of living, we experience the interrelatedness--the synthetic totality--of all of these spheres that we so neatly cut up and package in their own little boxes and university faculties.

(Dara Culhane Speck, 1987)

For the word (and, consequently, for a human being) there is nothing more terrible than a lack of response.

(Mikhail Bakhtin, 1986)
CHAPTER 1 - ELDERCARE: A WOMEN'S ISSUE

"...caregivers' needs are so many and varied"
(Caregiver, 1998)

This dissertation is about the care of senior family members or what is being talked about increasingly here in industrially-advanced Canada of the late 20th Century as eldercare or simply caregiving. In the dissertation, rather than focus on what academics, politicians, journalists and policy-makers say about caregiving, I spotlight caregivers themselves. These caregivers are mostly women who struggle daily with the ongoing work and emotional entanglements which their caregiving entails (See discussions of caregiving in Angus, 1994; Aronson, 1998; Abel and Browner, 1998; Whalley Hammell, 1992; Lock, 1993). Caregivers' narratives are also situated in wider social and political contexts.

I introduce eldercare as a complex and timely topic. Its relationship to language, gender, race/ethnicity, class, positionality, co-construction and social structure each requires explication. One of my main concerns is how caregiving is being constructed amid health care system restructuring that makes women's increased unpaid informal care, such as family health care and eldercare, necessary. A goal of my dissertation, therefore, is to make visible how health care reforms, as well as demographic and family changes, are a primary reason for the increasing responsibilities of diverse women.
I also present caregiving as a *women's issue* (See Kaden and McDaniel, 1990; Sodei, 1993; Aronson, 1998) since the majority of both caregivers and care-receivers are women. Caregiving is underpinned by various ideologies, including the ideology of scarcity (Angus, 1994). This ideology concerns economic burden and the state's recent efforts to contain costs--for example, within the health care system. Deinstitutionalization has been a major strategy over the years and the current emphasis on self, family, community and home care continues this trend. In order to make deinstitutionalization an attractive proposition, in the ideology of scarcity, *family values* are stressed. Through glamorizing the family and emphasizing its positive qualities, women are urged to keep contributing their unpaid health-related labour to family well-being. The home is not viewed as a site at which violence, hate and oppression occur, but rather it is deemed to be a site of shelter, love and caring. As Angus (1994:36) notes:

> Normative conceptions about the home as a site of restful relaxation and the family as the locus of mutual help and caring inform the notion of family care and encourage its acceptance....(Angus, 1994:36)

Another ideology, the ideology of separate spheres, views the labour of women and men as occurring within separate work worlds (Smith, 1987:5). Women are said to make their main social contributions in the domestic realm (unpaid labour) whereas men make their major contributions outside the home (paid labour). In such a formulation, women are viewed as the appropriate nurturers and men as the appropriate breadwinners.
Most women already take on full responsibility for the health of family members, whether they are full-time homemakers or work full- or part-time outside the home (Canada, 1993:20). But much women's work is unseen, unacknowledged and framed in the gender-neutral language of family care (Stoller, 1994:187). If women's work is glossed as family care without clarification, then women's greater contribution to unpaid domestic work is rendered invisible, and women's caregiving is thereby devalued (Anderson and Elfert, 1989; Angus, 1994; Kaden and McDaniel, 1990).

**PURPOSE AND ORGANIZATION OF THE DISSERTATION**

The purpose of the dissertation is to examine the variety of meanings which are being given to caregiving by 24 women (and 6 men) of three different ethnocultural backgrounds. It is particularly necessary to hear what meanings individuals give to their caring work, rather than allowing experts to impose meanings for their own purposes. Caregivers' definitions and conceptions constitute valid alternative perspectives of the social world (Wittenstrom, 1996), and it is their assorted meanings upon which theories, compensation packages, and service programmes should be based. What is missing in most of the vast literature on caregiving is an examination of how, and to what extent, the intersection of gender, race/ethnicity, and class affects experience. Indeed, some authors even complain about a "limited focus on gender in aging research" (Kaden and McDaniel,
1990:5). My study, therefore, helps to fill a gap in our knowledge of the variations of caregiving in particular contexts.

Visibility and valuation are problems of all women's work, including mothering, cleaning, and healing. This is especially true of labour that has been designated as caring rather than work (Wittenstrom, 1996). Likely a major reason for this is because caring has been deemed to be part of women's natural function (see Messing, 1998:178). My dissertation is relevant for all caring work that women perform, therefore, not just elder caregiving.

For the dissertation, mainly I am interested in learning what eldercare narratives--generated in conversations with Canadians of Japanese, Italian, and Anglo ancestry--can tell us about participants' varied interpretations of caregiving. And since I am more generally interested in the sociocultural construction of caring and ageing, to an extent I also examine meaning-making in public discourse.

In Chapter 1 the topic of eldercare is introduced so that readers can orient themselves to some of its dimensions. In Chapter 2 I present aspects of my own positionality, information on eldercare as a women's issue, and matters arising from the positionality of particular groups of caregivers.

In Chapter 3 I discuss theoretical issues and how I am using personal narratives as a starting point from which to examine questions of cultural hegemony. This chapter presents the rationale for my study in terms of its research design and
perspective, and in it I present logical as well as personal and emotional reasons for undertaking the study.

Chapters 4, 5, and 6 are comprised of the eldercare narratives themselves, while I simultaneously inquire into fundamental methodological issues concerning co-construction. Here I examine contextualizing factors purposefully chosen on the basis of whether they have been identified, either by myself or caregivers, as significant to an understanding of eldercare (See Personal Narratives Group, 1989:23). Contexts examined include:

a) Language itself;
b) Narrator/researcher dynamics;
c) Intersections of race/ethnicity, gender and class;
d) Shifting health care ideologies/policies; and
e) Local/national/global/historical connections.

Family, emotion, and ageing have not been cited as separate contexts because these emerge as both textual and contextual elements which are usually taken-for-granted and integral components of all text/contexts being constructed. Their exclusion from selection also highlights the impossibility of any clean separation between text and context.

In Chapter 7 I explore methodological issues, research methods and theory construction. Chapter 8 concerns more practical issues: in the context of health system restructuring, I analyze policies and practices affecting caregivers and care-receivers.

My discussion is finalized in Chapter 9, where I summarize findings and their implications, identify possible limitations of the dissertation and make recommendations for future projects.
Positionality

A major part of the challenge of writing the dissertation lies in investigating the position from which I write. Through the research and writing, I problematize the meaning of being a woman in Canadian society and I examine my own experiences of being white, female, middle-class, and of mixed ethnicity. The dissertation is a narrative journey of discovery during which I try to make sense, through reflection and writing, of my own life, people around me, and the times and places in which we live. It is also an academic work, informed by my background in anthropology. It is, therefore, also a response to criticisms of the way in which anthropologists have represented themselves and others over the years.

In order to emphasize gender and power concerns I begin by calling caregiving a women's issue (See Kaden and McDaniel, 1990; Sodei, 1993; Aronson, 1998)--although I understand that women and their issues are both the same and different. Naming caregiving a women's issue risks other mystifications too. It falsely implies that other variables (such as race/ethnicity and class) are less centrally important than gender. Furthermore, it suggests that a single factor can sufficiently explain caregiving issues. Nonetheless, I use the word women politically, emphasizing similar connections to caregiving, with the recognition that the single term women binds together a diverse range of individuals and situations. In other words, although I call caregiving a women's issue, I still take seriously the call
to feminists to finally pay attention to "women's lives as marked by the simultaneous impact of gender, sexuality, race and class" (Frankenberg, 1993:52).

As a further part of my positionality, I want to draw attention to some recent developments in the study of ageing which affect how I view and study eldercare. Academic studies of ageing, caregiving, and gerontological issues deeply affect (and are affected by) how ageing and older persons are perceived and represented. At the local level, these perceptions shape the narratives that caregivers tell (about themselves, their work, and older relatives). In addition they affect how caregiving is being constructed within public domains. In response, therefore, to the ideas from recent scholarship in critical gerontology, I try to identify complexities, ambiguities, and contradictions in the way in which ageing is conceptualized and spoken about.

From my position, as a woman in globalizing systems of entrenched patriarchy, it seems essential that my point of departure is how and why elder caregiving can be understood as a women's issue. After discussing this, I plunge into a sea of various complications and examine how being perceived as an immigrant woman can pose special problems for the caregiver.

**Eldercare: A Women's Issue**

There is no denying that men are involved in some form of caregiving (male caregivers have been interviewed for this study, for example), and sometimes family members co-operate and share care. A case might be made, then, for making the family or
family caregiving the unit of analysis or focus of attention, as has been done in other discussions of caregiving (such as McKellin, 1995 and Perkinson, 1995).

One might even wish to talk about family culture—notwithstanding the fact that both family and culture are problematic concepts these days. A wide range of variables has been used to define the family, including household composition; economic, sexual and reproductive functions; and kinship ties and emotional bonds. And in public discourse, true families are nearly always two-parented, heterosexual, nurturing havens (Hale, 1995; Pratt, 1984; Coontz, 1992) which seem to mirror and promote the current conservative emphasis on a monolithic, nuclear family type and uniform family values. In contrast, Sylvia Hale (1995:341-364) recognizes a more contested family which is "the site of love, exploitation, and oppression." And historian Tamara Hareven (1991:95) even suggests there is an increasing appreciation of "the changing and diverse nature of the family, rendered fluid by shifts in internal age and gender configurations across regions and over time."

In recent years the concept of culture has also been queried and problematized (See Whittaker, 1992; Abu-Lughod, 1993). Although I struggle with the concept later in the dissertation, here let me note that too often ethnographers have represented culture without regard to either politics or poetics (Clifford and Marcus, 1986). They have used the concept of culture as a way of avoiding examination of the social contexts of inequality.
In addition, they have represented groups of people as isolated and homogeneous entities whose members are passively sharing cultural values, traditional knowledge, language, and a uniform worldview. James Clifford (1986:10) stresses the dynamism and fluidity of culture, however, and he notes its inability to be captured. He says:

'Cultures' do not stand still for their portraits. Attempts to make them do so always involve simplification and exclusion, selection of a temporal focus, the construction of a particular self-other relationship, and the imposition or negotiation of a power relationship.

At any rate, I reject the characterization of elder caregiving as a family matter whose culture can be easily grasped. This is because caregiving is primarily a women's issue. It affects growing numbers of women who make up the majority of caregivers and care-receivers. Within families, responsibility for eldercare usually falls upon daughters, daughters-in-law, wives, sisters, and other female relatives, and often a female primary caregiver shoulders most of the so-called burden. Eldercare should be viewed as part of a whole complex of women's work that is undervalued, invisible and unpaid (Angus, 1994).

It should be noted here that the majority of older people do not require care. Most are self-sufficient and in good health, but regardless of their health status, as Haim Hazan (1994:19-20) wryly notes:

...it is ageing itself that is seen as the disease. The social image of the entire phenomenon of ageing has been transformed into a pathology.
Also, we mystify ageing by viewing age as a leveller. Within countries such as Canada, differences among older people are greater than similarities, yet older persons are still lumped together under collective, non-gendered names, such as the elderly and the aged. Each such category Others and can be "used to sustain the social position it reflects" (Hazan, 1994:2).

When help is needed, women are the usual recipients of care (Kaden and McDaniel, 1990:3-26). This will increase as record numbers of women live beyond the age of 75 and into the years when disablement becomes prevalent. If an older person cannot manage, she or he is likely to turn to family, friends, and neighbours (in that order) (Kaden and McDaniel, 1990:7). Another consistent finding is that informal care constitutes up to 90% of the total care provided to elderly people, with approximately 10% being supplied by formal health care and social services (Aronson, [1990] 1998; Chappell, Strain and Blandford, 1986).

The terms informal and formal are becoming fuzzier, however. For example, wives, daughters and other family members are spending long, stressful hours providing care in formal institutions, such as long-term care facilities. One might rightly ask, therefore, whether such care is formal or informal? And what should be the criteria upon which these are distinguished?

Betty Kramer and Stuart Kipnis (1995:340) also note that, "Study after study documents that women provide significantly more assistance than men." In this regard, it is estimated that approximately 70% to 80% of caregivers are women (Mui, 1995:86).
Here in British Columbia a recent survey found that 73% of the province's 152,000 informal caregivers are women (British Columbia, 1996:88). In North America, adult daughters are the usual family caregivers and, compared to adult sons, daughters are much more likely to become so-called primary caregivers as well (Brody, 1985; Crawford, et al 1994; Mui, 1995:86).

Many caregivers are elderly themselves. Some of these people are spouses and usually wives, but in addition, many caregivers are offspring who are seniors. In an American study of seniors aged 65 years or older, 10% of the study sample also had "a child" over 65 years of age (Brody, 1985:20). Ironically, however, increasingly seniors are at risk of being perceived as economic burdens to their families and society. Older women seem particularly vulnerable to ageism and being viewed as old and useless. This is partly due to their greater numbers and their greater longevity (with its attendant disabilities and the increasing medicalization of ageing), as well as the general devaluation of women. But it is also due to their greater economic need, which is often derived from a lifetime of unpaid caregiving and service to others at the cost of a career and continuous paid employment.

Studies of caregiving also find gender differences in the actual performance of caregiving tasks. It has been reported that, for the most part, women carry out daily hands-on duties, such as bathing, dressing, toileting, cooking, and feeding, while men contribute more in the way of weekly, monthly, sporadic, or
episodic caring work, such as banking, transportation, yardwork, snow removal, and shopping (Kramer and Kipnis, 1995).

According to the literature, there are gender issues associated with the health consequences of caregiving, including the effects of stress—with women experiencing more negative consequences. Some authors state flatly that women are more apt to suffer mental and physical health problems as a result of caregiving (Angus, 1994). But it has also been suggested that levels of stress and burden are similar for female and male carers, despite differences in tasks. Ada Mui's study (1995) indicates that although daughters experience greater "perceived emotional burden" than sons, this may stem from situational variables, such as resource availability and perceived interference with paid work. But various authors (Angus, 1994; Lock, 1993; Whalley Hammell, 1992; Aronson, [1990] 1998) draw attention to the powerful mix of feelings and work, love and labour, of which women's caregiving is composed. Jan Angus (1994:31) cautions that:

This entanglement of emotion and labour, together with normative expectations of women, may lead to feelings of guilt on the part of those who are unable to perform caring work for family or who find the work unpleasant and frustrating.

Recently "caregiver research has begun to shift...from caregiver stress or burden to the 'harder' outcomes of caregiver morbidity, both psychiatric and physical" (Biegel and Blum, 1990). And it seems certain now that caregiving soon will be undeniably linked to various health problems.
Karen Whalley Hammell (1992) also points to the critical issue of women carers whose husbands have become suddenly disabled due to accidents or strokes, for example. On top of reciprocal emotional bonds which complicate care, Whalley Hammell notes that often women have virtually no choice in whether or not they will take on the caregiver role. Frequently it is just assumed by professionals that on discharge a person will return to the community and to his family.

Another issue women caregivers face concerns paid employment. Women are more likely than men to quit jobs, reduce working hours, and put careers "on hold" in order to accommodate caregiving (Canada, 1993). And whether women are engaged in paid labour or not, they provide identical levels of care. This means that women often shoulder "double burdens" in terms of paid and unpaid labour (Angus, 1994; British Columbia, 1996). Rather than quitting their jobs, they continue to struggle with dual workloads. Like men, women derive self-esteem from their jobs as well as present and future economic benefit. This is a time in history when there are more women in the workforce than ever before. Yet just as some women are beginning to see a glimmer of hope regarding justice in the workplace (in terms of equitable employment opportunities and competitive pay grades), they are simultaneously being urged to go back into their homes to give more care and consequently to risk financial losses in addition to health breakdowns.
Elaine Brody (1985) notes that "parent care" has become a "normative family stress." Although this phrase hides heterogeneity, glosses women's contributions to caregiving, and constructs the experience as uniformly stressful, Brody does draw attention to the fact that caregiving has become an extremely common family experience. She debunks the popular myth which asserts that, "In the 'good old days' people took care of their loved ones, whereas today nobody really cares." Nowadays, says Brody, there are more women engaged in more caregiving (and more difficult caregiving) than ever before. She maintains that the persistence of this myth underpins women's failed attempts to receive justice for their caregiving efforts. Writing about social policy in the USA, Brody (1985:27) says,

The myth is being invoked as a rationale for a philosophy that would shrink the formal support system and encourage its non-use to save public funds.

She goes on to warn that, "Overburdening family members can increase the costs to the community of the mental and physical health problems they experience as a result" (1985:27).

**Eldercare: Complex Issues**

Apart from the gender issues described above, throughout the immense caregiving literature there are scattered references to what I call more complex issues of certain populations. These include issues related to groups or aggregates of elderly people who are childless, never-married, homosexual, homeless, or mentally-ill. Within these groups there are complicated issues to do with such matters as family, poverty, and housing, which
have sometimes been ignored by planners and policy-makers. Caring for an elderly member of such a population, as for example a homeless person with Alzheimer's Disease or a First Nations' elder who has experienced residential school abuse (Day, 1999), may involve solving some especially difficult problems. But what I would like to discuss are some of the special caregiving issues in the lives of immigrants and members of racialized/ethnicized groups. The neglect of this topic is a major shortcoming of the gerontological literature.

In Canada, all non-Anglo or non-white people tend to be perceived as immigrants, even if they were born in Canada or entered the country 60 years ago. This is an example of a word--the word immigrant--taking on a certain evaluative connotation and then being used for purposes of identification and exclusion. Bonnie Honig (1998:1) reminds us, however, that immigrants are variously evaluated; the term immigrant has multiple and diverse accents. She describes how people already established as full citizens tend to view immigrants with ambivalence. In addition to negative stereotypes which cast them as job-stealers and gangsters, immigrants are also seen as embodying energy, fresh ideas, and strong family values--all the things many North Americans feel we have lost and wish to regain. Immigrants are viewed as having chosen Canada or the United States (or whatever country they migrate to), and this tells disgruntled local citizens that the place is still worth living in. Immigrants, as Honig argues, symbolize the positive qualities of revitalization,
growth and prosperity and, simultaneously, negative characteristics such as conservatism, stagnation and poverty.

Here in British Columbia a somewhat similar discourse concerns the economic value of people who are perceived as immigrants. They are seemingly both loved and despised. Many people credit immigration, especially from Hong Kong in recent years, with producing a strong British Columbian economy, while the rest of the country foundered. Yet at the same time, racism flourishes and immigrants are still demonized and blamed for a variety of problems from building large monster houses to poor driving.

Despite the ambiguities surrounding *immigrants*, however, I share Peter Li's (1988:134) view (and complaint) that ethnicity and race have a market value under capitalism. He says (1988:134) that "employers can decide to pay some ethnic and racial groups less, even if they have the same qualifications as others" and he adds that:

In this way, it is the social evaluations of ethnicity and race, and not ethnicity and race themselves, which are the grounds for differential rewards. Discrimination then, is justified on the basis of assumed cultural and physical differences, and ethnicity provides a convenient rationale for labour segregation and exploitation.

Clearly the interplay of race/ethnicity and class affects women and their work. If women are perceived as immigrant women, they are frequently channelled into particular jobs. Although technically the term *immigrant women* refers to all women who hold landed immigrant status, women perceived as immigrant women are generally those who are perceived as coming from Third World
countries and who are members of so-called "visible minority groups" (Hale, 1995:443). Women who are white and English-speaking are not usually so viewed.

**Immigrant women** may end up anywhere in the labour market hierarchy, but frequently they are channelled into jobs as housekeepers, nannies, cleaners, and factory or agricultural workers, or they may work at piecemeal sewing at home (for example, see Anderson, 1987; Ng, 1986; and Ng, 1988).

Dan Hiebert (1999) recently conducted a study of local labour market segmentation in three Canadian cities (Montreal, Toronto, and Vancouver). The statistics he examined show complicated labour market patterns at the local level in each of the three cities, but they also suggest that people are not always adversely affected by their immigrant status. For example, in Vancouver he found that women and men of British origin are "fairly evenly distributed across the labor market," women of Vietnamese origin are "highly concentrated in manual occupations in manufacturing," "Jewish women in social sciences, law, teaching, and health care (as doctors)," while "Indo-Canadian women [are concentrated] in farming and manufacturing."

Nevertheless, the overall picture prompts Hiebert (1999:23-24) to state the following:

...immigrant and visible-minority women receive fewer benefits from education than they should; men and women of color occupy more than their share of 'secondary' occupations; and immigrant women of color are frequently locked into the least-paid, least-secure jobs.

In short, while the labour market variously responds to
"immigrant and visible-minority women," and those perceived as immigrants, there are some undeniable disadvantages to being so perceived and positioned.

A myth also exists that Othered families, such as so-called ethnic families, are generally extended and are always able and willing to take care of their own at home. Those families portrayed as non-ethnic and non-immigrant, however, are conversely thought to be nuclear, and less able and willing to caregive. Services may be funnelled, therefore, away from families who need help the most, towards those more privileged by virtue of their greater economic, social, and linguistic resources.

The literature is incomplete on many family-related issues (Gelfand, 1994), but several points need to be raised. For example, large, traditional, extended families may never have been a feature of the ethnocultural group being studied (Gelfand, 1994)—either in their country of origin or in Canada. If extended families do exist in Canada, these may not be traditional. Instead, they may merely be an adaptational response to harsh conditions and living together may be temporarily endured for financial or other reasons. Alternatively, even generations after immigration some groups may display traditional patterns of emotional closeness and physical proximity. It should be remembered too that multiple, intersecting factors now influence these residence patterns (Gelfand, 1994).
Family is a term which has been variously defined, as mentioned previously. Families are exceptionally diverse. Also, the reasons for their similarities and differences are complex. In addition, as Rosemary O'Day (1994:xv) states, there is a gap between theories of the family, on the one hand, and the characteristics of actual families on the other. Another point that needs to be stressed is that ethnic groups and ethnic communities are not homogeneous entities. They are hybrid and fluid, and there is a huge amount of interaction between members of all groups.

Sometimes there are barriers to receiving appropriate health and home care services. These may be easily removed. Alternatively, there are situations where culturally sensitive/culturally safe care seems virtually impossible to achieve due to cultural perceptions as well as material conditions. In An Error in Judgement: The Politics of Medical Care in An Indian/White Community (1987), Dara Culhane Speck describes the politics of a local health care system in British Columbia. She demonstrates how difficult it can be for post-colonial Native people to achieve non-racist, non-sexist, non-paternalistic care due to the entrenchment of racism and sexism.

Race/ethnicity and cultural diversity have been ignored by gerontologists, or dealt with only simplistically, until relatively recently. For example, in this connection, Emily K. Abel and C.H. Browner (1998:316) state that there is still "an
urgent need for research examining how factors of class and race affect the caregiving experience."

Canadian sociologist K. Victor Ujimoto examines the topics of ageing, ethnicity, and health (1987). He views some theories of ageing as Eurocentric. For example, Ujimoto says that one gerontological theory, activity theory, posits that seniors need to maintain multiple social roles and keep physically and psychologically active after retirement in order to maintain well-being. He claims that the theory does not take political considerations into account. Ujimoto (1987:126) maintains that for Canadians of Japanese heritage:

The historical aspects of prejudice, discrimination and concomitant racial segregation into concentration and internment camps experienced by the Japanese-Canadians minimized their optional role resources in their later life. A result was that as one aged and retired from the work force, compensatory activities did not take place readily.

Then he concludes with a major point:

The theory does not address the relationship between the social structural conditions and what aged ethnic minorities are or are not able to do. (Ujimoto 1987:126)

In Ujimoto's article, however, as in much traditional research on ageing and other work in the human sciences in general, race/ethnicity, gender, and class are not approached together as intersections.

This kind of omission of complexity is underscored by writers such as Roxana Ng and Himani Bannerji (See Returning the Gaze: Essays on Racism, Feminism, and Politics, Bannerji, 1993). Ng (1993:182-196), for example, says that women who are identified as visible minority immigrant women frequently feel
left out. Too often their interests are subsumed under those of immigrant men (especially community leaders). Within women's groups their concerns are also sometimes viewed as marginal. Furthermore, Ng decries the way in which researchers treat race, ethnicity, gender, and class as distinct categories, separate from any integrating conceptual framework. Her view is that sexism, racism, and class-based labouring are processes which ensure the retention of white supremacy and allow Canada to exist as a white nation.

Caregiving in ethnocultural groups is shrouded in myths and stereotypes. Often people hold the belief that particular groups always take care of their own without hardship. For example, it may be thought that people of particular ethnocultural backgrounds follow customs of filial piety, filial harmony and filial sacrifice (see Kyu-Taik Sung, 1994). These customs are then imagined to force individuals to serve the parental generation without fail. And, alternatively, certain groups are said to be cold-blooded: they easily push children out on their own, have little allegiance to ageing seniors, and are quick to dump their seniors in nursing homes. Similarly, not only is there a widespread misperception that males are incapable of providing care, but it is thought that males from certain ethnic groups never involve themselves in personal care. Certain ethnic females, and this includes Asian and Italian women, are perceived as uneducated, nurturing, used to hard work, compliant, docile, passive, and as having few interests outside the home (except
perhaps religion). And such characteristics are perceived as making them perfect natural caregivers.

Such ideas constitute "common sense racism." Sylvia Hale (1995:444-445) summarizes ideas about this everyday racism. She notes, for example, that women perceived as immigrant are routinely ushered into a narrow range of occupations in the lower echelons of the workforce. And media, government, and sociological accounts of immigrant women lay the groundwork for stereotypes (which facilitate further channelling). Immigrant women are thereby stereotypically ascribed with qualities--such as putative positions of powerlessness within the family--which are then used to justify their placement in the labour force and their suitability for so-called family caregiving.

SUMMARY

The whole area of caregiving and its intersection with factors such as gender, race/ethnicity, and class needs to be investigated. We especially need to view caregiving as a women's issue and demonstrate how gender interacts with other factors, especially race/ethnicity and class. It is imperative, therefore, that we seek answers to questions such as the following: Why do people caregive (and why do more women than men give care)? What have been people's experiences? And, what effects do they perceive to follow from these experiences?

In this first chapter, I have introduced the topic of caregiving and provided background information which informs my thinking and research. I have also outlined the purpose and
organization of the dissertation, and noted some aspects of my positionality.

In addition I described why I see caregiving as a women's issue and I drew attention to the ways in which caregivers are variously positioned in terms of gender, race/ethnicity, class and experience. In the dissertation, I use the term women in a political way to signify commonality. But it is also used with the recognition that the rich diversity of women's lives is being glossed thereby. In this connection, my dissertation seeks to make up for necessarily universalizing women in this manner by simultaneously illustrating the variety and complexity of women's lives, experiences, and narratives. This allows women to be seen as both the same and different.

In the chapter following, I describe how I use theoretical perspectives on textual analysis, and in particular the ideas of Mikhail Bakhtin, to formulate a way of analyzing my interview transcripts. I call my strategy critical personal narrative analysis.
Notes

Bryan Green and other researchers are critical of mainstream gerontology. Green claims that through the production of formal, empiricist research--coupled with the uncritical use of paradigmatic concepts and categories--discovery in the field of gerontology has been foreclosed. He states that although the possibilities for sophisticated scientific study exist, gerontologists make assumptions which interrupt knowledge-production. For example, Green (1993:179) maintains that:

Specific openings to critical reflection are built into gerontology by its methodological commitment to scientific inquiry (meaning inquiry in the natural science mode).... The commonplaces of scientific method ensure places of prescribed critical reflection in the field. The very commitment, however, that allows and prescribes these openings carries with it presuppositions that act as serious closures on reflection.

He is particularly critical of the assumptions that social reality can be represented in objective measures and that there exists a "unity of science" which allows the unproblematical transfer of methods from the natural to the social sciences.

Turning to caregiving, Haim Hazan (1994:17) also notes that:

The social discourse on ageing involves a vocabulary that combines moral order with practical needs: 'handling', 'managing', 'organizing', 'looking after', 'caring for', 'placing' and 'planning'.

I count caregiver and care-receiver as related to this discourse. These words suggest dichotomous active/passive, one-way flows of support. They gloss recognition that all relationships, social interactions, and communications involve dialogue and reciprocity, and instead they construct the dyadic relationship in simple, manageable, easy terms.

To make matters worse, Green focuses on the construction of ageing as a social problem and on how theoretical concepts such as the continuum of care are used. He notes (1993:82) that:

...the continuum of care is not simply a response to prior needs of the old, it is, in conjunction with the dependency continuum, a means of making the old a determinate knowledge object.

Hazan (1994) has called some constructions in the language of ageing "self-subversive." I agree, and therefore I write within a dilemma. But I use words such as caregiver and eldercare to remain consistent with other studies as well as to avoid awkward sentence constructions. And many caregivers themselves have adopted these terms and use them in connection with themselves, others, and caring.

Still, I am acutely aware of how caregivers and older people are being short-changed by one-sided constructions and derogatory evaluative accents and overtones. My hope, therefore, is that my study at least will draw attention to the intellectual and
political problems which can arise when narrowing definitions are applied to complex phenomena.
A rich description of an immediate experience is an indispensable point of beginning, but it must expand into a complex analysis of forms of social mediation.

(Himani Bannerji, 1995)

At the beginning of Writing Culture, James Clifford quotes Barthes as saying,

...To do something interdisciplinary it's not enough to choose a 'subject' (a theme) and gather around it two or three sciences. Interdisciplinarity consists in creating a new object that belongs to no one.

(Roland Barthes quoted in Clifford, 1986:1)

Following these instructions, in my interdisciplinary work I have not just gathered disciplines around a topic. Instead I have attempted to create a new object, something uniquely mine. The creation of this new object involves applying what I call critical personal narrative analysis to the study of caregiving and eldercare. Critical personal narrative analysis begins with the complexity of narrated experience, then examines how this experience is linked to positionality, co-production, patterns in a body of narratives, larger configurations, power, and a strong reflexive component.

My goal, however, is not to create a neat synthesis. My dissertation is messy because I borrow from a number of qualitative research traditions developed, for example, in ethnography, biography, and literary criticism. As such, the dissertation is more like an expanding collage than a seamless portrait.

The formulation of critical personal narrative analysis, and my dissertation in general, also contain deliberate gaps which
can be read as *messiness* in the sense that George Marcus (1994:567) uses the concept: a messy text has "a contingent openness as to the boundaries of the object of study."

I have not set out to revamp disciplines either, even if this were possible. Rather, I have tried to build bridges across and between disciplines, seeking points of agreement between opposing views--including those within broad disciplines. In developing ideas about a critical personal narrative analysis, my aim is to show that there are sound, if complex, ways of linking the individual to larger worlds. I try to make connections between research perspectives in the health sciences, gerontology, women's studies, anthropology and sociology, literary studies and cultural studies in order to identify the processes through which meanings are being given to caregiving. What my dissertation also does is invite response.

Complex issues require complex answers. Simple explanations will not resolve difficult disputes nor solve complicated problems. In my dissertation, therefore, I try to orient myself to interdisciplinarity, dialogue, interconnections, bridging, fluidity, language, and the social world as a "kaleidoscope of power struggles which can never be transcended" (Craib, 1992:184).

**NARRATIVE**

In this section I review various characteristics of narrative which I have used in the context of my dissertation. These include its universality, multiple definitions,
relationship to general discourse and texts, and most importantly, its basic role in meaning-construction.

Many authors claim that narrative is universal. For example, J. Hillis Miller (1995:66) writes that,

Surely there is no human culture, however 'primitive,' without its stories and habits of storytelling, its myths of the origin of the world, its legends of the tribe or groups of stories about folk heroes.

And Nancy Walker (1993:117) even maintains that narrative keeps us alive when she says that:

...narrative keeps alive for our imaginations the real or fictional experiences of human existence; it provides a complex record of consciousness that constitutes human history. If we live by telling stories, we also remain alive in the stories that have been told.

But what is narrative? I will have to personalize this question because narrative is polysemic (Ricoeur, 1991b:70).² It is given a variety of definitions and below I specify how I am using it.

I consider narrative to be a particular form of discourse. To be more specific, it is a form of discourse which has been usefully characterized by Ricoeur. He states that:

...any narrative combines, in varying proportions, two dimensions: a chronological dimension and a non-chronological dimension...the activity of narrating does not consist simply in adding episodes to one another; it also constructs meaningful totalities out of scattered events. The art of narrating, as well as the corresponding art of following a story, therefore require that we are able to extract a configuration from a succession....This complex structure implies that the most humble narrative is always more than a chronological series of events.

(Paul Ricoeur quoted in Mishler, 1986:148)

This is the definition that comes to mind whenever I try to identify narratives in an interview or interview transcript.
That is, instead of distinguishing just a succession of events, I listen for/look for configurations which I deem to have meaning.

As Nancy Walker (1993:118) reminds us, however, it cannot be assumed that there is one true message or meaning within a story. This is an exceptionally important point. Walker insists that multiple meanings are created through the interaction of author, text, and reader. Although Walker's point is salutary, especially to those who think that "hidden at the heart of a story, waiting to be sprung loose like a jack-in-the-box, is a secret 'message'" (New and Rosengarten 1991:485), her view may still be simplistic. How we can talk about author, text and reader and their interactions needs further clarification.

To give some indication of this three-way process of meaning-making, focus for a moment on the reader. Reading is an interpretative process. As readers interact with texts they are not set-up video-cameras that merely register and record data. When I read, I am framing, decoding, translating, and interpreting second by second. I can also re-read by skipping back a few lines or pages. All the while I ponder proposed meanings and evaluate ideas from my unique position in the world. At some level, readers (and listeners) flexibly respond, cognitively, emotionally and bodily to the most boring or banal of texts.

Narratives are generally told in the past tense during which the narrator not only reports on a series of events, but offers reasons why events unfolded as they did: how they began, what happened next and after that, and how they ended.
Edward Said (1985), however, discusses how we only choose and accept a beginning point long after we have begun. That is, we retrospectively construct beginning points to explain the present and to justify future actions. He also concludes that there are really two kinds of beginnings which are like the opposite sides of a coin. One Said (1985:76) calls "temporary and transitive"; it "foresees a continuity that flows from it." From this beginning, "Thoughts then appear related to one another in a meaningful series of constantly experienced moments."

The second kind of beginning aligns itself with what has not been said and with future trajectories. Its source is what is left over after a narrative is seemingly finished. Of this beginning, Said (1985:77) comments that: "It is perhaps our permanent concession as finite minds to an ungraspable absolute." Said (1985:78) also notes that it is this second kind of beginning and its very openness which "makes us--and with us, our world--possible as a vessel of significance."

Narrative beginnings, middles and endings seem always chosen for particular purposes, then, including the desire to tell a good story or to justify a controversial action. Only retrospectively can we identify which beginnings seem to have initiated our present-day endings, which events significantly have shaped our present circumstances, and when events come to an end. In a nutshell, as Kierkegaard notes: "Life is lived forward but it is understood backward" (quoted in Geertz, 1995:166).
Future happenings modify how we view the past and the present. These happenings require us to go back and modify our narratives to explain and give meaning to altered conditions and situations. This process can be seen clearly in illness narratives. After a devastating medical diagnosis, half-forgotten events that previously seemed unworthy of mention are often reinterpreted as highly significant beginning signs and symptoms of sickness (See Williams, 1984 and Good, 1994).

Re-interpretation and narrative reconstruction can be glimpsed in eldercare narratives too. The following fragment from one of my interview transcripts illustrates many of the foregoing points. In this excerpt, Maria narrates the story of her mother’s death:

Oh, I think she wanted to die. She just was not happy. And 94, and--I don't know: are we the type of beings that can't face reality or what? But we all went home and she died in her sleep. I felt I should have been there. I kind of felt she was going to go because she wanted to go. Now she was hot, and my brother was fanning her, and my other brothers were standing around and, um, then we all went home. We should have stayed. I thought we should have stayed, you know. Maybe if the nurses had suggested, Why don't you stay? But anyway, I think she was happy to go.

Here the narrator not only describes a sequence of events, she speculates as to why they occurred as they did, all the while interpreting, constructing meanings, and attributing motives and blame.

In this fragment, the narrator specifies the events leading up to and following her mother's death, beginning with the point that her mother wanted to die. This is a selected point; it occurs just after a discussion of her mother's at-home care,
placement in a facility, a hairline fracture, movement to a second facility, plus the overall discussion of Maria's lifelong participation in caregiving, which has caused feelings of both pride and guilt.

Said's unspoken, "ungraspable absolute" beginning-at-the-end of this short tale concerns questions Maria raises in her comments. That is, what kind of beings are we? Are human beings unable to face reality or what? In other words, what is human nature and what is the relationship between reality and consciousness? And the all-encompassing "or what?" To seek answers to questions such as these would be to embark on an expansive study of both poetic and political understandings of human nature, perhaps to push past Maria's caregiving into the mists of evolutionary time as well as into the territory of the divine. Ultimately answers would be "ungraspable." At any rate, we are left at the end of Maria's narrative with a new beginning prompted by a fresh series of unanswered and unanswerable questions.

Coming back to the here and now, however, narrative analysis is currently popular in the human sciences, as well as within a variety of other disciplines and fields. For example, medicine and narrative is the joint topic of works by Kathryn Montgomery Hunter; Byron Good; Oliver Sacks; Arthur Kleinman; Arthur Frank and many others. Recently researchers have made the discovery that narrative elements are important in almost all texts, including those previously deemed to be purely scientific or
factual. Nowadays narrative analysis, variously construed, is used to identify meaning in everything from illness, medical and psychiatric cases, news reports, advertisements, ethnographic accounts, historical reconstructions, and many other non-literary texts.

Gérard Genette (1988:13) claims that the following divisions are well-accepted:

*story* (the totality of the narrated events), *narrative* (the discourse, oral or written, that narrates them), and *narrating* (the real or fictive act that produces that discourse--in other words, the very fact of recounting).

Other authors, however, make little or no distinction between *narrative* and related concepts. For instance, D. E. Polkinghorne (1988:13) not only uses *narrative, story, tale* and *histories* interchangeably, he says:

'Narrative' can refer to the process of making a story, to the cognitive scheme of the story, or to the result of the process--also called 'stories,' 'tales,' or 'histories.'

My own view is closer to Polkinghorne's than to Genette's. Fine distinctions seem to serve no useful purpose in my analyses since my meanings seem clear from the contexts in which I recognize and use the terms. Narrative can be contrasted with unconfigured facts or series of events, such as chronicles or annals. These are not what I am seeking. What I am interested in are configurations of "meaningful totalities" in which lived experience is recounted and, like Polkinghorne, I consider terms such as *narrative, story-telling, stories, tales, histories, and so forth all to be useful."
Another point I want to raise is that the I who is narrating a story is not identical with the actual author who in real-life experience creates the text. Nor is the I identical with the image of the author (whose presence is felt in the text), for that image is also created by the actually-writing/speaking author (Bakhtin, 1986:109). I stands for the variously-experienced self (or selves) of an individual speaker drawn together into a single word. I is a vehicle used to give unity to a speaker's viewpoint in the context of a specific communicative event in a particular time and place. In essence it is a site at which an individual struggles to bestow meaning on what Bakhtin (1993:2) calls "actually lived and experienced life." I refer to this as a struggle, after Bakhtin, because as he rightly notes:

> When someone else's ideological discourse is internally persuasive for us and acknowledged by us, entirely different possibilities open up. Such discourse is of decisive significance in the evolution of an individual consciousness: consciousness awakens to independent ideological life precisely in a world of alien discourses surrounding it, and from which it cannot initially separate itself; the process of distinguishing between one's own and another's discourse, one's own and another's thought, is activated rather late in development. When thought begins to work in an independent, experimenting and discriminating way, what first occurs is a separation between internally persuasive discourse and authoritarian enforced discourse, along with a rejection of those congeries of discourses that do not matter to us, that do not touch us. (Bakhtin, 1981:345)

It seems, therefore, that an emergent I draws this struggle together, although it is always a difficult, conflictual process to think one's own thoughts, to resist hegemonies, and to create and maintain one's own interpretative meanings.
Polkinghorne (1988:9) claims that "research into meaning is the most basic of all inquiry"—but the term meaning needs explication. "Meaning' is...a very fuzzy concept which itself has many meanings" (Dijk 1997:8). Byron Good (1994:98-101) tells the story of a young patient who is a Jehovah's Witness. He emphasizes the positioned, relational quality of meaning by showing that she and her doctor hold distinct ideas about the meaning of blood, primarily based on their interpretations of its religious and medical qualities. Good says, therefore, that there is "a discrepancy between medical and religious formulations of reality--within a single culture, and in relation to a clear, physiological symptom" (Good 1994:101). This example illustrates an ideational definition of meaning. I view these as native or personal interpretations, which are linked to ideological systems.

In her glossary-definition of meaninglessness, Sylvia Hale (1995:520) suggests a behavioural definition of meaning. She notes that meaninglessness refers to an absence of worthwhile activity. Hale (1995:509) also makes connections with the Marxist term, alienation as follows:

Marx uses this term [alienation] to refer to the dehumanizing character of social relations, particularly under capitalism. The term is used more generally to describe a syndrome or combination of characteristics including powerlessness, meaninglessness, isolation, and self-estrangement.

Hale's discussion discloses, however, that it is imperative to specify whose meanings are being privileged: the participant's (the emic) or the researcher's (the etic). This distinction is
necessary so that readers can tell whether it is the worker or the researcher who thinks a particular activity—such as caregiving—is worthwhile, meaningful, or alienating. Whether meaning is defined in terms of ideas or behaviours, it still needs to be made clear whose thoughts and actions are being described.

Meaning can also be framed by ontology or spirituality. Gareth Williams (1984) discusses meanings which are linked to telos (or purpose and direction in life). He uses case material from three individuals whose lives have been profoundly disrupted by severe arthritis. Williams argues that through the selective identification of reference points, a narrator is able to tell a story which is coherent and makes sense. The individual affirms through this narrative reconstruction of life events that, despite illness, life still has meaning or telos.

I also see parallels between eldercare narratives and illness narratives or stories about individual illness episodes. Medical anthropologists and sociologists such as Byron Good, Arthur Kleinman, Margaret Lock, Arthur Frank, and Gareth Williams maintain that illness narratives serve the vital purpose of restoring a sense of meaning to the lives of those who are suffering. For example, Good (1994) writes about the power of narrative to remake broken lifeworlds, and Williams's (1984) notion of narrative reconstruction involves re-interpretation of life events after sickness. Williams states (1984:197) that:
Narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society.

Laurie Price (1995:466) also claims that illness narratives bolster self-identity. She advises that although "key qualities and characteristics of the self vary cross-culturally," life narratives present ethical positions, as well as suggest possibilities for appropriate behaviour, and in so doing play an important role in "establishing the moral value of that self."

Price (1987:315) notes that Ecuadorian illness stories provide a vehicle for caregiving performance evaluation. When narrated by the caretaker, the implicit messages of the story tend to be, "I did the right thing" and "I care deeply." Price (1987:315) concludes that:

This public declaration constitutes a way of negotiating the meaning of the illness events and may be an important source of social validation for the narrator.

In a similar vein, Sam Migliore suggests that among Sicilian Canadians he interviewed, one function of illness stories is to draw attention to suffering—of both care-recipient and caregiver. When the caregiver tells the illness story, the implicit message is, "The person I'm caring for is suffering—but I'm suffering too" (Migliore, 1998).

In analyzing the eldercare narratives, I am aware that the narrator and addressees hold socioculturally-shaped expectations about themes, and stories, and how these will be presented, in terms of a chronological dimension and beginning, middle, and
ending, for example. The meanings of elder caregiving, therefore, do not simply reside in texts. Furthermore, although I understand that narratives can function to remake lifeworlds, restore *telos*, craft identities, justify actions, and plead for assistance, I believe there are endless other functions they could perform, each of which would occur within particular and unique situations. In this connection, I am suggesting that content, form and function emerge in a shifting, negotiable fashion through the telling itself as narrators frame their stories to elicit particular responses which will always be interpreted in multiple ways.

A point I want to underscore is that interpretation and understanding are always positioned and meaning is always constructed through experience. Byron Good (1994:140) suggests that:

> We understand the experience of others in some measure by the experiences provoked in us when we hear such stories, experiences which are affective, sensual, and embodied.

Our understandings, and the meanings we, as listeners and readers, attach to the words of others are always unique and positioned, and produced intersubjectively through negotiation and struggle. Also they are always situated in our own personal lives, as well as in the larger contexts in which we live.

With regard to the eldercare narratives, I am a positioned interviewer, co-producer, interpreter, and listener/reader of the narratives, and my position in the world, as an academic white woman, etc. influence how my tasks can be performed, and what
meanings I will derive from the narrative material. Furthermore, I am positioned by virtue of my past embodied, affective, sensual experiences (for example, of caregiving, mothering, marriage, sickness, and death). I am not identifying just any story from a text then; I am identifying a story which has been told to me and, even more importantly, interpreted by me as a structurally- and subjectively-positioned representative of particular intersecting worlds. It is a story which touches me personally. The stories I hear and remember resonate with my own similar, yet different, caregiving experiences.

Following Mikhail Bakhtin, Rick Bowers and Katherine Moore (1997:72) say that "meanings are attained through mutual intersubjectivity rather than hierarchical levels of understanding." In other words, meanings are not simply imposed, they are dynamically negotiated through language and interaction.

Narrators struggle to tell meaningful stories about their eldercare experiences, just as individuals struggle to tell their own version of an illness episode. Kathryn Montgomery Hunter (1991:13) also describes how patients and doctors vie for ownership of stories about sickness:

A silent tug-of-war over the possession of the story of illness is frequently at the heart of the tension between doctors and patients, for that tension is in part a struggle over who is to be its author and in what language, a struggle for the interpretation of life (and death) events.

I myself experienced this strong need to tell and write about my mother's death, just after she died and again while in the midst of interviewing caregivers for this study. I wanted to preserve
my version of her death, to memorialize it. I wanted to make sure I got it right in the sense of making sure it was my own interpretation of her sickness and death (and my caregiving), and not those of the doctors, nurses, or my brothers.

Narrative, as I am using the term in my dissertation then, has a number of characteristics which distinguish it from other discourse. Its most important feature for my purposes—since I am seeking to understand what meanings are being attached to eldercare—is its ability to allow speakers and listeners to "construct meaningful totalities from scattered events" and "to extract a configuration from a succession" (Mishler, 1986:148).

DISCOURSE AND CRITICAL PERSONAL NARRATIVE ANALYSIS

When social theorists focus on a narrow, fixed period of time, it makes sense to analyze human actions as constrained by social structures. But, given a longer time frame, we see that these structures were themselves produced by human actions. (Sylvia Hale, 1995)

In this section, I want to discuss the question of how eldercare narratives can be a starting point, or springboard, from which to reach beyond to larger social questions and wider registers of meaning. In effect, I explore the possibility of a critical personal narrative analysis through the examination of the concepts of narrative and discourse. As discussed, I view narrative as a particular type of discourse (more specialized, patterned, and constrained than most general discourse) from which, as Ricouer notes, we are able "to extract a configuration from a succession" (Mishler, 1986:148).
In contrast to Ricoeur's definition of narrative, discourse is sometimes loosely and broadly defined as anything said or written on a particular topic. But Dijk (1997:1) thinks that discourse cannot be squeezed into any handy definition—even a generous one. He maintains that like other complex concepts, such as communication and meaning, discourse is also fuzzy. Despite this fuzziness, however, we need to be as clear as possible about what we mean by discourse and, in this regard, Michel Foucault offers some useful clarification in his discussion of discursive formations in The Archeology of Knowledge (1972). He maintains that a discursive formation is composed of dispersed and heterogeneous elements, contradictions and oppositions, and this is how I envision discourse in my analysis. He (1972:155) tells us that:

A discursive formation is not...an ideal, continuous smooth text that runs beneath the multiplicity of contradictions, and resolves them in the calm unity of coherent thought; nor is it the surface in which, in a thousand different aspects, a contradiction is reflected that is always in retreat, but everywhere dominant. It is rather a space of multiple dissensions; a set of different oppositions whose levels and roles must be described.4

A case in point is the discourse on home care. This is truly a "space of multiple dissensions" wherein the stories of caregivers, older persons, health care professionals, women, politicians, artists, business people, policy makers, media workers and academics interact and sometimes clash. Furthermore, the home care discourse also intersects with related discourses (on
Building on Foucault's ideas of discourse in *The Archeology of Knowledge*, Dorothy Smith (1987:61) claims that "A discourse ...is like a conversation in which utterances are abstracted from particular participants located in particular spatio-temporal settings." Smith seems not so much interested in whether discourses are conflictual or smooth-flowing, but rather in how women have been excluded from many such conversations and, therefore, how our many dissensions and oppositions have remained unheard. That is, she is concerned with how women have been excluded from the very discourses through which their everyday/everynight experiences have been mediated. In the dissertation, I also am concerned with women's exclusion and, therefore, I quote their narratives at length.

I now turn to Mikhail Bakhtin's perspectives. I initially draw on Martin Barker's (1989) interpretations of Bakhtin's work. Although Barker (1989) analyzes comics not interview transcripts, he has prepared a useful summary of certain of Bakhtin's ideas which he feels are significant. I reproduce his 4-point summary here:

1. **Themes** - the sedimented meanings from the past. These carry with them their proposals for kinds of talk (speech genre), and social relationships.

2. **Speech genres** - the live associations of people with rules and conventions for talking to each other. These are not simply phenomena of speech and communication. They are the result of groups of people forming common purposes within material social situations. Any talk within a speech genre inevitably refers, even if only
implicitly, to past speech. It also inevitably draws on past 'themes', however great or small their importance.

3. **Evaluative Accent** - every act of speech not only draws on past themes and refers to previous talk. It also comments on it, and thus inevitably puts it at risk. Every new act of speech is a new proposal. For it to be understood, hearers must newly orient themselves to it, laying down sets of answering words. The evaluative accent guides us on how we should orient ourselves to the communication. It invites a certain kind of response.

4. **Power in communication**, therefore, has to be a particular unification of themes, speech genre, and evaluative accent which is able to persuade a particular group or groups to reorient themselves to become the 'natural audience' of this kind of talk. (Barker 1989:272)

Of particular interest to my work are Bakhtin's thoughts regarding themes or sedimented meanings, speech genres, and evaluative accents. Rather than viewing language primarily as a thinking-tool for categorizing and classifying elements in our world, Bakhtin believes the major purpose of language is its communicative function. He also maintains that we need to look at how language is being used in specific communicative events, to study speech and speech genres.

Bakhtin believes that language is in itself neutral, but whenever a word is used its neutrality cannot be maintained because acts of speech and writing are motivated, positioned, and variously evaluated. Discourse, therefore, is full of ideological potential. Bakhtin writes (1986:85) that,

> Words belong to nobody, and in themselves they evaluate nothing. But they can serve any speaker and be used for the most varied and directly contradictory evaluations on the part of the speakers.

What is being stressed here is not that words have no inherent
meaning in themselves (in which case linguistic communication would be impossible!), but that all words only have specific meaning when placed in contexts. They are thereby always at risk because of their availability for ideological connections in different contexts.

The meaning of discourse, including narratives, is to be found, therefore, in how words are used and evaluated during interactions, and what goals they accomplish. Bakhtin (1986:69) notes that speakers expect listeners to do more than listen. Speakers expect them to be "actively responsive." Bakhtin (1986:69) maintains that our words constantly echo and respond to those of others:

...any speaker is himself [sic] a respondent to a greater or lesser degree. He is not, after all, the first speaker, the one who disturbs the eternal silence of the universe. And he presupposes not only the existence of the language system he is using, but also the existence of preceding utterances--his own and others'--with which his given utterance enters into one kind of relation or another (builds on them, polemicizes with them, or simply presumes that they are already known to the listener). Any utterance is a link in a very complexly organized chain of other utterances.

Discourse, therefore, has an ideological past, present, and future, in the sense that present utterances are rejoinders to past formulations and are spoken with the expectation of future responses.

Bakhtin (1986:60) identifies speech genres which consist of "relatively stable types" of utterances. Martin Barker (1989:267) gives the following description of Bakhtin's term:

'Speech genres' are established ways of talking to each other. They have been formed from shared purposes; and
they have rules, conventions, procedures for progress and so on that reflect those purposes.

At the same time, Bakhtin (1986:60) warns against the notion that genres straight-jacket speech when he writes:

The wealth and diversity of speech genres are boundless because the various possibilities of human activity are inexhaustible, and because each sphere of activity contains an entire repertoire of speech genres that differentiate and grow as the particular sphere develops and becomes more complex. Special emphasis should be placed on the extreme heterogeneity of speech genres (oral and written)....

In Bakhtin's work two contradictory notions exist in tension side-by-side: freedom and constraint. In the Introduction to the book, *Speech Genres and Other Late Essays* (1986:xix), Michael Holquist tells us that Bakhtin often writes of a need to exceed boundaries, to push past limits. However, Bakhtin also recognizes constraints, which allow for only a relative degree of freedom (1986:xix). His position seems to be that a first step in breaking free consists of acknowledging that barriers exist.6

Essentially what can be concluded from Bakhtin's work is that words are only meaningful when readers/listeners/addressees are able to orient themselves, and to make connections between words and specific contexts. Within utterances, there are certain sedimented meanings which help orient readers. There are also usual ways of talking about particular topics. Furthermore, each utterance contains an evaluative accent or overtone which also orients readers, and which calls forth a certain kind of response. In Bakhtin's view, discourse encompasses all these factors, and to repeat Barker's (1989:272) summary:
Power in communication, therefore, has to be a particular unification of themes, speech genre, and evaluative accent which is able to persuade a particular group or groups to reorient themselves to become the 'natural audience' of this kind of talk.

Although at times Bakhtin's way of looking at language suggests a highly-structured, rule-governed world, he also recognizes numerous points at which individuals can, so to speak, step beyond rules and structures. Bakhtin's work has much to do with appreciating an individual's positionality and potential, and with emphasizing that each of us possesses a unitary responsibility to answer for the existence of structures of oppression and to exercise our own agency to modify social constraints.

Bakhtin argues that speakers and listeners are uniquely and deliberately positioned both to comply with and resist regulating structures. He sees danger in both aesthetic and theoretical thinking (Bender, 1998:187). Courtney Bender (1998:187) claims that both ways of thinking are problematic for Bakhtin because each "abstract[s] what they imagine to be 'important' from actual events located within real time and space," then these "gain life of their own within this abstract realm of thinking." In contrast, Bakhtin emphasizes the significance and validity of our own concrete, actual experiences as we live them. He also believes that each of us has a life which is "composed as an uninterrupted deed-performance" (in Bakhtin, 1993:xix). During my lifetime, for example, I have an obligation to overcome what Bakhtin calls, a person's "non-alibi in Being." That is, I have
a responsibility to answer for being alive in my unitary place in
the world and for thinking and acting as I do. This concerns my
centre, an I, from which my agency is exercised. He writes of I,
any I, saying: "I cannot be relieved of answerability for none of
us can claim to have been elsewhere than at the place of
commission." Therefore, I must assign meaning to my own
existence and to the actual, unfolding events of my life, and I
alone must take responsibility for my actions and non-actions--
even though none of us are ever free of contextual constraints.
I must do this by performing answerable acts and deeds or,
rather, by "the taking of a step" (postupok) (in Bakhtin,
1993:xix), which, in turn, invites responses from observers and
listeners.

To illustrate how I use Bakhtin's ideas concerning language,
Bakhtin's work has encouraged me to view transcripts generated in
the field as texts of communicative events. Even though speakers
may be grappling with how to identify, represent, categorize and
classify themselves and the world, we each use language to
communicate information as well as feelings about our
experiences. I assume, therefore, that the function of eldercare
narratives is primarily communicative.

I also use Bakhtin's theory of speech genres and the notion
that words have ideological potential. As a concrete example,
sometimes people draw attention to putative parallels between
children and seniors. While describing an incident involving her
husband, Emiko said that it was "sad that he didn't know what was
happening...." Then she began talking about caregivers who are caring for individuals who show little awareness and comprehension, and she suggested that their work is important because, "it's just like babies: they say some people don't talk to their babies, but they say babies absorb everything. They can't answer, but they hear you."

Terms such as child and baby in themselves are neutral, but when linked to seniors they automatically become part of a demeaning age-based ideological system which works to control how much status, wealth, and power older people can acquire or maintain. Such usages also suggest how much we, as a society, are willing to invest in the health and well-being of older persons. Common ways of talking justify continued social segregation and exclusion (in special housing and care facilities). I am not just listening to the words of others, therefore, I am being an "actively responsive" listener/speaker and my act of identifying and writing about this usage, constitutes a "step taken" towards the demystification of ageing.

But, subsequently, in a "highly organized chain of other utterances," another active listener who is listening/thinking/reading in a different context, and speaking from another position, may not find my words convincing. He/she may then exercise his/her responsibility to answer that child and baby are merely cute, innocuous descriptors which are devoid of ideological function--and that I am overreacting. Or, alternatively, that analogies between children and older persons
help to garner support for older people by pointing out that, like children, they also require understanding, care and attention. In other words then, I am using Bakhtin's ideas to identify:

a) Ageing and caregiving as themes in the eldercare narratives;
b) Speech genres or usual ways of talking about ageing and caregiving;
c) Evaluative accents and the ideological uses to which eldercare narratives can be put; and,
d) Expected responses to the narratives and their analyses in particular contexts.

Another concrete example of how I use Bakhtin's theories involves the way I have employed Bakhtin's theory of the text and meaning to analyze the interview transcripts. Bakhtin's theory concerns the notion that meaning can only be ascertained from viewing words (including personal narratives) in their contexts. He writes that: "Each word of a text is transformed in a new context" (Bakhtin, 1986:165).

Using Bakhtin's theory, I make the assumption that by examining the immediate contexts in which caregivers interpret and talk about their lives and actions (in personal narratives), we can begin to understand certain of their experiences, and the processes through which accounts of these experiences are being generated. Like Bakhtin, I stress the communicative/social nature of language, its "'inner sociality' in speech communication" (Bakhtin, 1986:101). From my initial starting point of framing personal narratives in their immediate contexts, I then assume that they also must be placed in larger or more remote contexts (to render them more fully meaningful). In Bakhtin's
theoretical perspective, a text only is meaningful if viewed within contexts which join it to a dialogue. He says that,

The text lives only by coming into contact with another text (with context). Only at the point of this contact between texts does a light flash, illuminating both the posterior and anterior, joining a given text to a dialogue. (Bakhtin, 1986:162)

By placing an eldercare narrative in context, therefore, I am able to specify its dialogical relationship to the elements of mystifying discourses. I can then attempt to explain its role in perpetuating or resisting the status quo.

Another complementary and useful way to look at the eldercare narratives is through the concept of agency and Antonio Gramsci's notion of cultural hegemony (Turner, 1996). Hegemony involves ruling through control of the way people think, not through force (Hale, 1995). Once accepted, hegemonic ideologies may become natural, and unnoticed, at least for a time. Gramsci's ideas about hegemony incorporate dynamism. He maintains that ideologies are not just imposed upon people and accepted by them in an unthinking manner. Hegemony must be continuously accomplished. It must be won, and this frequently involves some accommodation on the part of dominant groups.

Gramsci argues that individuals often respond with resistance to hegemonic ideologies, no matter where the ideologies originate from. This leads to ongoing struggle over meanings. Those who want to control the way people think must constantly reformulate or reinvent their ideas. They must come up with new mystifications which are attractive and seem
convincing, in order for these systems of ideas to become incorporated into our everyday thinking and feeling. As Graeme Turner (1996:198) explains,

Hegemony describes the attempt to produce uniformity and coherence, but it also implies that such attempts must always, eventually and necessarily, fail. Therefore the analysis of cultural forms and practices should involve a search for 'contradictions, taboos, displacements in a culture' that might fracture the fiction of homogeneity.

Gramsci's ideas are compatible with a more complex conceptualization of narrative, discourse and ideology (which incorporates Bakhtin's ideas). Only through discursive struggle (such as through contestation and negotiation), do ideological truths become hegemonically installed. And these then become the basis for acceptance of structural constraints.

SUMMARY

In this chapter I described how I am using the term narrative to signify complex, personally- and socially-meaningful configurations. In addition, I explained how I am using the term discourse. I cited Foucault's (1972:155) notion of a discursive formation, which he defines as "a space of multiple dissensions, a set of different oppositions whose levels and roles must be described." Personal narratives compete for attention and confirmation with other narratives within these multiplex formations or what Dorothy Smith has called conversations.

Discourse, including narrative, is messy and complex. It is at once poetic and political, local and global, smooth-flowing and conflict-ridden. Although discourse might be described as
process and ideology as effect, as Purvis and Hunt (1993) suggest, I agree with Bakhtin that all language becomes ideological when used and, therefore, that discourse and ideology cannot be neatly separated (and this includes detaching neutral-appearing personal narratives from frankly ideological productions).

Discourse gains ideological potency in particular contexts in which speakers variously respond—through dissent, opposition, challenge, negotiation, and endorsement—to hegemonic constructions. Therefore, we must examine discourse in general and, in this thesis, personal eldercare narratives in particular, in the contexts in which they occur. This must be done so that we are able to grasp in what sense they are dialogical and ideological (how are they being used, what purposes they serve, and so on). Also, like Gramsci, I believe we must search for "'contradictions, taboos, displacements in a culture' that might fracture the fiction of homogeneity" (Turner, 1996:198) and thereby assist us in revealing mystifications.

In the following chapter, I discuss contemporary and background information about Canadians of Anglo, Italian and Japanese ancestry, as well as information about myself as an auto-ethnographer. In effect, I situate the three groups and myself in our local geographical and historical contexts.
Interdisciplinarity involves "activities that cross disciplinary borders" (Vertinsky and Vertinsky, 1998:2). In the dissertation research, I tried to learn about the links between society, power, and caregiving by crossing into unknown disciplinary territories. In addition, I interacted with caregivers themselves, and I gave priority to their words and viewpoints over disciplinary perspectives. As such, my research is consistent with the activities Margaret Lock and Nancy Scheper-Hughes (1990:71) promote in the following quotation:

The transformation of a culturally rich form of communication into the individualizing language of physiology, psychology, or psychiatry is inappropriate. What is crucially important...is to demonstrate the way in which polysemic terms such as nerva, solidao, hara, and stress, and the language of trance, ritual, dreams, carnival, and so on can be made use of in order to facilitate the bringing to consciousness of links between the political and social orders and physical distress.

Ricoeur (1991b:70) notes that, "Polysemy is readily defined as the property of words in natural language of having more than one meaning....This feature is a universal feature of words in natural languages."

The term lived experience has recently been problematized because its boundaries are too permeable. Related questions increasingly popping up are: "What counts as experience and why?" and "What constitutes meaningful experience?" In this connection, I consider the lived experiences of interviews also to be meaningful to participants.

I interpret Foucault's explanation of discursive formations in this quotation as being compatible with Bakhtin's ideas concerning language and dialogue.

Smith (1987:61-69) locates women's participation in sociological conversations as falling outside the frame of sociological discourse which is being generated within and regulated by what she calls "the ruling apparatus of society." She says that women "are not part of the workings of the professional, administrative, and managerial apparatus into which sociology is locked" (1987:64).

Martin Barker uses M.M. Bakhtin's and V.N. Volosinov's work to address the problem of ideology in popular culture. There is much controversy over certain books which have been attributed to M.M. Bakhtin and one of these is the book on which Barker partially bases his analysis: Marxism and the Philosophy of Language, published in 1929 with V.N. Volosinov as author.
Bakhtin thinks that words are only meaningful when placed in contexts. His idea can be proven by taking any word or set of words and trying to imagine their meaning outside of a specific context. Barker (1989) gives us examples of meanings-in-context. Following Bakhtin, he asks readers to "orient themselves" by considering contexts for the following: a dog and the dog.

Barker helps us by suggesting that a child might enter a pet shop and announce: "I want a dog." For the second phrase, there might be a choice of raffle prizes, with the winner saying, "I'll take the dog, not the toaster." The phrases (a dog and the dog) become meaningful when placed in a context. Also, there are an infinite number of contexts in which either of these phrases might occur. This is part of what Bakhtin means when he claims that each speech event is unique.

Next Barker asks readers to imagine the following phrases, in order to demonstrate how words not only depend upon contexts for their meanings, but that they also retain themes or sedimented meanings from past usages. First imagine the phrases, a vote and the vote. He says that the former could appear in a sentence such as, "Let's take a vote." (A situation which might arise at the end of a meeting, for example). Then Barker argues that the latter term, the vote, holds a particular sedimented meaning associated with political freedom. For example, suffragettes (a word with sedimented meanings of its own) might have had a slogan or banner containing the words, "Give us the vote!"

Another of the examples Barker (1989:270) uses is the situation of going to the doctor. He says,

If I visit my doctor, and am told I ought to be getting some exercise, the doctor-patient speech-genre has rules (which I defy at my peril) which tell me to take this seriously, to examine my life-style, to adjust my self-image. I am supposed to turn this into self-instructions. The same advice, in a casual conversation, does not have the same force. How far outside the immediate contact between speaker and hearer (reader and writer), then, do the rules apply and orient the participants? And what is implied about how ideas, knowledge etc. gained within that situation may be used outside? In communicating, then, we orient ourselves to the rules of that situation. Others, hearing us, orient themselves to our speech in the light of that history and its embodied rules.

In short, words only become meaningful when readers, listeners, addressees, orient themselves and connect words to particular contexts. Within utterances, there are also themes or sedimented meanings which help hearers become oriented. Then there are speech genres or usual ways of talking in particular situations. In addition, each utterance contains an evaluative accent which further orients hearers and invites a certain type of response.
Detachment is not a condition of science. Indeed we
must begin from some position in the world. The method
recommended here is one that frankly begins from somewhere.
(Dorothy Smith, 1987)

It is crucial to understand the contexts within which
eldercare narratives are being produced because contexts both
constrain and give meaning to our lives and narratives (Personal
Narratives Group, 1989:19). In this chapter, I investigate the
following questions which relate to the meaning-centred theme of
my dissertation: "Why am I interested in caregiving among
Canadians of Italian, Japanese, and Anglo ancestry?" and "How
have I gained knowledge about the local worlds of eldercare, as
well as the larger worlds of which they form a part?"

In Chapter 1 I presented general background information
which allows readers to orient themselves to major themes arising
from the caregiving literature. For example, I described why
caregiving should be called a women's issue (although it is not
always so named). I also described how complex issues arising
from the intersection of factors such as gender, race/ethnicity
and class have been glossed over in the caregiving literature.
Here in Chapter 3, I now sharpen my focus on the contexts within
which caregiving occurs. I suggest that it is important to
examine both the historical and contemporary contexts of caregiving, as well as the researcher's own positionality.

BACKGROUND INFORMATION

Historical Contexts

Canadians of Italian and Japanese ancestry have been racialized and ethnicized since immigrating to British Columbia in the 1800s. During World War II, both groups were discriminated against, with Canadians of Japanese heritage receiving by far the harshest treatment (See Adachi, 1991; Omatsu, 1992).

Less well-known is the fact that Canadians of Italian descent, like those of Japanese descent, were also called enemy aliens during the War. Many suffered hardships and were interned regardless of citizenship or birthplace (Culos, 1998; Migliore and DiPierro, 1999). All individuals of Japanese ancestry, however, were expelled from the West Coast of British Columbia and interned. Their property was confiscated, careers destroyed, educations terminated, and even after the War, people were not allowed to return to the Coast until 1949.

As a group, Canadians of Anglo heritage, on the other hand, have been economically, socially, and politically privileged. Elite and ruling classes have been largely composed of Canadians of Anglo background, especially males. Canada continues to be constructed as homogeneously white, bicultural, and bilingual, and immigrants are perceived to threaten our putatively white, Anglo/Franco character (Thobani, 1998). Anglo ethnicity and
whiteness remain largely invisible and knowledge produced from this special white, Anglo vantage point is generally accepted as normal, natural, neutral and authoritative.

Cultural Representations

Along with other groups, Canadians of Japanese, Italian and Anglo ancestry have been stereotyped in flat, cartoon-like representations which provide the basis for discrimination, ethnocentrism and racism. These representations draw upon universalizing notions of Italianness, Japaneseness and so on. For example, typically Japanese society and Japanese families have been depicted as homogeneous, corporate entities. Within these imaginings, the Japanese Woman has been portrayed as relatively powerless, nurturing, submissive, silent, compliant, and non-assertive. A powerful statement about such exaggerations occurs in the Japanese film parody Tampopo. In this film, the husband and children of a dying, bedridden, middle-aged wife and mother request that a last meal be prepared--for themselves! The "good wife, wise mother" (See Margaret Lock, 1993:86) drags herself from her deathbed, her face ashen, to comply. She performs this last feat to the delight of her family, then keels over dead--as the father nervously urges his family to continue eating because Mother would have wanted them to! Such stereotypes, I believe, have been generalized to Canadian families of Japanese ancestry because we have blended images of Canadians of Japanese ancestry with stereotypes of Japanese people living in Japan.
Nurturing of Japanese elderly people is also the subject of various stereotypes. Ageing, it is sometimes suggested, is somehow better and easier in Japan or among people of Japanese ancestry. For example, women are nearly always represented as happily providing care to invariably honourable elders. But Lock (1993:122) points out that ambivalence about older people occurs in stories from ancient times to the present, and that the dilemmas surrounding their care is another relatively common topic.

Selfless representations of the Japanese Woman deeply touch and affect North American women of Japanese ancestry. In Crafting Selves, Dorinne Kondo (1990:301-302) describes her style of writing against negative images of Japanese women and men. She says,

...my writing strategies are deployed as an oppositional discourse to other insidiously persistent tropes that constitute the phantasm 'Japan' in the contemporary United States: not only Organization Man and automaton, but submissive, subjugated Japanese Woman, domineering, sexist Japanese Man, Japanese despot, or perhaps most basically, 'the (undifferentiated) Japanese.'...The current disturbing tendency to use martial metaphors--invasion, trade wars, beachheads--in descriptions of U.S.-Japan relations underlines the embeddedness of such representation in specific historical, political, and economic situations. As a Japanese American and as an Asian American, whom some will inevitably see as foreign and whose fate is intimately tied to the state of American relations with Asia, I see the political weight of those representations take on a vivid and searing immediacy....What and how I write is no mere academic exercise; for me it matters, and matters deeply.

Women of Italian ancestry have fared little better. They are depicted as being uniformly chained to kitchen, family, and Church, as strongly defined by a maternal function as La Mamma
(Dorazio-Migliore, 1999; Johnson, 1978; Perry, 1978) and as lacking individual lives of their own. Giovanna Del Negro (1997:17) states that in North America the Italian Woman is pictured in "inaccurate stereotype" [Is there such a thing as an accurate stereotype?] as "a passively subservient, uneducated, family-oriented person" living in a "patriarchal and authoritarian milieu." And on becoming mothers, Italian women are said to be revered to the point of "motherolotry" (Johnson, 1978:234-244).

Our view of actual Canadians of Italian descent have been shaped by American movies which commonly feature gangsters and crime families. Lee Lourdeaux (1990) describes how Catholic Marian values (extended to Italian men--even gangsters sometimes) stamped the immigrant Italian's movie and real-life character. This occurred in early Hollywood cinema, but continues to the present through transformational representations presented in highly influential American movies and TV shows. Lourdeaux (1990:66) says:

Essential to the communal identity of Italian Americans is a sense of themselves in famiglia. Even an outburst of joy or bad temper on screen implied a trust in community, as if it were all one family. Add maternal Marian devotion and a rich aesthetic sensibility, and Italian immigrants have had much to offer Anglo Protestant America, with its isolating, often austere individualism.

Attesting to ambivalence towards the immigrant various moral failings have been attributed to ethnocultural groups since their arrival in North America. Historian Karen Dubinsky (1993:139), who has written about rape and heterosexual conflict in Ontario
around 1900, tells us that non-Anglo immigrants were suspect—especially with regard to their sexuality:

At the turn of the century, Canadians of British descent believed that racial and ethnic minorities in Canada had a distinct set of sexual practices, attitudes, rules and systems of regulation, and that this was a very bad thing indeed.

Italians were considered to have "spurned the institution of marriage" and to have loose sexual mores. Furthermore, the private lives of immigrants received an inordinate share of scrutiny and policing, and newspaper reports always referred to the ethnic origin of people who were purportedly committing crimes. Dubinsky (1993:139-140) says:

Part of the reason immigrants were so susceptible to sexual immorality, so the story went, was that they tended toward criminality in general....In crime reporting, the racial or ethnic background of protagonists was made prominent in a manner ranging from the patronizing (women described as 'comely, as Galician women go') to the vicious (the panic about 'stiletto wielding Italians' which followed any news of violent crime among southern Europeans). The exception to this rule was, of course, when crimes were committed by Anglo-Saxons.

Such images of Italian people, and their representations over the years, affect the way Canadians of Italian heritage are currently perceived, how they identify themselves, and what boundaries still exist and exclude. The Italian Woman is a martyr and saint. She is simultaneously faulted for investing too much in the household and for too eagerly catering to the coddled Italian Male who may be hard-working, but is never to be entirely trusted (due to his criminal connections and lusty sexuality).

Despite variations on such themes, and in addition to always existing in famiglia in popular culture (Lourdeaux, 1990),
Italians are also stereotyped as always ready and willing to take care of their own. Taken to the extreme, individual families (and individual women) are depicted as ready to do just about anything to protect their own. Under such circumstances, therefore, they can become fiercely pitted against one another and society at large—with general chaos the result. Canadians of Italian heritage have also been represented as having divided loyalties, of being wedded to the corporate family, yet of also being emotional, enterprising, creative free spirits. In other words, there is a tension between the family and the individual, as if these were polar binaries.

People of Anglo descent are represented in all manner of cultural productions (including novels, ads, TV shows, and films) in terms of individualism, with an emphasis on self-reliance of individual families and their separate members. In contrast to corporateness, family-orientation, and family-dependence—used to characterize people of Japanese and Italian ancestry—people of Anglo heritage are expected to display autonomy, self-interest, and independence. Sometimes people of Anglo ancestry are stereotyped (as in the above quotation by Lourdeaux) as individualists who are isolating and austere. Cold-blooded when it comes to family, they are imagined to neglect and dump their elders and place them in institutions at the drop of a hat. Reciprocally too, elderly members of this group are portrayed as uniformly consumed with maintaining their independence and dignity in old age (which generally means living alone, without
financial or other help, or being able to afford to hire helpers without burdening family members). Margaret Laurence's influential, moving portrait of Hagar Shipley in *The Stone Angel* depicts this fierce struggle to maintain a measure of independence and individual dignity in old age.

Stephanie Coontz (1992) draws attention to the way in which 1950s TV sit-coms such as *Father Knows Best* and *Ozzie and Harriet* depicted white, middle-class women as achieving their identities through domesticity and the nuclear family. Coontz claims this was something new. It signalled a break with Victorian ideals because white, Anglo Victorians had strict gender divisions and middle- and upper-class women happily left housework and child-rearing to servants. After WWII, women's labour was no longer needed in factories. They were then encouraged to remain at home, perform their own housework, and become highly involved in the lives of their children. Coontz writes that, "Acceptance of domesticity was the mark of middle-class status and upward mobility" (1992:28). But she also notes (1992:29) that "Contrary to popular opinion, 'Leave It to Beaver' was not a documentary." Coontz (1992:30) tells us that,

...real life was not so white as it was on television.
...Such families [as the Nelsons, the Andersons, and the Cleavers] were so completely white and Anglo-Saxon that even the Hispanic gardener in 'Father Knows Best' went by the name of Frank Smith.
Black feminist scholars (for example, see bell hooks' *Feminist Theory From Margin to Center, 1984*) have drawn attention to the manner in which mainstream feminists have helped to create notions of womanhood with which many women of colour (as well as other non-mainstream women) cannot identify. Sylvia Hale (1995:440) writes that,

> Feminist theory has challenged demeaning conceptions of womanhood embodied in ideals of femininity, the presumed delicacy and daintiness of women, their need to be helped, and their dependency on men. But such notions of womanhood were never applied to black women....The gendered identity of black women bears little in common with the constructions of white femininity that is the focus of mainstream feminist writing.

Compared with submissive Japanese caregivers, saintly Italian mothers, and strong women of colour, white women are also stereotyped. Images of Anglo or white women are not usually explicitly labelled as such. Essentialized and universalized representations of generic women (or North American or Canadian women) are derived from and incorporate white, middle-class behaviours and values more often than not. Basically, what I am suggesting is that in these stereotypical representations *Generic Woman* and *White-Anglo Woman* are conflated. *The Canadian Woman*, as constructed in the media, the arts, advertising, etc. is white, Anglo-Saxon, and middle class. Whiteness itself, therefore, needs to be noticed and problematized.

All groups of women have been represented in care-related situations which can become the basis for stereotypes. These affect subsequent representations of women, as well as the conceptualization and enactment of caregiving. In contrast to
stereotyping, what I hope to achieve in the presentation of
eldercare narratives are dynamic, nuanced representations which
trace the interplay of gender, race/ethnicity, and class.
Obviously these will still be positioned, interpretative
portrayals, but there is no escaping this.

CONTEMPORARY CONTEXTS

Part I: Selected Contexts of Caregiving

a) Health care reform

Examination of what meanings are being given to caregiving by
caregivers who are positioned by virtue of the intersection of
characteristics such as gender, race/ethnicity and class is
timely research. As the Canadian health system undergoes
restructuring, critics worry that local concerns will be glossed
over. For example, the development of a national home care
programme is underway and here in British Columbia the health
system is being reorganized regionally. Also, institutional care
has been decreased, while self, home, and community care are
being promoted (See Closer to Home: The Report of the B.C. Royal
Commission on Health Care and Costs, British Columbia, 1991 and
New Directions for a Healthy British Columbia, British Columbia, 1993). These moves, seemingly based on a desire for greater
efficiency not equality (Stingl and Wilson, 1996), potentially
ignore the significant and growing heterogeneity of caregivers
and care-receivers. If such heterogeneity is ignored, however,
this would lead to inappropriate and unacceptable health services
at the local level. And, ultimately, women would be expected to
ultimately, women would be expected to perform more unpaid work to make up for deficiencies, omissions and shortcomings.

Since the inception of medicare, there have been criticisms. Many of these relate to universality and accessibility. Some critics argue that there is too much accessibility which has led to abuse and overuse. Others emphasize the barriers of cost and distance, and more troubling still, restrictions on quality care based on sociocultural characteristics like language, perceived race/ethnicity, gender, class, sexuality, and age (See Bolaria and Dickinson, 1994; Coburn, D'Arcy and Torrance, 1998).

Over the years, there have been numerous complaints that the system is too narrowly focused on biomedicine too, and that most funding goes to curing disease rather than promoting health. For years we have known that the major determinants of health fall outside the realm of biomedicine (Hertzman, 1998:4). Poverty, income equity, nutrition, shelter, racism, homophobia, ageism, pollution, and occupational hazards are all social factors or "social determinants" that physicians are virtually powerless to control. Clyde Hertzman (1998:4) says that our increased life expectancy (from 45-50 years to 70+ years in this century) is due to factors "outside the one-on-one health care service provision," such as various physical and economic factors, child spacing, and nutrition. In addition, he notes that there has been a sharp decline of 80-90% in "the infectious diseases of antiquity" and this occurred prior to the advent of vaccines and antibiotics. It is a mistake, therefore, to view biomedicine as
the only answer to questions of health. Indeed, it makes sense that more emphasis on the prevention of sickness and the promotion of health—for example through greater occupational hygiene and broad home care services—would mean a less costly and efficient health care/health promotion system, and ultimately better health.

b) Demographic change

Like populations around the world, Canada’s population is steadily and inescapable ageing (Desjardins, 1993:4-5; Desjarlais, Eisenberg, Good and Kleinman, 1995:206). M. Anderson and Karen Parent (1999:21-22) state that in 1951 Canada’s population was 14 million, with 7.8% of the population aged 65 and over. By 1996 our population had risen to 37 million, with 12.2% over age 65. For the year 2016, it has been estimated that the population will be just over 37 million and the percentage aged 65 and over will have risen to 16%. There will be 5.9 million seniors, 1.5 million of whom will be aged 80 or over.

Most populations are rapidly ageing as: 1) people born during periods of high fertility progress into their senior years; and 2) people live longer. In addition, globally those aged 85 and older are the fastest growing senior group and this is the age group of individuals who require the most care (Desjarlais, Eisenberg, Good & Kleinman 1995:209). Furthermore, the ratio between old and young is increasing as fewer children are born today than in the past, and the proportion of younger
people (who are potential caregivers) thereby shrinks accordingly (Desjarlais, Eisenberg, Good & Kleinman 1995:209).

The total population of the City of Vancouver is 514,000 people with 66,430 being aged 65 or older (1996 Census, Statistics Canada). Therefore, seniors make up approximately 13% of Vancouver's population—a percentage which is close to the provincial (and just above the federal) figures (British Columbia, 1997:1). British Columbia's population is also ageing steadily and this trend will continue well into the next century.

Due to recent immigration (mainly from Asian countries, particularly Hong Kong), British Columbia's population has also undergone various other changes. In 1995, 44,073 immigrants came to British Columbia, 37,000 of whom settled in the greater Vancouver area (British Columbia, 1997:1). In British Columbia, and especially in the Vancouver area, seniors who were already ethnoculturally and linguistically diverse will continue "to diversify dramatically" over the next few decades (British Columbia, 1997:1).

c) Increasing incidence of informal eldercare

As the health care of Canadians is shifted toward non-institutional settings, informal eldercare is stepping into the spotlight. A study by the National Advisory Council on Aging found that between 75% and 85% of all eldercare is provided by informal caregivers (Happy, 1997:1). Kaden and McDaniel (1990:4) note that although nowadays it is common to have a very old family member, in the past it was a rare occurrence. Previously,
therefore, informal caregiving was only experienced by a small number of individuals.

In 1996, 2.8 million Canadians provided some form of assistance to others with long-term health problems or physical limitations (Anderson and Parent, 1999). Most of these caregivers were between 45 and 64 years of age (Anderson and Parent, 1999). In British Columbia, a 1994 survey conducted by N. L. Chappell and R. Litkenaus showed that 8.4% of households had informal caregivers and that there were 152,000 informal caregivers, 73% of whom were women (British Columbia, 1996:88).

The number of senior caregivers is on the rise. These are mainly senior wives caring for husbands, but nowadays there are also many senior children (mostly daughters) who are taking care of elderly parents (mostly mothers) (Kaden and McDaniel, 1990).

Contrary to popular belief that more caregiving was done in the past, Doty (1986:67) says that informal care "remains at a high level" and Brody (1985) maintains that more informal caregiving is being performed now than in times past. This trend is also likely to continue as more people live longer and the state promotes home and community care. Additionally, even when family members are institutionalized, care is still provided by unpaid caregivers to a remarkable extent (Happy 1997:54).

Neena Chappell (1993:51-53) claims that a new role is developing for Canada's caregivers, one which would give them greater recognition. At the same time, she warns that the Canadian health care system is in a "state of flux not seen for
many decades" (Chappell, 1993:53). So, although the new vision holds promise, it also holds dangers. Chappell (1993:53) says, therefore, that, "We do not yet know the details of the system that will emerge but now is the time for families and caregivers to make their wishes known."

d) Women and work

Today more women are in the paid workforce than ever before and their participation continues to grow (British Columbia, 1996:87). In 1941, less than 19% of British Columbian women participated in paid employment, while in 1991, their labour force participation had risen to over 59% (British Columbia, 1996:87). Many women perform two jobs. They "carry a double workload: one in the home and one in the workforce" (British Columbia, 1996:87).

Eldercare often reduces the ability of women to achieve satisfactory work lives and careers. It also curtails their ability to achieve the recognition, security, and equality such careers can bring. Employed caregivers may either take on less paid work or forfeit paid employment altogether in order to perform unpaid, undervalued and invisible caregiving work. Alternatively, they may work two shifts--from 9:00 to 5:00 at the workplace and from 5:00 to 9:00 at home (Canada, 1997:6). That is, women may continue to labour full- or part-time while still engaged in stressful caring work, with negative consequences for wages, benefits, and pensions.
Although women derive self-esteem from paid employment, just as men do, they work mainly because they have present economic need and they wish to stave off poverty in old age. In male-female partner households, women perform 2/3 of the daily household tasks, such as cooking and cleaning (British Columbia, 1996:87). This has remained virtually unchanged over recent years (Canada, 1997:6). Ultimately, women's labour may have a detrimental effect on women's security, health, and well-being, and result in negative consequences in their own senior years.

One "double bind" is that compared to older men, older women are more apt to be "poor, widowed, living alone in poor health, receiving assistance from both formal and informal supports, as well as being institutionalized in long-term care facilities" (Kaden and McDaniel, 1990:3). They are also more likely than older men to be providing care to an elderly person (Kaden and McDaniel, 1990:20). In other words, caregiving may precipitate women's unequal economic and social status in old age (in addition to having negative consequences in earlier years).

**Part II: Positionality and the Research Process: 'Field' and 'Home'

...'The field,' seen as a place of writing, leaks. Once one complicates and historicizes the 'notes' in 'field/notes,' the boundaries of the first term, 'field,' begin to blur. How is the field spatially and temporally defined?.... Fieldnotes are by definition written 'in' the field. But with increasing coming and going, better global transport and mobility, where does the field begin and end?....As the historical and political relations of different parts of the planet shift, as cultures interpenetrate, and as ethnography turns back on its own culture, 'the field' becomes more and more evidently an ideal construct. (James Clifford, 1990)
Now I would like to turn to my experiences with actual research participants in the field. To me, the concept of positionality refers to how a person conceptualizes his/her position of power and influence in the world, and to how others perceive and position him/her as well. Furthermore, it refers to how we are positioned by our experiences. In thinking about my own position, I am interested in my relationship to self and others, the groups with which we are affiliated, natural and supernatural worlds, and time and space. Below I describe aspects of my positionality which prompted me to undertake this study of the meanings being given to eldercare.

There are several reasons why I chose to do the study. I was born and raised in East Vancouver. Almost five years ago I moved back to the Vancouver area after spending almost 20 years in other parts of Canada. When I returned things seemed both the same and different. I found myself curious about the changes that had taken place in East Vancouver over the years, as well as about things that had remained true to memory. It was as if I was re-entering a lost/changed world. I consider that this research, in a sense, is auto-ethnography and native ethnography. It is as much a journey back into my past as a description of the present, or an interrogation of the future. It is also an investigation of the people who have formed my identity—and I theirs—both through talking and silences.

My interest in ethnicity and in all three ethnocultural groups probably stems from childhood and early adulthood just
after WWII in what was then a predominantly white neighbourhood. I am of Italian and Anglo/Irish descent, and married to a man of Italian ancestry. I grew up in Vancouver—less than a mile from both the Pacific National Exhibition grounds and the Vancouver/Burnaby boundary. This is a neighbourhood in which people of Anglo, Italian, Yugoslavian, Chinese, Korean, and Japanese descent (and members of other ethno-backgrounds as well) were—and still are—neighbours, friends, acquaintances, and sometimes enemies. A number of families living there were mixed like my own. Although a few of my relatives still live in East Vancouver, most have moved to other nearby locations.

I have been in close contact with Canadians of Italian and Anglo background throughout my life. Both my paternal grandparents, and my father, came from Abruzze, Italy. My grandparents, who were peasants in the Old Country, lived just down the street and when my grandfather passed away in 1959, my grandmother came to live with us part-time. She also took me on a 3-month trip to Italy in 1965 to visit the relatives.

My maternal grandparents came from England and Ireland, but I know little about them. Mom was born in Alberta and orphaned by the time she was 5 years old as a result of the Great Flu Epidemic which swept through Canada in 1918. I remember her stories about poverty, oppression, loss, and longing; her separation from beloved brothers (who were taken to live on a farm); and her own experience as the informally-adopted child of an impoverished, disabled, and short-lived maiden aunt.
I have also been connected to Asia, in one way or another, since childhood. Both parents spent time in Asia before I was born. My father worked on a Canadian Pacific Empress luxury liner, in the ship's orchestra, for several years during the 1930s. He regularly sailed to Japan and other parts of Asia on five- or six-week cruises. For a year, during 1936 and 1937, my mother lived in Yokohama visiting another maiden aunt who worked for a British oil company and who paid for her entire trip. Much later, Dad also accompanied a youth band to the World's Fair in Osaka in 1970.

As a child I remember objects I deemed exotic around the house: carved chests, lacquered boxes, silk kimonos, and a 78 rpm record (of high-pitched Kabuki music, I think it was) that my brother and I thought was hilarious. Then there was my father's jerky 8 mm Expo movies too...

I also remember my parents' verbal and written descriptions of their Asian adventures, my dad's black-and-white photograph albums, and especially my mother's depictions of her fairy-tale life in Japan. She felt like Cinderella there after the harshness of the Prairies, then her escape to Vancouver only to become an unhappy domestic servant. But in Japan, she was treated like a cherished child in a financially-secure family. She and her aunt even had house servants themselves!

At any rate, Japan was always very intriguing to me, although my view of the country was deeply coloured by what I now recognize as Orientalism, a notion developed by Edward Said.
(1978). Said means several interdependent things by Orientalism. These include a style of thought which pits the Orient against the Occident and a corporate institution for dealing with the Orient (1978:3). He notes that his book, Orientalism, "tries to show that Europe gained in strength and identity by setting itself off against the Orient as a sort of surrogate and even underground self" (1978:3). I wonder now if I also gained in strength and identity by setting myself off from those whom I perceived as Orientals or Asian others. Growing up I had little connection with Canadians of Japanese origin, apart from a few acquaintances, but I probably did regard Canadians of Japanese ancestry as exotic Others.

I believe it was during the 1960s or 1970s that I read about the treatment of Canadians of Japanese heritage during World War II. I wondered how this could have happened? Why had I never heard of the Hastings Park internment and the evacuation? We only lived about 10 blocks from Hastings Park, where all British Columbians of Japanese heritage were rounded up, kept like animals, then shipped off to internment and prison camps. Later I learned that their homes and other property had been confiscated and that even after the War they were not allowed to return to the Coast. It was about this time that I also talked to two young men who had recently visited Japan as sightseers. They described a side of Japan which my parents had never talked about: Hiroshima and Nagasaki.
Later still, I also wondered about the care of elderly family members of all three groups as more and more women continue to enter the workforce. I wondered if traditions of eldercare reported in the literature, such as filial piety, existed here in Canada, or whether these were merely a figment of Orientalist minds. If traditions do exist, are these changing with women's greater participation in the workforce? Are women able to caregive and maintain satisfying employment? And I also wanted to know how health care restructuring affects caregiving.

I decided to investigate such questions at multiple sites, which included a variety of private and community environments where I could meet caregivers (and care-receivers, health care professionals, staff members, etc.) and where eldercare and community activities could be observed and participated in. I began, starting early in 1997, by attending a 10-week course designed as an education-cum-support group for caregivers. During this period, I also spent nearly 70 hours as an official volunteer and participant/observer at an Extended Care facility, attended caregivers' support group meetings, visited two local stroke clubs, and participated in other events related either to caregiving or to the ethnic groups from which subjects were chosen.

During 1997 and early 1998, I also conducted in-depth interviews with 30 informal Canadian caregivers of Japanese, Italian, and Anglo ancestry all of whom have strong ties to Vancouver or nearby municipalities in the Lower Mainland. Although groups of
people of Japanese, Italian, and Anglo ancestry have been resident in British Columbia for over 100 years, their experiences have differed in terms of group privilege and exclusion. Also, typical representations of gendered caregiving associated with these three groups, while linked in terms of the dominance of female nurturing themes, are each distinctive.

I chose a purposive sample of 30 individuals, not a probability or random sample. My choice of how many people to interview depended on what I needed to find out. As noted by Norman Denzin and Yvonna Lincoln (1994:201):

Different sampling issues arise in each situation. These needs and issues also vary according to the paradigm being employed.

What I needed to find out was the range of meanings being applied to caregiving through narrative construction. I, therefore, tried to maximize variation in my sample by:
a) keeping criteria for inclusion to a minimum; and b) choosing a sample large enough so that variation would be expected to occur. Therefore, I conducted in-depth interviews with 30 individuals (10 of each ethnocultural background) chosen on the basis of being: 1) identified as caregivers, and 2) of Italian, Japanese or Anglo ancestry. The decision to make 30 an adequate number of people to interview was an initial decision based on judgement and experience (Sandelowski, 1995) and my decision to employ narrative analysis. Because of its interdisciplinary nature (Catherine Kohler Riessman, 1993:1), narrative analysis can be performed on a single text or on a corpus of texts. At any rate,
I decided that my sample should be small enough to allow "the deep, case-oriented analysis that is a hallmark of all qualitative inquiry," but not so small as to preclude "a new and richly textured understanding of experience" (Sandelowski, 1995:183). In other words, I chose a sample size that was modest enough to permit in-depth narrative analysis of particular cases, yet substantial enough to show contoured patterns among the cases.

With a sample size of 30, my sample proved to be small enough so that I could examine content and structure of the eldercare narratives, and aspects of the co-construction of meaning. Yet, it was large enough to encompass contextual variations in parental/spousal care, home/institutional care, mental/physical care-receiver problems, light/heavy caregiving, working/retired caregivers, and so forth. I could, therefore, identify unique as well as patterned caregiving experiences and narratives.

Most of the individuals I interviewed were referred to me by staff members of care facilities, support group leaders, and other caregivers whom I interviewed. A few individuals were people whom I already knew. One caregiver also took on the role of finder of participants and she was of great help to me. But numerous people who were asked to participate declined to do so. They either ignored the letters and brochures distributed by myself or care-facility staff members, or told us they were simply too busy to participate. Therefore, those individuals
most deeply involved in caregiving, and perhaps those most isolated and in need of assistance, may not be represented in these pages.

After an initial meeting or phone call, generally one major in-depth interview was conducted in which a life history and an eldercare narrative were recorded. Sometime afterwards a second interview was set up to go over the transcript. During this second interview a lot of valuable information was also obtained and I made fieldnotes after each meeting with a participant. Then besides the regular interviews, I talked (either over the phone or in person) with several of my participants on other occasions. Also, I remain in contact with members of the groups included in my study and, in a sense, these individuals have acted as so-called key informants. For example, one of the participants is a neighbour who lives within a few blocks of my home and I am in regular contact.

In retrospect, any difficulties I experienced finding participants also may have been due to my decision to conduct "multi-sited" research (Marcus, 1995). This is research which is spread out over a number of sites of "observation and participation." In my case this meant different care facilities, caregivers' homes, a hospital, and various other locations in both Vancouver and other local municipalities. Multi-sited research contrasts with traditional ethnographic research which is generally sharply-focused on one site and one cultural group. Although working at multiple sites and with three ethnocultural
groups broadened my coverage of caregiving situations and issues, my nomadism resulted in less familiarity with one site and one group than ethnographic fieldwork has traditionally demanded. It also encouraged me to wonder: Can my work even be called ethnographic? The real advantage of multi-sited research, however, is that it facilitates the interdisciplinary investigation of "more complex objects of study" (Marcus, 1995). Marcus (1995:105-110) suggests that this kind of study, by its very nature, concerns mobility and attention to hierarchy. Instead of a deep involvement with one location, a researcher might wish, as Marcus suggests, to follow the people (for example, migration studies); follow the thing (such as commodity-chains); follow the metaphor (see Emily Martin's work on the immune system); follow the plot, story or allegory (tracking situated stories of social memory, for example); follow the life or biography (for instance, tracing the lives of scientists or a family dynasty); or follow the conflict (such as Dara Culhane Speck's study, An Error in Judgement: The Politics of Medical Care in an Indian/White Community, 1987). Marcus also suggests that traditional, single-site ethnography can be viewed as a fore-shortened project that "examines its local subjects' articulations primarily as subalterns to a dominating capitalist or colonial system" and is only "local circumstantially." He also suggests that in multi-site research an articulated "system-awareness" is crucial and, furthermore, that the ethnographer can act as a "circumstantial activist" in various locales.
In a way, I feel like I have been doing fieldwork in the Vancouver area all my life, or at least during much of the last twenty-five years—not just since January 1997. I feel uncomfortable specifying the moment my current fieldwork began. Did it start 15 years ago and on subsequent annual visits, as well as through long and frequent phone calls with Mom before and after she became a widow? Did it begin when I started interviewing her back in the late 1980s? Or, was it when I arrived back in British Columbia in 1994 and began helping her a little bit? In the summer of 1996 when my husband and I visited Slocan and New Denver, where people of Japanese ancestry had been interned, was that part of my fieldwork too? And, what about decades earlier when I first read about the internment of Japanese Canadians at Hastings Park? Or when at some dateless time I learned that my father, a Canadian citizen born in Italy, was asked to resign from his job on a coastal ship during World War II because of his Italian ancestry.

Bakhtin has helped me clarify some feelings which I have gradually become aware of over the years, and especially since returning to Vancouver in 1994. These ideas have affinities with Bakhtin's idea of chronotope or time-space which he illustrates with reference to Goethe's visualization of time (Bakhtin, 1986:41-42):

Let us sum up our preliminary analysis of Goethe's mode of visualizing time. The main features of this visualization are the merging of time (past with present), the fullness and clarity of the visibility of the time in space, the inseparability of the time of an event from the specific place of its occurrence (Localität und Geschichte), the
visible essential connection of time (present and past), the
creative and active nature of time (of the past in the
present and of the present itself), the necessity that
penetrates time and links time with space and different
times with one another, and, finally, on the basis of the
necessity that pervades localized time, the inclusion of the
future, crowning the fullness of time in Goethe's images.

Although my feelings are usually kept private, I reveal them
here because they may help to explain why I wanted to undertake
this particular study.

Currently I am living in the Vancouver Heights area of the
City near Boundary Road (which separates Vancouver and Burnaby).
From my backyard and on walks around the neighbourhood, I am
afforded a magnificent view of Vancouver. Part of what I
immediately overlook, however, is Hastings Park, and from my
position in the Heights, I experience what Bakhtin refers to as
synchronism or "the coexistence of times at one point in space."
Bakhtin (1986:41-42) says that "the space of Rome, revealed for
Goethe the 'fullness of time'" with its images of historical
events, and so forth.

Hastings Park conjures up all sorts of memories and images
for me. As a child, I used to walk to the old Forum to skate,
and my brothers, as well as my son in the 1990s (on in-line
skates instead of ice skates) played hockey there. It is also
the site of the Pacific National Exhibition which marks the end
of summer by turning the whole area topsy-turvy for a couple of
weeks every year. This used to be a special time and place for
our family. My father invariably played in bands at the
Exhibition, and I remember Grandpa giving us money to spend on
rides and games. Later mom and I worked in hamburger stands, and my entrepreneurial older brother set up a parking lot. The annual excitement with its wonderful smells, sounds, and sights, deeply pervaded our lives.

Now when I look down at those grounds, memories are bittersweet. Interwoven with the remembrance of midways and fireworks are images of people and children held captive in animal stalls!

I also wonder about the future. More vivid now is the realization that all of us are at risk in a society in which discrimination and racism sit side-by-side with equal opportunity and acceptance. As the saying goes, "If any of us is oppressed, then we all are." This dissertation, therefore, is a kind of ethnographic study of connections between ethnocultural groups, genders, and selves. In a way what I am doing is taking the present-day world of eldercare as an ongoing, moving discourse. ElderCare narratives are textual windows into that discourse, and I am a positioned observer watching myself interpret these narratives as well as construct the larger texts of which they form a part.

Now that interviewing and participant/observation are finished, I am still very interested in, and linked to, the people around me, some of whom are caregivers. These are people who are part of my home-base, neighbourhood, community, and also part of the field. I suppose, therefore, I will still keep asking questions, listening to responses, participating in
activities, writing in my journal, and in a way, remain at home/in the field....

SUMMARY

In this Chapter, I presented information about historical and contemporary contexts which both constrain and give meaning to caregivers' lives and narratives. Such information includes descriptions of historical positioning and cultural representations of the groups appearing in my dissertation. I also presented information concerning contemporary social and demographic contexts and my own positionality.

In the next three chapters (Chapters 4, 5, and 6), I shift to the eldercare narratives themselves. In general terms, the eldercare narratives are presented in order to demonstrate what meanings are being given to caregiving among individuals of Anglo, Italian, and Japanese ancestry in specific contexts. I hope to convey some understanding of why caregivers agree to undertake unpaid eldercare work, what has been their lived experience, and what are the perceived effects of caregiving. Furthermore, I want readers to become aware of the ways in which the narratives have been crafted and the ideological potential of these seemingly neutral stories.
Notes

1 The novel Memory Board by Jane Rule (1987) is striking because it contradicts gender and ethnic stereotypes of white, upper middle-class Canadians of Anglo heritage. It depicts both a heterosexual male's and a lesbian's loving care of a woman whose memory is slowly deteriorating.

The choice of a beginning is important to any enterprise, even if, as is so often the case, a beginning is accepted as a beginning after we are long past beginning and after our apprenticeship is over. (Edward Said, 1985)

My arrangement of material in this and subsequent chapters represents a critique of inflexible, concrete categories (or the impression thereof). For example, I interrupt Othering (Fine, 1994; Kincheloe & McLaren, 1994) by refusing to create and reinforce putative difference through employing an analytical framework which groups narratives on the basis of ethnocultural labels (which, in themselves, suggest bounded cultural differences). Likewise, I reject a presentation founded on personal characteristics, such as kinship designations, which would concretize a framework structured by fixed, rigid, uni-dimensional social identities or caregiver/care-recipient dyads, like mother/daughter or wife/husband. Such labels, categories, and frameworks occlude convergence, overlaps, and connections between people. They hide complexity and promote static comparisons, as well as the identification of only superficial correspondences and differences.

Formulations like these make it easy to Other—that is, to view certain people as different from, and inferior to, oneself and one's we-groups, and to disregard the fact that there are bound to be all kinds of similarities and differences between individuals and groups. Othering means viewing ethnocultural groups as homogenous, and sometimes as exotic or culturally
frozen in time (Sara Mills, 1997). Othering also makes it easy to reproduce the ideology that Canada is comprised of fixed, discrete ethnocultural units each composed of people who look differently, behave differently, and think differently about just about everything, including eldercare.

Sara Mills (1997:119) argues that texts can provide opportunities for contestation as well as acceptance of images, and they frequently display "gaps, contradictions and inconsistencies." Once a text containing an inflexible organizational framework is in place, however, it tends to channel thinking in certain directions. Unintentionally, it can become ossified and eventually become internalized and unnoticed.

I employ a framework, therefore, based on assorted themes. And through the use of this framework, I suggest the fluid criss-crossing of ideas and experiences. Although immediate and more remote contextual factors are consequential, as the author in this chapter I temporarily step aside and spotlight the voices of caregivers. In other words, it is from a more distanced, meta-textual position that I comment on the eldercare narratives, even though it should never be forgotten that the narratives have been produced through face-to-face encounters. Then in Chapter 5 I focus on the immediate factors of co-construction and in Chapter 6 on questions concerning macro-contextual meanings.

The themes I discuss emerge from the implicit contexts of position, language, memory, emotion, dilemma, family, home, and the process of representation itself. Or one could say that all
these factors are embedded within each narrative, and, in a sense, are both text and context. But it should also be remembered that it is impossible to focus on themes without, in a way, sacrificing context.

The narratives I present are filtered through my own interpretative lens and are affected by my positionality. But since eldercare narratives are personal experiences shaped into narrative forms, I am somewhat loathe to interrupt these forms for fear of separating an author from his/her work. Bakhtin (1986:160-161) even goes so far to maintain that,

A work's author is present only in the whole of the work, not in one separate aspect of this whole, and least of all in content severed from the whole.... We see the creator only in his creation, and never outside of it.... [and] we feel his presence most of all in form.

But it is up to me as the writer/ethnographer to analyze the narratives and to present excerpts which illustrate themes and sense-making processes. Reproducing each transcript in its entirety would mean the reader would have to wade through tedious and tangled seas of words. Therefore my selection, titling, organization and identification of excerpts is necessary--although these are not tasks to be taken lightly, because as Bakhtin (1981:340) also cautions:

...the speech of another, once enclosed in a context, is--no matter how accurately transmitted--always subject to certain semantic changes. The context embracing another's word is responsible for its dialogizing background, whose influence can be very great. Given the appropriate methods for framing, one may bring about fundamental changes even in another's utterance accurately quoted. Any sly and ill-disposed polemicist knows very well which dialogizing backdrop he should bring to bear on the accurately quoted words of his opponent, in order to distort their sense.
Patti Lather (1991:90) also draws attention to the "end of description." She explains that we do not so much describe as we inscribe. The cases I cite, therefore, in addition to being less than innocent descriptions or "clean" interpretations (Rosaldo, 1993:69) are inscriptions of positioned views of the worlds studied (See Denzin 1994:510). In essence, then, my inscriptions are also concretized versions of dynamic, fleeting caregiving worlds which have become fixed in written texts, and thereby bestowed with the permanence of snapshots or engravings. And, as such, they can be read and reread, interpreted and reinterpreted, used as templates, and otherwise employed in various contexts in continuing ways, which are beyond my control, much less that of the speaking caregiver/author.

In general, I present excerpts that offer readers a chance to learn more about particular caregiving experiences, as well as to better understand the interpretative processes through which people give meaning to their experiences. In other words, in choosing the cases, I am "leaning toward those cases that seem to offer opportunity to learn" (Stake 1994:243). I have purposely selected material which allows readers to vicariously experience (as far as is possible) caring for an elderly relative or friend in a specific situation. I thereby hope to extend readers' awareness of the caregiving experience and specific issues of eldercare, and to further the knowledge-base upon which matters such as care practices and policies can be decided upon (with regard to day care, respite, and so on). I also hope that the
chosen excerpts will provide insights into the entire process of narrative production. In particular, I take pains to emphasize the significance of context to narrative creation (increasingly so over the next two chapters), and to downplay the narrator/caregiver as a solitary island, isolated from listeners and social influences, simply telling his/her monologue in a vacuum.

**ORIENTATION**

My primary conclusion from the material is that although there are major differences among the caregivers I interviewed in terms of history, racialization, ethnicization, gender oppression, care situations, and so forth, all caregivers face similar problems which revolve around care and justice, personal sacrifice and service to others, and emotional ties.

The first set of excerpts highlights the theme of acting morally or *Doing the Right Thing*. In their narratives caregivers struggle to define what is just in the context of family responsibility and reciprocity, explain how and why they try to do what is right, and demonstrate how barriers can constrain moral action. In these excerpts, narrative is an idiom of moral debate. That is, narrative functions as a vehicle through which individuals can verbally work through their concerns, worries, decisions, and dilemmas.

In the second set of narratives which concern reciprocity/family responsibility, individuals justify their decisions to caregive (and the amount and type of caregiving they provide) by evoking emotionally-charged ties and personal worthiness. Here
narrative functions as an *idiom of emotional expression* more than anything else.

With the next set of excerpts, I turn towards demonstrations of individual agency and negotiation. I present ways in which people respond to the call to care---through mixtures of accommodation and resistance. I also remind readers that care-recipients themselves possess various degrees of power to act in the world. Narrative, in the cases presented in this section, functions broadly as an *idiom of negotiation*. In each case, individuals describe how they negotiate whether or not to care and the parameters of their involvement.

Finally, the fourth set of excerpts describes larger worlds and supernatural systems of knowledge which underpin eldercare. In this and other sections, I also refer to ideologies which are linked to gender, race/ethnicity, class, and age. For example, in their narratives, two of the caregivers express humanitarian concerns about older people, the government's failure to provide adequate resources for their care, the treatment of older people in institutions, the use of pharmaceuticals, and so forth.

All the eldercare narratives in the final set address systems of understanding and knowledge and, in a sense, narrative functions here as an *idiom of ideological expression*. In the narratives, there is evidence that systems of belief are not just imposed upon caregivers, however. Rather, knowledge possessed by individuals has been dynamically shaped, with emotion, logic and creativity, to meet their own present needs and desires.
REASONS FOR PROVIDING/NOT PROVIDING CARE

A) NARRATIVE AS AN IDIOM OF MORAL DEBATE: DOING THE RIGHT THING

Material is presented below in which a core concern is moral action. Some participants report doing the right thing. More typically, constraints and limits are recognized, and caregivers describe their negotiation of a balance between personal sacrifice and right action. People also query what really constitutes right action too. That is, they struggle to define what is the right thing to do and narrative functions as an idiom of moral debate.

Caregivers report multiple motivations and moral dilemmas. My analysis points to assorted meanings and messages, as well as difficult quandaries, which are talked about or talked through during narration.

i. The Right Thing to Do

In the following case, Roy, a 58-year-old business executive of Anglo ancestry, describes his reasons for looking after his 95 year old mother. Together with his wife, Lynn (whose motto seems to be, "you get; you give"), he visits, keeps in touch by phone, shops for groceries, makes repairs around her condominium, and does other things to help keep his mom happy. There are limits beyond which Roy is not prepared to go, however. He would not, for example, quit his job. Lynn believes in reciprocity, but Roy says that he does not think of watching out for his mother as a duty.
This Is What You Do

...within reasonable expectations, I guess....Or if she required 24 hours a day care, I wouldn't provide it--but when people do that, I find that it's a real imposition.... There's a limit that one should go to, as far as I'm concerned....

It's the same as if people go into hospitals. I mean--if things are practical (I guess we are the product of practical raising)--and the thing is with some of these people who truck up day after day after day to see someone who is laying in a coma because they think it's their duty, it doesn't bother me at all and I wouldn't do that. If there's some way you can have value or see somebody or talk to them or whatever else--communicate--then that is fine or if they can't communicate but they know you're there, it would be fine to some degree, right? But I never think of it as a duty....It's well within the acceptable bounds....

...[We are not] trying to change our position in the pecking order or anything else, right? It's interesting like it is an absolute paradox....If you actually drew a profile of someone who should get very little support and have very few people go to see her--right?--she'd be on the top of the bloody list, right? And yet, and I've puzzled about this, I mean this is an interesting subject, but all of them want to do it and none of them do it out of fear or none of them do it out of currying favour or anything else, right?

Like there's my dad, I'm a lot like he was, just: You do what's right. And also partly with her, it's like, on the other side of the door there is no...there's not a lot of warmth or love as such but.... She's practical so that's what you are, you're practical too, right? So she lived in a practical way and you do it in a practical way.

...well, I guess it's the safest...98% of the people have a baby and raise it and 2% don't, right? You have a mother and you look after her. Two percent don't, or whatever, or maybe 50 percent don't. You don't think about it. If you ask a person why they looked after a baby, Well, yeah...

I quote Roy at some length because he outlines several ways of thinking and talking about doing what is right through narrative. He also tends to remain aloof and analyze situations (so he told me). His reasons for caregiving generally constitute a moral imperative which he suggests has little to do with duty,
emotion, or self-interest. Instead, global principles of fairness, practicality, naturalness, and family tradition are evoked as rationales for caring work, and he seems to view caregiving as determined by a set of rules. He says that this is, "what we should do.... I mean, this is what you do."

Roy also presents caregiving as something that is or should be modified to fit local circumstances, so that it remains inside the limits, "within reasonable expectations," and, "well within the acceptable bounds."

Roy's language and perspective suggest his long association with the worlds of business and free enterprise with their allusions to value, work, logic, practice, competition, investment, self-reliance, individualism, authority, hierarchy, percentages, rules, and communication. In fact, he told me that his mother is quite easy to care for because she "works with" him. He also tends to commodify, for example, when he talks about drawing up profiles, and ranking those profiled hierarchically on a list—although there is a humour in his words which suggests that he is deliberately exaggerating.

Some participants construct narratives about more conflicted endeavours to act morally. Sue, for example, wants her mother to leave long-term care. Her mom is unable to live alone, however, and Sue's husband refuses to live with his mother-in-law. Sue, therefore, visits her 94-year-old mother for several hours each day at her care facility.
Throughout Sue's narrative, ethical issues and moral tensions loom large. Sue's story is primarily concerned with social relations with others, such as her mother and husband, who are seen as the cause of the amount and type of caregiving she now provides as well as the degree to which she is able to do the right thing. She describes her moral dilemma this way:

...emotionally it just tears you to pieces...and if you've got two sides pulling at you, it's just horrible.

Lucy, a 40 year old woman of Italian ancestry, has a different problem—but one similarly related to emotional conflict and family ethics. Lucy looked after her Aunt (who raised her and was like a mother to her) for several years. Then her Aunt's dementia worsened—even though a medical "specialist" assured Lucy she was "just getting older." So Lucy's husband, also of Italian ancestry, decided that they should bring her into their home because Lucy was spending too much time "always running down there" to her Aunt's house (often dragging her young children with her). Lucy breathlessly recalls, "The first day was a total nightmare..." and "I mean, every day was another nightmare, every day."

One day while she was at her part-time office job, the housekeeper left early. Coming home to find the house smelling of gas, Lucy decided that her children were in danger, and that something had to be done immediately. She got her Aunt admitted to Emergency, then a few days later was able to place her in a facility. She remembers leaving the facility, sneaking away:
I left. I finally left. But she didn't see me and I knew they were able to keep her there. And that's when, of course, the guilt set in, and then I felt that I was doing the wrong thing.

Several ethical questions are raised by the above excerpts. These are the same questions which are found in the general caregiving literature, in participants' eldercare narratives presented in other chapters, and in discussions throughout the dissertation. They include: How should care be distributed (that is, between men and women, spouses, siblings, formal and informal care-providers)? Is it necessary to care about someone in order to care for them? How are principles of care played out in concrete, local situations? What are the roles of emotion and reason in relation to abstract, objective principles of caring? What, if anything, do we owe our parents, or our spouses or other loved ones for that matter? And what material and socio-cultural factors constrain our ability to do the right thing? All of these questions--and others--constitute dilemmas for caregivers and bear on what meanings they attach to their work.

ii. Reciprocity/Family Responsibility

In the following cases, of Maya and Joy, in addition to caregiving as a family responsibility (and perhaps obligation), and other factors associated with upbringing per se, there are strong historical factors which prompt a desire to provide care. Their narratives raise moral issues concerning care for the elderly based on history and suffering.
Maya is a retired professional, widow, and only child. She recently moved back to Vancouver from Central Canada to care for her 90-year-old mother who has diminished mobility and failing memory.

According to Maya, caregiving has been something natural and expected—in fact, something she has thought about doing for more than 20 years. She says that gradually, especially over the last 2 years, she decided that her mom should not remain on her own. Maya told me about herself and her mother before describing her current caregiving situation:

**Mother Did More Than Her Share**

Well, I'm a Canadian of Japanese ancestry....born in Vancouver, and it's interesting how people these days wonder where...why I speak English so well. It's the kind of thing that Asian Canadians get all the time, but I usually have to tell them: 'My grandparents came before yours.'

My grandparents actually came in the early 1900s. And my mother was born in British Columbia, but her parents were farmers and so they weren't able to farm and look after children, and send them to school, and there weren't any good schools nearby anyway, so they sent their first three children to Japan to be educated.

So, my mother—although she's Canadian born—hasn't had even one day of schooling in English. My father, however, was born in Japan. His father was an early pioneer in lumbering around this area. But he was left in Japan to sort of look after the ancestral home. But when he was 29 or 30, he didn't want to be there by himself, so he came—well, he was with his grandparents—and so just about that time my mother also returned to Canada, after getting her secondary education and teacher training, I believe it was. So it was—what do you call it?—one of those arranged marriages.

But anyway I was born in Vancouver.... And so my early years I went to Elementary School, and they had a shop—although Dad had studied in Japan. And Mother had a diploma to teach. Of course, they couldn't enter their own professions here, so they made the shop. But with the Second World War, we were all evacuated and sent to the
Interior. But just before that my mother had TB, so she was in the Sanitorium. Dad, of course, was sent to the Road Camps to work....

So grandmother and I, along with our relatives, were evacuated to a small town in the Interior.

It was a ghost town, a mining town. But after high school in the Interior, I took Senior Matric and then came down to take Teacher's Training.

And so I taught. In fact I guess I was one of the first Japanese Canadians to teach in the Vancouver schools because before the War no Japanese was able to teach in the Vancouver School system--because of the prejudice....

...My parents are Buddhists, and so I left home to study. I was teaching, and then came back to work in the Church briefly, and then went to Japan for awhile to work with Koreans. And it was a real interesting cross-cultural experience, because Koreans are aliens in Japan--just as Japanese were aliens in Canada. I went back to teaching for awhile, got married, became widowed, then worked for the Church again.... My husband and I had always planned to come back to look after Mother, ever since Dad died more than 15 years ago. But I was widowed a few years ago, and so I'm back by myself. But this is what we thought we would do...

...Mother's the second eldest. The oldest brother died--oh, just last winter--and she's the eldest of 5 [who are left out of 7]. Anyway, they're all old and ailing. Some are even worse off than Mother is. So I can't ask them to come [to help out]. And their children are all busy and they are concerned about their own parents, so.... [laughs]

I feel it's quite fortunate that I'm able to do this now. And it's a family pattern, but something I've done quite willingly.... In fact, I've always felt that Mother did more than her share of looking after her mother-in-law--over 13 years when she was bedridden. So I think it's time that someone looked after her.

Joy is a 55-year-old woman who is part of a family network composed of more than 35 individuals. She is a nurse by profession, as well as a provider of care to her 99-year-old Issei (1st generation) Grandmother who came here from Japan as a picture bride² around 1915.
At the time of the interview, Joy, family members, as well as a paid "baby-sitter," were involved in a kind of round-the-clock vigil. This was occurring in a busy facility, while Grandma's long life quietly drew to a close.

Joy describes caregiving as a kind of natural thing to do—but one which is socially regulated to quite an extent. As Joy says: "There is a process in this family for Grandma's care." A sequence of events occurs when the family has to do anything important, and this occurs as Grandma lies dying. Her sons, Joy's uncles and the decision-makers, arrive from out of town. The eldest son handles the finances, releases the funds, and so on. The hands-on caregivers, like Joy, provide "comfort things" like language translation and back-rubs, and anything else she requests.

The family feels that Grandma, at nearly a century old, has earned care. This is the way it should be. Joy also calls caregiving the family's responsibility and their obligation (See Appendix II for Joy's story: Grandma Earned the Right to be Spoiled). In the following excerpt, notice how Joy talks about culture. To her, culture is something concrete and static. Years ago, her grandmother transported Japanese culture to Canada where it remained unchanged and is now outdated. She says,

...we've hung on to something that she brought with her when she was 17. And that's the only experience we have because none of us have been to Japan, so consequently we grew up in kind of an oddball Japanese culture that's now very old-fashioned.

My view, however, is that individuals are always molding abstract
traditions to fit local, contemporary circumstances and that these everyday improvisations make up the cultural—not the exotic abstractions which may be deemed more authentic. Traditions are invented and they are constantly being re-invented at the personal level.

For Maya and Joy stories about the past mingle with present-day moral realities so that "the past has continuing relevance for the present" (Tuchman 1994:313). In their narratives there are multiple traces of a history which some people tend to forget: back-breaking labour inside and outside the home; continuous racial discrimination which causes deep pain and resentment; career interruptions and lost opportunities—as well as the horrors, shame, disappointments, upheavals, and dislocations of War. All these kinds of remembrances constrain and facilitate our willingness and ability to give care to seniors.

B) NARRATIVE AS AN IDIOM OF EMOTIONAL EXPRESSION: CLOSE TIES
i. Ties that Bind

A theme that runs through the narratives concerns emotional ties between the caregiver and the care-receiver. A wide variety of ways of talking about these ties occurs with some caregivers hinting that care has been or could be curtailed because of tensions between themselves and the care-receivers.

Audrey's eldercare narrative contains some hear-say. This is a story-within-a-story which illustrates how some bonds
between caregivers are ambivalent at best, and also how women are not genetically-programmed to be nurturers.

*Some Women Can't Give*

There are *some* women who can't give, who are very cruel, very cruel....

I have a friend who was going to leave her husband before he had a stroke, and now because he's had a stroke, she's got him where she wants him!

And so if he enjoys something, she tells everybody he doesn't want to come because he can't talk. Now she's not cruel to him, but she *controls*.

Many caregivers I talked with, however, stressed closeness to a loved one or family closeness as the main reason for caring. Their stories contain themes of pathos, and are often highly emotional.

In the case of a much-loved spouse, for instance, there are points at which I found the caregivers' situations overwhelmingly poignant. Lorraine is a 66-year-old woman of Anglo descent who appears young and zestful. She has been looking after her husband, Jim, for about 10 years. Both she and her husband grew up in Vancouver and have been together for over 45 years. They have four grown children.

Jim is now in his early 70s. When he was 50 years old he was diagnosed with a chronic disease. Carefully planning his meals and activities, Lorraine helped Jim manage his sickness and he was fine for several years. Then, during the week after he retired, he suffered a serious stroke.

The stroke left Jim paralyzed and weak. Lorraine says he could still speak and his mind was fine, but his body was not.
For years he was cared for by Lorraine at home, with the help of her unmarried son, as well as homecare workers. But over the years medical problems have increased his care needs, so that now he divides his time between home and an extended care facility.

Presently a family crisis is unfolding, however. As Jim's care becomes more complex and difficult, he faces full-time institutional placement. Lorraine stresses their closeness, saying that she and Jim "haven't had an argument yet--but we've got very close to it!" She talks about caring for Jim at home, then her voice drops very low, and she says, "I didn't--at the time--I didn't want to give up our home life." Then, "But you can only do so much." Currently Lorraine still manages to bring Jim home twice a week, but clearly she is distraught over Jim's unstable condition which threatens to finish their "home life" completely.

Then there is Mike, a retired skilled labourer who is nearly 80 years old. He is descended from parents who emigrated from Italy during the first quarter of the 20th Century in the first of two waves of Italian immigration to Canada. For many years, he has cared for his wife, Beth, who is also 80. Twice daily he makes his way to a care facility to visit Beth, ostensibly to make sure she is alright. Beth is severely disabled, brain-damaged, and can neither speak nor see. To me she seemed comatose, unresponsive. Mike oversees her care, however, argues with the staff, and says she is "all that matters" to him. Why
has Mike continued caregiving all these years? Very emotionally, he tells me that he loves his wife:

*Caring Through Love*

Well, I love the girl and I want to be of any help that I can to her. If I can give her 5 minutes of happiness or make her feel comfortable, I'm going to give that to her. My family--my son and daughter--they are mad at me because I won't spend my time with them. I'm with Beth all the time. They don't want me to go there everyday like that. I said, 'As long as she's alive, and I don't know when she needs me, I'm going to be there to see if she needs me. If she needs me, I'll stay longer. If not, I'll leave early. But you guys keep your mouths shut, and don't tell me what to do. She's my wife. And you should have more respect for her because she's your stepmother....'

Mike also describes a close relationship with Beth's whole family and what a terrific family they were. He tells a story, for example, about how much he especially enjoyed his elderly father-in-law and how, during the 1950s, every week he would treat him to wrestling matches at the Forum at Hastings Park. Mike would take great pleasure in watching his father-in-law "let his hair down" while excitedly watching the matches.

In the following case, the caregiver, Nina, also stresses the closeness of the whole family, and particularly the strong ties between her youngest daughter, Anna, and the care-recipient (that is, Anna's grandmother). Nina describes this with much flourish in the context of the home death of her mother. During the narrating it was clear that, among other things, narrative was functioning as an idiom of emotional expression.

Nina is a Canadian woman of Italian ancestry who is in her mid-50s. She immigrated to Vancouver from Italy as a young woman in the early 1960s. Here she joined siblings who had migrated in
the 1950s, during the second wave of Italian immigration, while she remained in Italy to complete her university education. Then Nina stayed home for 20 years to raise her six kids. She also occasionally worked part-time and now works as an administrative assistant in an educational/religious setting. This position is something that she has grown to genuinely like. She says this is really what she was "meant to do." In her job, she not only performs administrative work, she also helps comfort those in need of counselling.

Nina describes having her mother recently die at home as something she wanted to do for her mom, despite her sister's advice, and despite her fears that it would seriously upset her daughter, her family as a whole, and herself. She told the following story with her voice sometimes shaky:

**We Were Very Attached to Mom**

That was hard for me to do because my sister was saying, 'Oh, don't do that. Just let's bring her back to the hospital. Everybody dies in the hospital. She's going to die in this room, and then maybe your kids are not going to want to go into that room.'

And I was expressing this to the doctor. And I also said Anna, the young one, was very attached to her (and she's very emotional, and when my father died, she was 9, and she sort of got sick). So, I said, 'I'm worried about her.' Y'know, she was 20, 21 at the time; still very emotional, she's the baby of the family. I said, 'I'm worried about Anna. If Mom has to die here, and she's gonna be here?' He said, 'Don't worry. I saw her taking care of her grandmother. She's doing fine.' I said, 'Yes. But if she dies here....' He said, 'Don't worry, she'll be fine!' So I said, 'Oh, okay.'

I decided, let me do this for my mother because I know she would have really loved that, to die in the home, like they
did in Italy, y'know? So I told my sister, 'No. I'm gonna do it. I'm gonna keep her here. And I'm going to let her die here.'

And I said to everybody, 'If you are here, and I'm not here, and you know that this is happening, and Anna is around,' I said, 'find an excuse and send her to the drugstore or somewhere.' I said, 'Send her somewhere so she doesn't have to be here.'

But it happened at night. They were all asleep. Pia was awake though, so she came and Tony got up and Nick got up, but Anna was in the other room, and she didn't hear anything. All this commotion, but we were trying to be quiet.

And Dr. Ricco comes, and by that time my mom had passed away. And she passed away very peacefully. I held her hands. And I said, 'Mom, we love you.' And she nodded with her head. And I think she was still waiting for something or somebody to help her, but I knew she was leaving us. All I could say is, 'Mom we pray for you.' And when I said that a tear came down from her eye.... And she understood, I think, that she was going. But it was very, very peaceful.

So all the kids came to see her, and I said to Pia, 'Be quiet and don't wake up Anna.' Then Dr. Ricco came, and y'know, he looked at her, whatever, and he said, 'I'm sorry.' Talked to all of us, and then looked around, and he goes, 'Where is Anna, the girl that was with her grandmother all the time?' And Pia goes, 'She's asleep and mom doesn't want me to wake her up.' And he said to her, 'You go wake her up right now.' He says, 'Go wake her up, and tell her to come and see her grandmother dead.' I didn't know this. He told me not to wake her up. So she comes. And when I see her come, she goes over there, she kisses her grandmother and she cries. And she was fine. She was fine. I said to Dr. Ricco, I said, 'I have to thank you for doing that.' He said, 'I knew she'd be fine.' She was fine.

All she did, when we came from the cemetery, they had... When the boys were carrying the coffin, we gave them a rose. We sort of had, like a little wedding there, rather than the funeral. They had the flowers, and the girls had little flowers themselves. And when they came back, Anna and Nick put the flower on the pillow. I found it there. But...she was fine, and so was everybody else, and so was I.

In this section I have tried to show how close personal ties (usually of love and affection) between caregiver and care-recipient, and amongst members of the whole family, can motivate
caregiving. Caring about someone is cited as just as powerful a reason for caregiving as duty or reciprocity, and some people suggest that this is the only reason for participating in care. Lorraine summarizes this point of view regarding spousal care, but other caregivers agree that without emotional ties between interactants, it is virtually meaningless work. She says,

Most men couldn't look after an invalid--and a lot of the women--if it wasn't a good relationship, why should they bother? I mean you'd be pretty stupid not to figure that one out.

ii. Personal Worthiness

In some of the eldercare stories there is a desire to portray the care-receiver as an individual who is especially worthy of care as if to rationalize the caregiver's involvement. This is in contrast to narratives which focus on duty, or the social shaping of caregiving, or feelings of personal attachment.

Worthiness is not necessarily associated with affection, need, advanced age, disability, disease, or frailty, however, nor is it due to past deeds, such as sacrifices or contributions to family success, although all of these may be cited as justifications for caring. Rather what I want to emphasize here is a desire to identify individual characteristics of the care-receiver as reasons for caregiving. Examples include special personality or character traits, gender, their traditional ways, or intersections of various factors.

By centring on the care-receiver close-up, the caregiver downplays the fact that caregiving is a way of thinking, feeling,
and behaving embedded in historical, geographical, social, and cultural processes.

In the interview material, Roy half-seriously asserts that although his mother should be the last person people look after, instead she receives considerable attention. This is a puzzle to Roy. This fascinates him. She possesses some kind of mysterious charisma it seems, and a "tremendous mental capacity." Audrey's mother is depicted as particularly feisty. She refused to stay in an institution! She shredded her diapers and threw things at staff members. Amy tells me that her mother is always cheerfully giving and selflessly doing for others, and she confides more than once that, "She's almost a saint."

The following case likewise focuses on putative characteristics of the care-recipient which are woven into the caregiving narrative in order to persuade addressees that care, or its lack, is surely warranted despite how the caregiver feels about the care-receiver. Individual character is the basis for providing care, plus it seems to function as a means through which coherence and telos are realized in this narrative.

Jane is a white woman of Anglo heritage from a small Prairie family. She is articulate, well-dressed and attractive. Her age is about 62 and she cares for her 93 year old mother, Margaret, for a few hours 5 days a week. In the 1950s Jane moved to the Coast after earning a Nursing degree. Here she worked as a nurse for many years. She also raised 3 children who are married and
live out of town. Recently widowed after helping her husband through a devastating illness, Jane spends much of her time visiting her mother at a Vancouver care facility and participating in her everyday care.

Unlike some residents in this facility, Margaret is well-educated, articulate, attractively dressed, and mobile. In fact, she gives the impression of still being a powerful individual. Margaret receives considerable attention. This may be due to her personality, character, education, ethnicity, class, and her interest in and ability to talk to people. Jane's involvement in her care also definitely makes a difference.

Jane and Margaret are both going concerns and interested in whatever is happening at the facility. In our interview, Jane entwines her life story with her mother's illness story and her own tale of caregiving. She begins her narrative brightly:

Mom is Really Sweet

She's a real sweetie and it's no trouble to look after her. Well, for me it isn't!

I decided just last year that I would retire and, as I was telling you, my mother went to live at an intermediate care facility in 1989. And there she remained, until a year ago. So that would be early '96, when, because of her medical condition, she could not look after herself any longer. So we admitted her to Extended Care.

She realized that she could not look after herself and she couldn't even walk--although I had a walker for her--but it was too painful for her to even move at that stage. She was in bed, almost totally in bed, for about 4 weeks, and she was not doing too well but she finally persevered, and she's just wonderful now. She's getting up, moving around in the wheelchair, and walking with her walker, and she gets exercise 3 or 4 times a day around the ward.

She was wonderful. She made up her mind and just... It was
just bingo!: 'I can't live here any longer. I'll have to go to hospital and you'll have to move my things out of here.' So that's what I did.

...the 4 sisters were all professionals. My mother is 93, her next sister is 90, and the next one is 89, and the youngest is 85, and they're all very, very unique ladies, I'll tell you. Very bright ladies [laughter].

...she has an amazing number of friends that pop in and see her and she just loves to see people. She's a real people person and she's travelled a great deal, and a lot of the care aides are from the Philippines or from Fiji or from...she's never travelled to India, but she's just got memories from these trips that she can bring out as she talks to people about their home, and, you know, their customs. So people like to stop and talk to her, so she's very popular because, as you know probably, there aren't that many people on her floor that are as spry [?] and as alert as she is.

[A person from] The library comes to see her every month and she now reads the big print books, and they bring her about 12 books. Some of them she'll pick up and she'll say they're dreadful--but she'll persevere. But she's always been a great reader.

And I have a little television for her and she watches her programs which are Jeopardy and Wheel of Fortune, and she's a great sports fan...

She's never at a loss for words and, as I say, I bring her here every Sunday and as soon as she sits down, I put the phone in her hand, and I dial all her friends and she has a wonderful time for about an hour. She'll talk to her friends so she's a very amazing lady. She really is. So it makes it easier for me to visit with her and enjoy her company, which I thoroughly do, you know? I enjoy going to see her. It's no burden.

Jane also revealed details of the struggle to care for her husband who suffered from Alzheimer's. This was a crisis-ridden downhill slide and Jane says: "I mean they're not living. There's nothing there. There's nothing there." Jane adds,

I look at these people and I think, you know, it's the caregivers that just go through torture. I know it's hard on the patients but they're being looked after and a lot of the time their mind is so demented that they don't
really know what's going on, but it is the caregiver who has all of this to cope with and it's hard. That's a terrible disease.

My solution, you know, because I think you can get very, very depressed, and you can go through some awfully, awfully tough times, but when I look back—especially with my husband, that was the worst experience I have ever, ever, ever gone through and I would never wish it on anybody because it's a terribly, terribly difficult illness to deal with—I think you need all the help you can get. I mean my mother is lucky because she's got her mind, and her body isn't often willing, but at least she's got a very keen mind and we can talk and laugh and joke about things, whereas if you've got nobody to do that with, it's very hard, very hard. Yes, but you must meet my mom.

Just as Jane emphasizes her mother's qualities, Julia suggests that the gender of the care-recipient, and the gendered behaviour of an Italian man of his age, may be taken into consideration when care is provided. Julia is a 50-year-old woman of Italian ancestry. Julia's representations of herself and her mother contain features of the idealized Italian woman who does everything for her family. In her narrative, for example, there are references to chastity, forgiveness, Church, duty, and self-sacrifice. But Julia also distances herself from the all-encompassing housewife or mamma role her mother still performs. She tells addressees about her mother's caregiving excesses, and her father seems to be represented in stereotype:

_Dad Has Never Had To Do Anything By Himself_

It's hard. It's hard on my mom. It's hard on mom because he was so dependent on her: 'Do this.' And, y'know, she'd do everything for him. So it's harder on her, because she's not sleeping—because he wakes up at night. He wants to go to the washroom, although he doesn't know where he is or..., just wakes her up. But it's put a toll on her too: stressed out. Mom is 80 and she's hyper. Even with her surgeries, still no setbacks. She forgets. She'll go, go, go. She forgets she had surgeries. That she has to slow down.
My dad was really strict with us.... He's stubborn in his ways.... The old-fashion is still in him a little bit, so he thinks that he can.... He wants something, he gets it right away.... He's never had to do anything by himself; it's always done for him. That's why they're spoiled in their way. Our husbands are different. Yeah. The younger generation.

Later Julia snaps out the comment that if her father has to go into a care facility on a permanent basis, then he should because he is difficult to cope with and care for. On second thought, however, she thinks this would be a decision the family would have to make.

The point I want to stress is that caregivers suggest that certain care-recipients are worthy or unworthy of particular amounts and kinds of caregiving, or their own personal attention. Care-recipients are deemed to be worthy or unworthy due to personality or character traits, or as in the case of Julia's father, due to behaviour deemed to result from the intersection of gender, ethnicity, culture, and generation. Individuals may express their feelings about care-recipients in their narratives, but additionally they may emphasize the extent to which particular senior care-recipients are unique or deserve care.

C) NARRATIVE AS AN IDIOM OF NEGOTIATION, EXPLANATION AND AGENCY

What I want to emphasize in this section is how people are able to negotiate caregiving through acts of accommodation and resistance. This aspect of caregiving is important because it affects the extent to which individuals are viewed as autonomous agents who can create new ways of viewing the world and fresh, improved social systems or, conversely, the degree to which
people are envisioned as constrained by oppressive situations and structures.

Caregiving may not seem to involve much conscious choice, and in particular narratives, caregiving is portrayed as beyond the control of individuals. For example, it may be said to creep up stealthily, through habit or tradition, and suddenly be right there. In such cases, the reasons proffered for caring may be virtually absent or appear fuzzy. Alternatively, agreement or refusal to participate in caring work may be described as a vivid moment in time, a genuine turning point. In addition, instances of accommodation and resistance may occur contrapuntally in a single narrative.

I refer to narrative as an idiom of negotiation, explanation and agency in the following cases because caregivers are negotiating and/or justifying the dimensions of caregiving participation through their narratives. Basically, narrators are explaining how present circumstances came about by examining their involvement in conscious decision-making.

i. It Just Happens

Ed is a 65-year-old Canadian of Anglo heritage. He has had major heart surgery and in the 1980s was laid off from an industrial job he held for more than 35 years. He went back to school, but says it was useless because, "I was too old. Nobody would hire me anyway. So I was unemployed for a year and then I retired." Currently he cares for his mother who is in a transition unit at a local hospital where she awaits placement to
a long-term care facility. His mother was widowed young and raised three children on her own on the Prairies.

Ed lives in the Lower Mainland, but his other siblings reside elsewhere in the Province. He does not call himself a caregiver because he associates this term with somebody who takes care of a person full-time. Furthermore, his wife probably does more than he does. Laughingly he suggests, "I'm just the driver." Then he says of his wife, "She's got a bigger heart than me, I guess." Then, "You do what you have to do."

Ed's family became imperceptibly involved in caregiving. As soon as Ed's son could manage a lawnmower, at around age 7, he started to cut his grandmother's grass. This began to be something regular. Expected. Requested. Then, if the grandson did not cut the grass there was guilt.

*It Happens Gradually*

...and the same as everything, it just sort of came gradually, from us taking the kids over there when they were small, and they would mow the lawn, and Mother was living in a house, living alone, so she had to have somebody to talk to, so I was the one that got out of the work by chit-chatting with her while everybody else was busy, and it just sort of escalated from one thing to the next. I didn't have to mow the lawn anymore but there was always something else....

Ed describes his conception of caregiving in the past, positing extended families, and inter-generational co-operation. No doubt this mythicized, essentialized, universalized representation contributes to what he views as proper moral behaviour in the present. He says,

Well, it's changed so much over the last--in my lifetime --where the older people looked after your kids, and were
part of the family, to people being out on their own. So in a way it's better--because they don't work them so hard. And in ways it's worse, I guess.

Mother baby-sat the kids, [and] although my grandmother didn't live with us, she lived with my uncle. She took care of his kids right up until she died.

And so my grandmother and grandfather never did have a home of their own. When they were first married my great-grandmother lived with them, and before she died their son, my uncle, was married and he was living with them. So their whole life was with somebody else in the house.

And I don't think that was so great, but that's the way things were done then.

Ed's narrative does not recount moments of choice or negotiation. He simply does what he more or less has always done, and what he thinks he should do now.

Then there is the case of Audrey (also see Chapter 6) who describes caregiving as something that happens suddenly, and it happens to nearly everyone. She is a 58-year-old caregiver to her 86-year-old mother who suffered a stroke over 10 years ago which left her partially paralyzed. Audrey and her mother are both of Japanese ancestry and both were born in Canada.

Audrey runs a busy household in her mother's small house which she moved into partly for financial reasons some years ago. Although seemingly an up-beat person who copes well with all that comes her way, Audrey tells me that she disagrees with the saying, "God never gives you anything you can't handle." Audrey says that she never decided to become a caregiver, "It's just like getting married. One day it happens." But she also advises that her mother definitely exercised her own agency when she wanted to leave the care facility. Audrey remarks:
I think that if she didn't fight so hard not to be there, I wouldn't have brought her home. So it had nothing to do with my moral obligation, all of those honourable things, it's just that she wouldn't stay there!

ii. A Natural Thing

Often reasons not talked about are the most compelling. Silences also tell stories (See Basso, 1994:57-66).

Caregiving appears, in certain narratives, as the perfectly natural thing to do. It is unremarkable—or at least it is presented as such. Here I am thinking of reasons that have been so internalized, habitualized, buried, denied, or taken-for-granted that they remain unspoken, unspecified, or barely hinted at. Caregivers also may not want to speak because they think it inappropriate to complain or to present anything other than altruistic reasons for caregiving.

Joyce (who is described later in this chapter in the section on Humanitarian considerations) talks about caring for her parents as something natural, something she always "really believed" she would do. Notice that while Ed invokes the past to contrast his current involvement in caregiving, Joyce invokes place (as well as time). She refers to what happens today "in some countries," as if here in Canada elderly people are not looked after at home, even though it is a common and growing phenomenon!

Although her father is now dead, her mom, who is severely disabled, is resident in a care facility which Joyce visits frequently and seemingly happily.
I've Been A Caregiver All My Life

It kind of came natural to me. Yes. Yes. I think I almost have a bit of a guilty feeling that my mother is even in a facility. All my life I kind of really believed I would look after my parents, and felt that is what people should do. And I know in some countries they still do, but I couldn't have had Mom in my house. It's too small and not wheelchair accessible. And their home would have had to be renovated, and.... It could have been done if we'd wanted to badly enough. But I feel that it's coming to visit her.... And if I am away for a holiday for a week or so, I have hired people--agencies, companions--to come in and stay with Mom. I have a sister who comes several evenings a week to visit Mom, and another one who comes one day on the weekend. So she really doesn't lack for visitors.

Likewise Lina, a 75-year-old woman of Italian ancestry, claims that her husband would be lost without her. She implies, therefore, that it would be unthinkable to abandon him:

Fred Would Be Lost Without Me

I have no loved ones in the hospital, but I find I have now a husband who is maybe on the verge of Alzheimer's. It is slowly progressing, but I think he is, you know, handling it. And some days he's good; some days he isn't. He doesn't do any more driving; you have to repeat everything, and then he'll forget about it; but he'll remember things that happened years ago. And some days it can be quite frustrating, and it's something you have to be very patient with. But other than that, I mean he's in no pain--but just very forgetful, very forgetful....

As with others I spoke with, it does not seem to occur to her to question whether she should or should not caregive. She seems to expect it and take it for granted. See Appendix II for more of Lina's story.

iii. Constraints and Resistance

In the following cases, the interplay between social constraints and resistance against these constraints is illustrated. In the first case, Maria feels obliged to care for
her father-in-law. In the second case, Doris refuses to jeopardize her own health and well-being, and her whole quality of life, to become more heavily involved in her mother's care.

Maria is a 55-year-old part-time nurse who was born in Canada and grew up in Vancouver. She is of Italian ancestry. Her mother and father are now in their late 70s, and her father resides in an extended care facility. She is also the main caregiver for her father-in-law who is of Italian ancestry, and who lives with her, her husband, and two adult children in a large suburban home. The atmosphere at the house is often tense. Maria indicates that she resents her father-in-law's presence. At first her father-in-law lived on his own, then he suffered a stroke. Maria tells the following story which occurred after his stroke:

_I Don't Have a Choice_

And they--physio, occupational therapy, all that kind of stuff--had said that he could probably manage on his own, but he said no he couldn't....

Anyway, when we had the meeting--they have the discharge planning, the social worker, and the occupational therapist and the doctor, and the nurse--there were probably about 10, 15 people there. He just sat there and said, 'Well, I'm going to live with my son and daughter-in-law--if she will have me.' And that was it. So basically I didn't feel I was given a choice.

And I thought, _Do I live with the idea that he is going to think that his family doesn't want him? If I say, 'No', I couldn't live with that._ So this is the way it worked out.

...But, it's... it's unfortunate. I have a lot of.... I guess you probably could call them _bitter feelings_...
Like Maria, many caregivers (especially women) feel constrained by social expectations and feelings of duty or moral obligation. Yet there are complex and diverse ways in which individuals negotiate issues such as: a) whether they will caregive or not; b) the extent to which they will provide care; c) the kind of care they will provide; and d) when they will refuse to give care. And care-recipients are not passive either; they also actively influence the caregiving process and sometimes even forcefully shape the extent and kind of care provided. The following case narratives are presented to demonstrate some of these points.

**Refusing to Care More**

Doris is a 69-year-old white Canadian of Anglo heritage who lives in a middle-class Vancouver neighbourhood with her husband and one adult daughter. She leads a busy life which includes helping her children and grandchildren, travelling with her husband, and attending various Church events and social activities. She also lives with her own chronic illness. Doris says that her 87-year-old mother is always complaining that there is little to keep her occupied at the nearby care facility in which she resides, but Doris thinks there is ample to do and that her mother should be thankful for what she has. If she had her mother at home, Doris maintains that she herself could not have the quality of life she now has. By this Doris means she would have to deal with her mother's dominating personality, as well as curtail current social activities. Also her own health would be
negatively affected--and this is an important consideration too. Furthermore her husband would not be receptive to the idea and, in addition, Doris says she would not be able to supply the same level of care that the so-called hospital now provides.

Doris does not consider herself to be a caregiver because she does not have her mother at home. The hospital, therefore, is deemed the caregiver. Doris does as much as she feels she can, however. She says that she enjoys doing it, and would not be looking after her mom unless she did. She also wishes her mother could be happier. She says, "I get up there 2 or 3 times a week and I guess I always feel it's never quite enough...."

To Doris, life is a treasure. She said that a minister who visited her mother told her she was lucky to have what she has, and that some people of 87 have a lot less. But Doris also acknowledges another viewpoint in the following narrative fragment. She says,

It's just sad that this has to be. And I've got an uncle who used to be Jehovah's Witness, and his lament in life is, How could God let people get old and suffer? He just can't relate that to God. That as you age, you suffer. So he just can't see that God can allow this to happen to people. And I mean that's why nobody wants to get old [laugh]. It's sad, pretty sad, and I'm just glad I'm here and close enough too to be able to help Mom as much as I do.

And we travel a bit too so that cuts into it, but I know Mom. She'll say 'Oh, you're going for that long?' You know, maybe 2 weeks or whatever, longer even, and you get back and the time has just flown: 'Oh, you're back already?' (or something like that).

My analysis of the above is that Doris makes conscious decisions regarding the extent of her caregiving. She consciously refuses to do more, and instead gives more control to
the care facility. She is involved in a balancing act between her own needs, those of other family members (husband, children and grandchildren), and those of her mother, and she recognizes that to become the so-called primary caregiver would be to injure herself, and others, in various ways. Although caregiving involves dilemmas and choices, and despite feeling she would like to do more, Doris deliberately resists being swept away by the role and its demands.

In this section I have tried to show how narrative can be an idiom through which individuals negotiate their involvement in caregiving. Now I examine how, through narrative, individuals give larger meaning to their caring work by uniquely embracing humanitarian and religious principles.

D) NARRATIVE AS AN IDIOM OF IDEOLOGICAL EXPRESSION: GLOBAL AND BEYOND

i. Humanitarian considerations

In our interview Ed tells me, "if there's no money, there's no money." The government is "sort of between a rock and a hard place" and vulnerable to being ousted. Nevertheless he says:

I see no reason whatever why the handicapped people, the elderly, in a rich country like this, shouldn't be living in the lap of luxury here. It just doesn't make sense to me.

Several other participants also show remarkable concern for people in general. For example, they speak at workshops, run support groups, sit on family councils, become official and unofficial helpers/volunteers, and act as spokespersons. All of
them also voluntarily participated in my study—many because they hoped the study might help older people as well as caregivers.

The words of Joyce, a 55-year-old woman who grew up in East Vancouver but now lives in a nearby municipality, illustrates the theme of general humanitarian concern for others. She says that for about 15 years she has been involved in caring for children, as an adoptive parent and as "a foster mother to many children—some with medical problems—and special needs children." She also worked as a nurse for years, and for more than 10 years she has been a volunteer at a local Hospital.

During the last 5 years Joyce has looked after her mother and father. Currently she cares for her 82-year-old mom who has experienced strokes and memory problems, and is resident in a bright local care facility. Joyce visits her 2 or 3 times a week. She also hires a private music therapist to come in weekly to sing "all the wonderful Scottish songs that Mom loves."

Joyce also talks about her own life. Although she claims to have taken time for herself, she also has a love of children and older people. Currently, she struggles to bring about improvements in the quality of living for her mom and other residents. Here, she recalls a memorable incident which has influenced her present caregiving:

I went in to visit Dad one day and found him....His legs were through the side rails on his bed and he was just hanging over it. He had no clothes on, and well I thought maybe he had died. I called his name and he didn't answer and I said, 'What has happened to my dad?' And they said they had given him a medication. A consulting psychiatrist had been in and looked at Dad's chart, without even seeing my father, and read that he could be a bit, um, aggressive I
think they called it. He used to swear a little bit and he was afraid in there; he didn't know what was happening, and this is what the drug had done to him. They knocked him out. And after speaking with a friend who's a pediatrician, she said the drug was an extremely powerful drug and very, very difficult to regulate in older people, and she suggested getting my dad right out of there.

There are several of these horror stories in which Joyce's mother or other residents are main characters. These are told prior to describing her current advocacy work (See Chapter 6), as if she is trying to persuade addressees of its necessity.

Additionally, Joyce provides some statistics. In her mother's ward there are about 70 residents. Of these 70, according to Joyce, there are "10 people who really don't have a family member or a friend...They have no one." Therefore, Joyce, concerned about their human rights, thinks they definitely need advocates. Joyce's story, All These People Deserve The Best, is in Appendix II.

**ii. Fate, Destiny, Religion**

Many caregivers speak about religious or philosophical convictions which inspire or require people to care for others. Theresa, a 68-year-old devout Roman Catholic, cites the biblical parable of the Prodigal Son (and she was not the only caregiver to mention this story). Theresa has mixed feelings about the tale. Her interpretation is that the offspring who stays home, the stable, steady offspring--the caregiver, in effect--is less appreciated than the irresponsible, adventurous sibling (the Prodigal Son) who goes off and leaves his father alone. That is, the caregiver's work is invisible and undervalued; only those who
leave the private sphere and go out into the public sphere are respected and rewarded.

In her narrative, Theresa includes one of her own stories which I have reconstructed from interview notes using her actual words. This story is most unusual.

*Is There A Message Here?*

When my mother and mother-in-law became widows neither lived alone. My own mother moved in with my sister, and my mother-in-law who refused to live alone, moved in with me. In the two households, the tension was unreal! I thought both me and my sister were going to have *nervous breakdowns!* Both of us had several children each, and both had been brought up in a Southern Italian family, and Italians lean towards the men and boys. Don't you agree?

Anyway, I vividly remember having to pick my brothers' dirty clothes up off the floor and wash them!

During those [caregiving] years, my sister nearly got a divorce too, and she almost ruined her health. In my family, Franco, my husband, was establishing his plumbing business and back then he was a businessman who was set on success, tense, high-strung, and impatient. I had to do everything myself, even cut the grass!

I hated the way my mother-in-law was so dramatic and constantly would throw that guilt! But all ethnic groups seem to have the same problem: a guilt complex. I also felt terrible about the way my mother treated my sister, and how she used to complain about her to me. My mother also never told me she loved me until late in life too.

I swear, I'll never live with any of my kids. I'll never inflict that on them!

Part of the way I coped with everything was to keep the two mothers apart. But can you believe this? *Both mothers* died within six months of each other--in the same care facility, and in the very same room!

*Is there a message here?*

I think so. I'm very interested in coincidences and I look for *signs*. Because of the tension, I thought it was a good idea to keep the mothers apart. But now I think that maybe the coincidence of their deaths is God's way of saying, You
should not have done this. You should not have kept them apart.

How does all this relate to reasons for caregiving? Well, today Theresa volunteers at a Community Church and at an Extended Care facility several days per week. In the first interview, Theresa really stressed the guilt parental caregiving can engender. But at the beginning of the second interview she wants to ensure that this has been well-noted. She says:

I don't know whether I mentioned this to you, Margaret, but I seem to have had a guilt complex after the mothers--both grandparents--passed away, and I thought this was one way of making it up with either end of the spectrum--either newborns or seniors--and looking after senior citizens was available for me, and so I thought it would be good, and so I started in on this.

In the case of John, Christian beliefs do not seem to play a big part in his caregiving. John is a young man of 33 whose only close relative is his mother, Louise, who now resides in an extended care facility in Vancouver. She comes back home to John's small suite every Saturday and Sunday. John mentions his beliefs during the interview, and on asking for clarification, this is his explanation:

It's God And Karma That Have Done This For Me

I do have, you know, a belief in God and afterlife and everything. And oh, of course, I believe strongly in karma. Quite strongly. And it's like you've got to be... Karma is like, you know, it's like if you do something nice then something nice will happen to you, or your life will always go smoothly. Or if you're going to be doing anything bad to someone, then you can expect something bad to happen to you. That's karma, you know? And that's what I believe and it's like: Don't lie. Don't cheat. Don't steal. And don't treat people badly--or else it's going to come back on you, I think. So I believe in it quite strongly. I never used to think it was true until the last couple of years or so, because I tried to be as nice as I could to everybody and I
always think well, It's God and karma that've done this for me: That I've got a nice place to live; I've got a good job; excellent people all around me; and my mom is well taken care of. Though I wish I could have her home and that bothers me quite a bit that I can't have her home. That really bothers me...

Religious motivation for caregiving is illustrated by 60-year-old Mari, a retired nurse, who years ago made a difficult decision to become a Christian despite her family's Buddhism. She summarized the reasons for her caregiving by saying that three things are major influences on her caregiving (and her life): "Nursing, Culture, and Faith."

Mari asked if I would be offended if she offered a prayer at the end of the interview. When I said no she said a very moving prayer in which she asked God's blessing for me and my family, and my "humane work." Praying together like this was something I had not experienced in a long, long time. But it was not altogether unfamiliar to me, partly because my mother--who had been exposed to the excitement of itinerant faith healers in large Prairie tents during the 1920s and 1930s--had sent me to a Baptist Sunday School as a child. Much later, during the 1980s, when mom was widowed and sick, she also found TV evangelists energizing and comforting, helping her to maintain "positive thinking." In a colourful story she liked to repeat, she testified that a particular TV preacher had once healed her completely of a certain chronic illness--and occasionally I watched the TV shows with her.

Later Mari also invited me to a Bible study group (which I did not attend). In addition she mentioned scripture--one of her
favourite passages—which she said concerned boundaries. At my request Mari looked up the reference, and when I got home I searched for it in the little *Gideons New Testament* (1955 edition) given to me as a child. I reproduce this verse below because I think it nicely conveys Mari's sense of being Othered and her disdain for racism and exclusion:

> And [God] hath made of one blood all nations of men for to dwell on all the face of the earth, and hath determined the times before appointed, and the bounds of their habitation. *Acts 17:26.*

Mari's interpretation is that everyone, individuals and groups alike, are exactly where they are supposed to be—where God wants them to be physically and otherwise—so that each of us is fulfilling God's ultimate purpose. Concerning her faith, Mari believes that we are "all valuable to God," that there is a purpose for all of us, even for the elderly (a sentiment echoed by other caregivers I interviewed, one of whom claimed that perhaps her mother's sole remaining function was to "pray for her grandchildren").

Like several caregivers I spoke with, Mari's faith seems to give her strength in the face of sometimes difficult caring work. It helps her carry on. What I want to stress here, however, is how Mari and other individuals take ideas and systems of knowledge and make them their own. Ideas are always creatively massaged into ways of thinking that are acceptable, local, subjective and practical. They are massaged, in other words, into systems of thought which are intellectually, affectively and aesthetically satisfying—even though material and social
circumstances still constrain our ability to be totally free-
acting agents.

An example of a flexible ideology and the local shaping and
reformulation of a system of knowledge is Maya's depiction of the
fluidity of Christianity. Rather than look upon Christianity as
monolithic and imposed from above, her listeners can sense how
she wrestles with beliefs and shapes them into something
meaningful for herself in her own particular situation. Below
she compares her own Christianity with her grandparents' and
parents' Buddhism:

It's, it's a bit of a conflict, in the sense that the
Christian faith tends to be more exclusive.... I have to
recognize that my... There is a sense--even if one is a
Christian--there's always a context in which you become
Christian, y'know? And, uh...[laugh]

Well, it's funny--of course, I am a Presbyterian---and I
know when I was asked about this, I remember at the
College...a paper I had to write, I sort of felt that God
worked even in my parents and my grandparents, if you know
what I mean. That God doesn't work exclusively within
certain Christian things. I mean, after all, we believe
that God created the world, and if God is god of the whole
world, then his spirit can work anywhere. In some ways this
sounds arrogant, but in another sense, I don't know. I
don't have a cut and dried...It's still a mystery. But to
me, everything in my life has worked towards...that nothing
is sort of exclusive.... And I guess as one gets older, you
sort of look at things differently too. Because there was a
time when I was really separated from my father, for
instance. And, of course, he was very angry about that.
But I have to acknowledge that there is something of the
past in me still which I don't think I should negate
completely. I think even Christian missionaries say this
now too. In terms of, for instance, Native spirituality.
There was a time when missionaries expected natives to...
cut out everything. Whereas now, they realize that the
Christian faith can take root in various cultures, and in
fact the Western-style Christianity is certainly embedded
in...in the Norse cults [and so forth]....You know what I
mean.
So why are we being so exclusive about Western things? But I think there is a gradual humility regarding other religions. I don't think there is the same triumphalism in Christianity. And this is not to say that everything is the same, but at the same time, I think you can certainly learn from one another.

What I want to underscore is that Maya's words represent an angry--although restrained--response to earlier dialogues. Christianity has been part of a general Anglo Canadian hegemonic discourse, which has constructed Canadians as White Anglo-Saxon Protestants (preferably male), a view which now invisibly permeates Canadian thought. And it is also evident that Maya is responding to more general exclusions centred on "Western things." Maya's narratives are a personal, negotiated counter-hegemonic challenge to ideological systems which racialize, exclude, and Other. But they are also part of much larger national and global post-colonial discourses as well. In the narratives of individuals such as Maya, if we listen, there can be heard critiques of Western ethnocentrism and imperialism. No matter how much of a detached monologue Maya's critical words seem to be, they are a dialogical response to previously-formulated hegemonic ideas and utterances.

I think Bakhtin (1986:92) rightly stresses that each utterance is related to what has gone before it. He writes:

However monological the utterance may be (for example, a scientific or philosophical treatise), however much it may concentrate on its own object, it cannot but be, in some measure, a response to what has already been said about the given topic, on the given issue, even though this responsiveness may not have assumed a clear-cut external expression. It will be manifested in the overtones of the style, in the finest nuances of the composition. The utterance is filled with dialogic overtones, and they must
be taken into account in order to understand fully the style of the utterance.

What Bakhtin argues here is that even if we cannot find direct references to previous discussions of a particular topic, that in the style of a given text one can notice tell-tale overtones and nuances which point back to previous statements. In my encounter with Maya, both the words she speaks and the way they are spoken, constitute a rejoinder that communicates to me that whatever else we do, we are wrong to exclude on the basis of putative difference.

CONCLUSIONS

In this chapter, I identified main themes, specified conflicts and dilemmas, and indicated the range and complexity of positioned lives and narratives. Since each narrative not only describes caregiving but also inscribes it, I presented as broad and rich a picture of the reasons for participating in care as the material allowed. This was important to accomplish because the trend in academic formulations and public debate is towards narrowing definitions which focus on a primary caregiver (often depicted as providing care alone) who is heavily involved in caregiving and who is often a white, middle-class woman.

Barbara M. Barer and Colleen L. Johnson (1990:26-29) notice narrow representations of the caregiver in "the caregiving literature." In their critique, Barer and Johnson (1990:28) also conclude that there are "predominantly arbitrary definitions of the caregiver" and "usually a vague consideration of needs." For
these reasons and others, Barer and Johnson (1990:28) argue that "it is possible that researchers and practitioners do not have a very clear conception of the caregiving process." Consequently, I hope the information presented in this and ensuing chapters will help to broaden and sharpen our picture of caregivers, their needs, and general caregiving processes.

In the next Chapter, I turn from the proffered reasons people caregive to the experience of caregiving itself. I do this in order to examine how caregivers fare after they make the initial decision to help out—even though there is some overlap between topics, themes, and other aspects of the eldercare narratives presented in Chapters 4 and 5.

Concurrently in Chapter 5, I examine the process of narrative construction. This is done in order to critique the idea that each caregiver has a story to tell which is akin to a monologue produced by a lone author. What I want to demonstrate is how the eldercare narratives are complex achievements. At the immediate level, each narrative is a function of the caregiver/researcher interaction. Each eldercare narrative is not just a single caregiver's story of initial decision-making, experiences, and the effects of caregiving. Rather, each is co-created in various ways and strongly affected by what use will be made of the generated material.
Notes

1 I have made minor corrections and removed most "um's" and "y'knows" for the sake of readability. Also, in order to protect identities, I have assigned pseudonyms and changed/omitted place names and other details.

2 The term, picture bride, is the designation given to women who came to Canada from Japan to be married after exchanging photographs with potential partners. This practice departed from the tradition of arranged family marriages. According to Tomoko Makabe in the book, Picture Brides: Japanese Women in Canada (1995:6), the "peak period for picture brides" occurred during the first two decades of the 20th Century. Also see Oiwa (1994:23) and Adachi (1991:87-108).
CHAPTER 5 - WHAT HAPPENS: EXPERIENCES OF ELDERCARE

Experience, as spoken, is always social and always bears its social organization. (Dorothy Smith, 1996)

The interview fragments in this chapter describe the experience of caregiving. Simultaneously, they also demonstrate the researcher’s role in co-creation of the eldercare narratives. In the last chapter, I presented narrative texts as monologues in order to privilege the voices of caregivers. Now I want to highlight how the interview material has been co-produced and, therefore, I frame the researcher and caregiver and their positioned contributions to production. So framed, narrative creation is seen to occur within dialogical and interactional processes, with no lone author. Also, when viewed in this way, it can be appreciated that the meaning of each eldercare narrative does not simply lie within the text of the story itself. That is, meaning is not intrinsically present within stories or textual elements, such as themes. Rather, there are multiple authors, readers, and negotiated meanings and the text is polyphonic and polysemic. If the interview is used as the unit of analysis rather than the putative monologue, then different meanings can be generated.

CO-PRODUCTION

Identification of themes is a traditional way for analysts to attempt to find meaning in texts. The assumption made is that themes themselves denote and connote significance. Also, the
texts within which these supposedly occur are construed to be meaningful wholes. In essence, a theme is thought to be readily identifiable and have a fixed meaning, while the text (often an interview transcript) is treated as closed and complete.

As I discovered while analyzing interview material, however, it is impossible to focus on themes without sacrificing crucial contextualizing information. This is partly the reason Chapter 4 is so long. It includes both themes and as much surrounding narrative context as possible—so that readers are better able to make sense of the narratives.

Below I examine excerpts from interview transcripts based on conversations between myself and three caregivers. The first set of excerpts arose from interactions between myself and a middle-class Canadian white woman. Our ages differ by nearly 10 years (Sue is older and in her early 60s), but we interact easily. Since my mother was of Anglo descent, as is Sue, we have been similarly positioned. Both of us also grew up in Vancouver and we both enjoy privileges associated with a middle-class whiteness which usually seems natural and invisible—although both of us have experienced gender oppression associated with jobs and careers (and other areas of our lives).

The next set of excerpts was generated in a long interview with an 80-year-old Canadian woman of Japanese ancestry, Emiko. She is nearly 30 years older than I am, and we share no bonds of ancestry or common history in terms of racialization or ethnicization. Quite the opposite in fact. People of Japanese
heritage have been racialized, ethnicized, and discriminated against by whites as well as by other groups here in the Vancouver area (see Choy, 1995) throughout their history on the West Coast of Canada. Although many people think these processes reached their peak during and after World War II, Canadians of Japanese origin always have been treated unfairly here.

From their arrival in the 1800s, people from Japan "fell heir to an unhappy legacy of prejudice" which was already in place against people of Chinese ancestry, who arrived during the gold rush and railway construction years between 1849 and 1885 (Ward 1982:10). Ward (1982:10) notes that,

In 1895, when the Japanese population of British Columbia could not have been more than 1000, Canadian citizens of Japanese ancestry were barred from the provincial franchise (and since the federal electorate was drawn from provincial voters' lists they lost the federal franchise in British Columbia as well). Save for a handful of military veterans given the vote after World War I, all Japanese who were Canadian citizens either by birth or naturalization were denied this fundamental right of citizenship. Consequently they had no political role to play in the public life of the country. Numerous other examples of white racism can be cited: a major race riot in Vancouver in September 1907, limitations upon employment opportunities, immigration restrictions, discriminatory housing covenants, and segregation in public accommodation. Some of these measures were acts of public policy, others grew out of private agreements, while still others stemmed from casual acts of petty discrimination. Whatever their nature and cause, they were expressions of widespread racial antipathy in white society...

The third group of excerpts is from interviews with a Canadian of Italian ancestry, Rita, who is nearly 50 years old. Since my grandfather, grandmother, father, and husband were all born in Italy, and I continue to be associated with Italian communities and Italian relatives, I feel as though I share some
ethnocultural bonds with Rita. But although we both have Italian names, unlike Rita I do not speak with an Italian accent nor do I have dark hair now, features which stereotype Italian people and which might identify me as Italian (see deRoche and Dorazio-Migliore, 1999). Furthermore, whereas Rita was born in Italy and remembers strong feelings of alienation which occurred during her Vancouver childhood and adolescence, I was born in Canada and my recollections of feeling different as a result of my ethnic background seem minor.

Generally speaking, however, people of Italian descent were both ethnicized and racialized early in Vancouver's history. McDonald (1996:235), writing about the period from 1863-1913 (during which time my grandfather arrived in Canada), tells readers:

The racial category of 'whiteness' illustrates as well the importance of status as an instrument of social differentiation. Vancouver must be seen as one small part of a larger Britannic world, the city's dominant culture influenced by the high tide of British imperialism. But 'whiteness' also proved useful as an instrument by which Vancouver's people of British heritage secured their status as respectable 'citizens' within the local community. The extent to which the city's British majority constructed a language of race to serve this status-defining function was revealed during the pre-war boom, when an influx of Italian workers challenged the majority's cultural and social identity. In response, the latter defined Italians as 'non-White' and thus as outsiders. In this sense, Vancouver's dominant ethnic group marginalized Italians as 'immigrants' just as it had the Chinese, Japanese, and Sikhs.

In short, my position in relation to the three women--Sue, Emiko, and Rita, and the groups we/they are affiliated with--varies markedly. It is influenced, among other things, by the historical relationships of Oppressor/Oppressed, Self/Other
outlined above. On the other hand, the Oppressor/Oppressed and Self/Other relationships are never clear-cut, strictly binary, or totally hierarchical. My assumption is that each oppressed individual, each group, possesses some powers which can be wielded in negotiations and each individual makes choices. Also there is much intra-group variation in terms of knowledge, values, and experience, and certainly some white people actively seek the elimination of racism. Since we are all human beings, some of our experiences will be similar to those experienced by others. The position from which a person speaks, however, influences their speaking and how much credence is given to their words.

Interactions between people in dyads, such as within these interviews, include power-laden dialogue, marked by negotiation, ambiguity, contradiction, and contestation, as well as by communication and the sharing of ideas and experiences. Many of the interviews affected me emotionally, for example. This was not just because our conversations were about loved ones getting old and needing care—although this was a definite factor. But I also felt as if I was learning about gender, class, and all three ethnocultural groups. I was thereby exploring myself, my identity and history as I was attempting to understand caregiving. I was learning about oppression (including my own), and I was learning about processes whereby my own we-groups, over time, have constructed and continue to construct, people of
Japanese ancestry, and to a lesser extent, people of Italian ancestry as Other.

EXPERIENCES OF CAREGIVING

1. The Joys and Pains of Caring

Many of the caregivers whose stories were presented in Chapter 4, express pleasure in being able to help a loved one. They say it is rewarding, pleasant, necessary work, even if also difficult.

SUE

In this section I present excerpts from an interactive interview with Sue who is a middle-class white woman of about 63. Her story is bittersweet. She presents herself as being very close to her frail, blind, and hard-of-hearing 95-year-old mother, who now resides in a care facility.

Sue spends several hours everyday at the facility, grooming her mother, visiting her and other residents, and wishing she could bring her mom home. Her husband, however, simply will not allow this, and he resents Sue's deep involvement in caregiving. Trying to be both a dutiful daughter and a good wife, Sue feels emotionally torn.

The following dialogue was tape-recorded (captured on audiotape) and transcribed (which involved listening, typing, paragraphing, spelling, punctuating, editing the typescript, etc.), returned to Sue to read and comment upon, then corrected, condensed, and finally reproduced here. My point is that along
the way, I played a large role in transforming a multi-sensory interaction into an aural recording then into a visual product.

My questions to Sue—and to all the other people I spoke with—activate narrative production and dialogical responses, structure the text, and influence what topics will be talked about. In the preamble, Sue feels free to challenge my request for information about her own life, although she quickly complies once I explain its purpose. I also ask about the negative and positive aspects of caregiving which prompt the following dialogue and edited narratives:

**Tape-Recorder Turned On.**

**Preamble/Beginning**

Marg: As I was saying, Sue, I'd like you to tell me about your own life and then go on to tell me about your caregiving.

Sue: Um.

Marg: So tell me as much or as little as you like.

Sue: [Laughing] Well, I guess it doesn't... It's not really relevant except as to where...the part where I ended up being a caregiver. Is it...really?

Marg: Oh, well, I'd like to know as much as possible.

Sue: I don't know. Like from the beginning? Really?

Marg: Just so I can, well, understand you and your situation...

Sue: Okay.

Marg: ...and also be able to place the caregiving...

Sue: Okay. Yeah.

Marg: ...in your total life context.

Sue: Okay. Well, I was born in Vancouver...

*He Sees That, but I Guess I Don't*

I don't know what the negatives are... Like my husband hates to go near the place. He loathes going in there. He can't stand to see those people. But I don't look at it that way. Like it doesn't--maybe I'm callous, I don't know--it doesn't bother me in one sense to see them that way because I know them as people, sort of.

Like I don't know, he goes in there and he.... Just like my mom says, because she can see enough.... She says,
'Oh. You go out there [to the common areas] and there's all these old people sitting around.' And he sees that, but I guess I don't. I just see it a bit differently, I guess.

The negatives are just seeing all the tragedies that....I mean, I spoke to one woman the other day and her husband is in there with a stroke and he can't speak and she said to me: 'I don't know this man.' And I thought, Oh, dear! I mean that was her husband and she said: 'I don't know him.' Like I don't know this man that he's become, and that's the sad part is seeing what people, you know... One man was an engineer and just knowing that these people were, you know, vital people, and now they're in the state they're in. That's the tragedy of it....

**The Rewards of Caring**

I enjoy caring for the older people. Like I try to get involved with a few others as well as Mom, and I think that I would always like maybe want to continue in a volunteer-type way, and I think I could have been a nurse, not a trauma nurse, that type of thing, but a caregiving-type nurse. I think I would have liked that.

I enjoy older people. There are some quite interesting old people in the care facility, and, in time, sometime, I would probably continue to do that on a volunteer basis--just not 7 days a week [laughs]....

I really get a pleasure out of hopefully giving some pleasure to those elderly people--or not even just the elderly--but the people who are there. I mean I hope that they get something out of my being there even if, like the Chinese, I can't speak to them, but I just.... You know, you try and hold hands and smile at them, and I just find that I get something out of it. I don't know if they get something out of it. Some of them just sit there for hours and hours and nobody bothers with them, so you try to just chat with them a little bit...

At the tail-end of the interview, Sue also confides that she has no one to talk to about her mother/husband conflict, and when I suggest she attend a support group for caregivers, she says,

Yeah, maybe I should go to one, eh? Yeah, maybe I'll go to one because you do sometimes....and there's nobody you can talk to. I mean I can't talk to my sister
about it. I can't talk to my husband about it. I have nobody really I can talk to about it. At least there would be somebody you can.... Probably that's why I'm talking, probably that's why I was talking to you....

END OF TAPE

Discussion

The above excerpts have been chosen from a transcript of about 40 pages of single-spaced text. They have also been informed by fieldnotes taken after phone calls and meetings, as well as by my impressions and memories--for example, of Sue's lovely house and garden and her mother, who as Sue says is "like a little doll," a fragile little doll. I know this because while Sue read through the transcript, her sunny, talkative mother sat close to me so she could see my outline and hear me, and she lovingly held my hand while telling me her life story.

Particular experiences are bound to influence my choice of excerpts--mainly because they draw forth emotions and remain vividly felt for a long time afterwards. Holding hands with Sue's mom was an emotional experience which lingers in my memory. Despite all her many frailties, ailments, advanced age, dismal surroundings, and her proximity to the end of life, she still shines. She sparkles. She is talkative and witty, loving, altruistic and displays many other remarkable characteristics. Traces of experiences such as these which are, for example, puzzling, spiritually engaging, out-of-the-ordinary, richly symbolic or emotionally-charged--including talking with an extraordinary person--may linger in the mind and body well after
the experience itself is past. And the traces of these experiences are what I want to share with readers.

In addition, when participants and myself are similarly positioned in the world, this influences textual co-production and what knowledge we are able to create. Something I want to emphasize is the frequency with which Sue references vision (for example, she says, "I don't look at it that way" and "I just see it a bit differently..."). Denzin (1997) describes how among Westerners the visual is dominant, and they tend to equate seeing with believing--but additionally with understanding. Understanding, however, may occur gradually or only after a delay and, therefore, the analogy with vision (which is generally immediate) seems faulty. On the other hand, shifts in points of view yield opportunities for shifts in knowledge, and such repositionings may yield instantaneous insights as blind spots are filled in.

My point is that both Sue and I discuss what can be known from seeing, and we conflate seeing and understanding, without remark. Sue also seems to assume that as a woman I will empathize with her desire to nurture her mom, as well as other residents at the care facility. I am someone she can talk with, like a sister or friend. Unlike her husband, I will not be appalled by residents, but instead I will think of them as merely needy human beings. Furthermore, she seems to assume I will be able to decode her ambiguous comment: "like the Chinese, I can't speak to them...." But I am left wondering if she thinks all people of Chinese ancestry at the facility cannot understand English or if
she recognizes other differences or barriers to communication which she has lumped into the phrase, "I can't speak to them."

In her final paragraph, Sue maintains that I am somebody she can talk to (about her problems), a confidante—in lieu of a sister or husband. She represents me as kindred (at least in spirit), using her need for someone like me to talk with as an explanation for her participation in the interview. She also reveals details of her family life, surmising that I will be able to understand her predicament, possibly imagining that I have experienced similar dilemmas in my roles of wife and daughter. And Sue may even be confusing me—as an academic and researcher—with someone who possesses direct powers to heal.

ii. What I've been through!

EMIKO

Emiko is an assertive octogenarian who has lived a life punctuated by multiple tragedies, uprootings, insecurities, and much caregiving. In 1942 she married her boyfriend because he wanted to avoid being sent to an Ontario prison-camp. Both she and her husband were born in British Columbia, and although he grew up on Vancouver's Powell Street in Japantown, she lived mostly on the outskirts of the city.

Emiko's experience includes childhood poverty in the Depression years, so that she was unable to complete school. Additionally, from a young age, she helped care for siblings, while her mother worked. Later came evacuation during the War, financially hard times afterwards, a house fire, sickness and
surgery, the tragic accidental loss of a cherished daughter, her husband's dementia, recent family deaths, and now her own developing health problems. She also told me that her husband was "not a rich man," although they had made enough money on the sale of their house to buy the comfortable apartment we sat in.

In her narrative Emiko tells illness stories and eldercare narratives interwoven with social critiques primarily aimed at professionals and bureaucracies. She feels especially burdened by all the paper work she must complete, visits to banks, government and law offices, etc. due to the deaths of several loved ones. She says this is the reason her apartment is a mess, adding: "I tell people, 'It looks like a newspaper office.'"

When Emiko talks about lawyers (and later doctors), the typical lawyer--and probably the ones she has experienced--are males. And when she describes health facility personnel, these are all females. Emiko says she is a feminist, but she criticizes whomever she thinks is acting unjustly, and as mentioned below, she says, without prejudice: "You have to fight everybody." The following gives only a suggestion of the conversation we had, and how Emiko interprets and describes her life.

TAPE RECORDER TURNED ON.

Preamble/Beginning

Marg: Thank you for agreeing to be interviewed. And, what I'd like you to do is to tell me about your own life, and then go on to tell me about your caregiving experiences? You can tell me as much or as little as you like.

Emiko: You mean to back when I was born?
If you'd like to.

Oh, yeah.

[Laugh] Yeah. That would be great.

I was born just outside Vancouver before 1920....It was all country and bush at the time. From there, we moved to Vancouver around 1930. Then we were in Vancouver until 1942 when we were sent to the Interior, and we got married just before the evacuation because at that time my husband was my boyfriend, and if he was single he was going to be sent to Ontario, so he didn't want to go, so we got married in '42, and so he was able to work at Hastings Park, until we got moved with my family to the Kootenays.

Doctor and Pills

I knew that my husband had something because I know people say that when you get older you, you do silly things or you are forgetful, but the things he did were out of the ordinary. But his doctor--I didn't like his doctor--he got mad at me. He said, 'I'm his doctor. I know what's the matter with him.' And he wasn't very nice. He didn't like me to be there. He used to say, 'Well, why are you coming?' The reason I was going was because when he used to go by himself, I'd say: 'What did the doctor say?' But he couldn't remember, and so I decided to go with him, and the doctor didn't like that. I used to ask him questions, and he'd say, 'Why are you asking me this?' And I'd say, 'Because I want to know.' And he was nasty.

But, anyways, he refused to change doctors.... But this doctor wasn't...he wasn't great. I didn't like him because he never dressed like a doctor. He was wearing sweatpants and running shoes; he wanted to do...talked to my husband about martial arts and things like that, and he refused to listen to anything I had to say. As a matter of fact, he resented it very much.

Did he?

Uh, huh. So, anyway, what happened was, it just... things just got worse. Of course there's no cure for Alzheimer's now, but he used to give him just pill after pill after pill. He used to get dizzy spells, and he'd give him...for seizures, he used to get seizures, he'd collapse on the street, and he would give him another pill. At one time he was taking 13 pills a day. And I bought this little thing...that, well my niece did, little thing where you...Monday, Tuesday, Wednesday and morning, noon, and night....and at first he used to be able to do that, be in control of it....later it became....he couldn't do it. I'd say, 'You haven't taken your pill.' 'Yes, yes, I did.'
Or else he'd take more than he should, and he'd get angry because I wanted to control it, but I couldn't do it because he would always say, 'Well, these are my pills.' He told me: 'Don't tell me that.' But, you know, just things like that with Alzheimer's. Y'know, you're not supposed to argue with them, you're supposed to agree with them, but lot of times you can't really agree with them. Oh, he used to do horrible things, and hide things, and then get angry with me. He was very unhappy too, I think. I always think the pills were bad. Because that doctor would give him a pill for this, and then in the side effects, it would say, **MAY CAUSE DIZZINESS.** Which is rather stupid because it was to cure something, and then the side effects were written right there, you know what I mean?

**Marg:** Was your husband born in Canada?

**Emiko:** Oh, yes. Born in Vancouver. He was raised in Vancouver. He was raised on Powell Street. It's not a ghetto, but in that sense, they were all together. That was the biggest group. There were groups all over the Valley. And he was very prejudiced against every [laugh] ethnic, I think.

**Marg:** Really?

**Emiko:** Whereas I was entirely the opposite. Because I was...I grew up in the...they were all...I never know what to call them, white families, all the time. And to me, people were people....

**Marg:** Do you think this was part of the...

**Emiko:** ...the way of his upbringing? I guess....

**Marg:** You don't think it was partly a reaction to what happened during the War?

**Emiko:** No, no. This was way before. He was brought up like that. And I think--Chinatown was close by--and I think Chinese people were his enemies. I mean that's how they grew up, cause...But I felt bad. I always think about these things later in life. Like young people. Everything starts from when you're born. Like you teach them what you say in the house, or whatever. And it was really sad, because it bothered him, all the time. And to me like I see people as people. Like my daughter, oh, she had a friend, and my husband used to ask her, 'Is she Japanese?' [Laughing] One day she'll say 'Yes', and the next day she'll say, 'No.' She didn't know. She didn't know the difference--well, she didn't have to know the difference, right? But, all these things, I think, bothered him.
...I'm 80 now, and I'll be 81 in September, and I told my kids that if I ever have to go into a home or something, even if I'm kicking and screaming, 'You take me because I'll give you permission to do that.' And 'Do you want it in writing?' And they said, 'No. No, No.' Because I've seen so many older people, and their house is full of stuff, and the poor kids have to clean it up. And like I say, basically your important papers should all be in one place.... But I certainly learned a lot [from being an executor]. And to deal with lawyers. Lawyers are only interested in themselves. We would go to a lawyer, and he'd ask the same questions over and over again: 'Oh, when was she born? What was she doing...?' I said to him, I kind of said to him, hinted to him that, 'You have all this information.' He didn't like that.

I don't think I'm well-liked by anybody! [Laughing].... I thought, You have that information, why ask me? They're taking time. They're making money. But, I found that you have to fight. You have to fight everybody. Stand up for your rights. Like I say, I'm not a very strong person, and I've had everybody run over me all the time. Now I'm a little bit wiser. And, to deal with everybody....Y'know what I mean? And, I found out that hospitals here are run by the social worker within the hospital. I've come to the conclusion that their social worker is trying to make money for the hospital, and trying to save money for the government. So where does that leave the people? Nowhere.

She makes all the decisions. She decides what's what. She was trying to tell me to send my husband to where the veterans were....

Anyway, I went to look at four different places, and I didn't like that place because it was full of all men veterans, and they looked so unhappy, and just not doing....Anyway, and I didn't like that place because....I basically was....I don't drive....In the wintertime, I'd have to walk in the dark places. So, I said, 'Location is a bad thing. I want him to go to Site X.' She said, 'Well, Site X has a waiting list.' Well, first of all I wanted to go up here, and she said, 'Oh, there's a waiting list. Two years. He has no choice.' She phoned me. She screamed at me, and said that, 'Your husband's been in the hospital too long. He has to go to this place (I forgot that name).' And then the next morning, she phoned me again
and said, in a sweet voice, 'Oh, he's been accepted at Site X.' And then the day we moved, on November 1st, I met her in the hallway, and she said, 'Oh, isn't it nice you got him where you wanted him to be.' And I thought: You're the one makes the decisions.

**Marg:** Yeah.

**Emiko:** She was miserable.

**Could your Husband Walk?**

**Marg:** Could your husband get up and walk or...?

**Emiko:** No. At first he did, but before that he used to get up and run around. He couldn't walk, but, I don't know what it was but the hospital phoned me three times (in the middle of the night, of course), that he was running and the nurse just couldn't control him. Twice I went. He's sleeping! And apparently the nurses managed: two nurses would hang on to him, and the other would give him a shot. And I would get a taxi, and then by the time I got there he would be sleeping.

And, he was like that, y'know. And then they phoned me the third time, and I said, 'Y'know, as soon as I get there, he's sleeping.' And I said, 'I just can't come.' I couldn't cope with...It's always 2 o'clock, 4 o'clock in the morning or something, and like I say, I just....It all caught up with me last December when I had that test. But I didn't know that it was coming to that [hypertension]. [Laughing] I thought I was okay. But I guess I wasn't. But I think--like you say, caregivers--I was just reading something here that said: 'Who will care for the caregivers?' [Laughing]

**Marg:** Yeah, that's right.

**They Know That Somebody is There**

**Marg:** Do you have anything to do with the Tonari Gumi [the Japanese Community Volunteers' Association]?

**Emiko:** No, um, I did do some volunteer work there sometime, but well since, since my husband got sick, I think I've kind of put myself out of circulation, so to speak, and people understand. And, I just want to get my things in order first, before I start doing something else. Whatever. There's always places to do volunteer work.

**Marg:** I just wondered maybe if they had helped you at all, when your husband was sick, or...?

**Emiko:** Um, not Tonari Gumi, but...when my husband was in the care facility, I know one church they came to see him, and they brought a box of Kleenex--which is a nice and practical gift. And I remember it was all wrapped,
gift-wrapped, and I gave it to my husband, and he started to rip it up [laughs]. So, it's sad that he didn't know what was happening--y'know what I mean--later, but then, like I say, I was just talking to somebody else, and I said, 'Y'know all those people in even [Site X], or anywhere, any place, and a lot of them, they can't speak or they're not aware of anything around them....' and I think a lot of family and friends don't come to see them because, Oh, well, it's no use going, she doesn't know me. And I've heard that so often, but then I say: 'No, that's not so. They might not be able to express their feelings, but they know that somebody is there.' (Y'know, somebody from their family.) And it's just like babies: they say some people don't talk to their babies, but they say babies absorb everything. They can't answer, but they hear you.

Marg: That's true.
Emiko: And it's the same with people like that who are unable to communicate. Just like people in a coma. They say to keep on talking to them and playing music to them, or whatever, to keep....Because they can hear but they can't answer, right?

Marg: Right.

END OF TAPE.

Discussion

It can be clearly heard in this interview how I, as a researcher/listener/speaker activate and shape narrative production. I ask Emiko to tell me about her life, then to tell me about her caregiving. Therefore, I request certain information in a particular order or form, and she seems to comply.

What is interesting to me, however, is the way in which my questions carry us into quite unexpected territories, and how some queries are skirted. For example, at the beginning of the interview, although Emiko says she is willing to start at the beginning (that is, "Back to when I was born?")
birth before 1920 to around 1930 then to 1942 with little or no information about intervening years. It is only much later in the interview that she fills in some of the gaps with stories.

Emiko says that she does not blame just whites for the problems she has encountered during her lifetime. She stresses how she does not care what ethnicity people are, and contrasts her attitude with that of her husband. She also does not mention the race or ethnicity of the doctor, lawyers, health care personnel, social worker, or of in-laws and friends, etc. What is important is that all these people have treated her with insensitivity or unfairness (or sometimes very well).

Might not Emiko tell other versions of her narratives to other addressees—such as those with whom she volunteered to request redress from the Canadian government? For example, her language seems to be carefully neutral, when she says that her husband "was able to work at Hastings Park, until we got moved with my family to the Kootenays" [my emphasis].

In the case of being treated badly by professionals, Emiko implies that she either asks too many questions or asks the wrong questions—or, alternatively, the professionals ask too many questions, etc. In any case, there are problems which arise from professionals trying to make money, maintain their expert status, adhere to institutional rules or otherwise enact the functions of their offices, professions, or institutions without due regard to the needs of ordinary people. Does Emiko view me as a professional or at least someone who is attached to a professional
School at UBC? Does she feel as though I am there trying to exploit her in some way? If she does, this will affect what we are able to say to one another.

Also of interest is that on occasion Emiko and I fail to communicate. For example, Emiko assumes that I will understand how her husband's prejudices arose from growing up on Powell Street (Choy, 1995 describes this period well in his book, *The Jade Peony*), whereas I try to relate his prejudices directly to the racism in British Columbia during and after Wartime and events such as internment, confiscation, and exile. It was not until I had read *The Jade Peony* (Choy, 1995), after the interview, that I obtained some insight into relations among Canadians of Japanese, Chinese, and Anglo ancestry in Vancouver during the 1930s and 1940s.

The other example is when I ask about Tonari Gumi. Emiko assumes I am asking if she volunteers at this organization, with the implication that I think she should be doing so. What I really want to know, however, is whether Tonari Gumi sent volunteers out to her home or to her husband's care facility in order to visit or provide meals, etc. We both know about Tonari Gumi, but we are viewing the organization from different angles.

Each person in the world has his/her own agendas and his/her own worldview, but these are also overlapping and connected. I felt a distance as well as a closeness to Emiko that afternoon. Our interview was rambling and long, although she said she was quite willing to answer my questions, and she told me many
interesting and instructive stories. Emiko hastily mentioned the loss of her daughter fairly soon after I arrived at her apartment and I wondered about that event throughout the entire interview. It surprised me, however, when suddenly--towards the end of our time together and maybe to signal its conclusion--she handed me a framed photograph of three young girls and said, pointing to one of them without elaboration except to give me her age and the year the photo was taken: "Here's her picture...." And I remember feeling oddly and thinking at that point: *she and I would have been the same age.*

**iii. It’s work!**

**RITA**

Feminist scholars (including Angus, 1994; Whalley Hammell, 1992) recognize that caregiving is not always simply a labour of love. That is, they acknowledge a variety of reasons for caregiving in addition to love. Furthermore, they maintain that caregivers should be justly compensated for their caring work with more than love because informal caregivers are providing services which would otherwise fall on the formal health care system. In addition, although individuals may talk about their experiences in multiple ways, some caregivers explicitly refer to caregiving as physical and emotional labour, and sometimes they even employ the phrase, *unpaid work.*

In the case of Rita, there may be especially good justification for calling caregiving unpaid work. Although the majority of caregivers I interviewed seem to have various
resources at their disposal, some, like Rita, appear to be less financially secure. Rita also has chronic health problems and disabilities (as did some of the other caregivers I interviewed) and she told me that financially her parents had a hard time in both Italy and Canada.\footnote{1} Neither she nor her husband presently work; her daughter is "on welfare"; and both she and her husband have financial concerns (expressed to me by each of them separately). In fact, Rita requested that my small gift to participants, valued at about $5-$15, be given in the form of cash.

Rita's emphasis on caregiving as unpaid work mirrors a long-standing feminist concern with fair compensation for women's invisible, undervalued work in the home. Just compensation for their unacknowledged domestic labour would help equalize the economic disadvantages many women experience throughout their lives, and which frequently are the result of answering yes to the call to care in an exploitative patriarchal, capitalist society and world system.

Rita came to Canada from Southern Italy after World War II (during the 1950s) when she was 8 years old. Her children, now in their twenties, live on their own, although they still require a helping hand occasionally. Some of Rita's health problems incapacitate her for days or weeks at a time, but fortunately her husband, a former health care professional, helps out considerably.
Endowed with an effervescent personality, Rita is assertive and bright. She also is very sociable, curious about others, and enjoys reading, learning, and attending Italian Canadian cultural events and being part of various social groups.

Rita's caregiving began almost 20 years ago when both her parents began to require assistance. Now only her father is left. He is institutionalized and in poor condition, mentally and physically. She says that because of her own health problems, together with her father's present state, she rarely visits his care facility now. Instead, her husband, together with her sisters, and numerous other relatives, tend to her father's needs. Additionally, of course, he is cared for by the care facility's paid, professional staff.

Throughout her prolonged caregiving, Rita claims to have grown to understand her father better—as well as herself and life in general. She even presents herself as, in a sense, becoming her father. This fits in with Hazel MacRae's claim (1995:145-167) that women give caregiving self-meaning and are able to "construct self through others." However, had she known what the job would entail, Rita says she never would have taken it on. In her narrative, Rita describes how much money and labour have gone into looking after her father. She also talks about the extreme stress she has experienced. After I activate narrative production with a few simple questions, the floodgates open, and Rita narrates a torrent of incidents and events:
Preamble

Life Story

Marg: Okay, what I was thinking I would like you to do, Rita, is to tell me first about your life--your own life--and then later on we can talk about caregiving....

Rita: Okay...

Marg: So just give me an idea of who you are and just tell me about yourself.

Rita: ...Okay, I'll be 50, I was born in Italy, I came here when I was about 6. I'm third of several kids.

Marg: You can elaborate as much as you want to and...just to give...

Rita: Okay.... We came here in the 1950s. I got married young--of course, moved out of the family home. Then was married more than 10 years [living outside the Lower Mainland]. Then I was a single parent for quite a few years after that. And now I've been married for several years and that's it.

....I'm basically a cheerful, happy-go-lucky person, if everything is going fine, but anything, but anytime one thing goes wrong I tend to get depressed. I do have trouble coping with stress but I think it's because I believe my childhood was unhappy and I think I have low self-esteem and that kind of makes everything work. I mean it makes coping with everything in life work. It does not come easy to me, to make friends, if you don't have high self-esteem. It does affect you when you're trying to reach out to make friends. So it does affect everything in your life and, um, so I've tried to be happy and make a new identity for myself but again my parents did the best they could, because I believe they were in culture shock when they came and still are...

Marg: Yeah.

Rita: The language was too hard for them: different money, different laws, different customs...it was just too much for them and they just couldn't cope and so unfortunately violence was there which nowadays you wouldn't see, you know, there's help.... But in those days you didn't speak about it, and the poverty didn't help...and we had a lot of kids, I lost two brothers...and one miscarriage so my mom was always pregnant and because we were so poor my mom had to make noodles from scratch, make bread, buns, pizza from scratch, cookies from scratch. I remember her living in the kitchen 12 hours a day and I swore I wouldn't be like her, but, um, my dad was very outgoing so I take after him. I'm a people-person. I love music and I found by taking care of my dad all these years we've kind of become the same person.
Oh, yeah. I've come to like opera; I used to hate it. I love music and dancing. I never wanted to be like my dad but I find I am my dad. I love music, dancing, singing, and that's my high in life. I don't need booze or cigarettes or drugs, so taking care of him which has been over 15 years, I've almost become him, so that my social life was his, and we would take him everywhere because he was so lonely and so I've tried to make the best of everything...

....My caregiving duties have gotten less because of my health deterioration and I cannot handle stress like before because it will hit me and I'll end up in the hospital. I realize that whenever I have an attack it is...because there's too much stress around, so I've had to really look at life and see what is a priority in the last three years and I think I have matured a lot from this incident in the hospital because you have 2 months to think (and you prioritize): Hey, what's really important? And it's not money like I thought, not at all, and that's it. [laughs]

It's Unpaid Work!

Well what happened is my sister--I'm jumping all over, I'm sorry--

That's okay. No, that's okay.

...until 1982 my sister was doing the odd paper work for him [her father] because he didn't really understand bills sometimes, so she would do the odd thing and then sometimes the drapes would need to be done and she would say yes, so when I started to arrive in 1982, and he'd say, 'Oh, Rita, the drapes need to be done.' I'd take them and they'd be done within a week because my dad had waited three months and they still weren't done from the other sister so eventually what happened is because I was so reliable, because I am efficient, my sister--even though she wasn't getting paid and was kind of keeping an eye on them--she kind of got fired.

Oh.

And I got the job--which I never wanted. I regret taking it, and every week there would more and more and more: bills, telephoning, transportation.... The language, loneliness, got more and more, where I did not have a life of my own.

[Rita narrates details of her mother's and father's braided illness narratives. Like a ribbon running through them is also]
the eldercare narrative. In a nutshell, her mother's medical problems worsen and she is placed in a care facility. Her father is devastated and spends a lot of time visiting the facility and interfering with procedures. This becomes a problem for the staff. Meanwhile the father is also developing various medical conditions. Eventually he is placed in another care facility--according to Rita because the one her mother was in would not take him. He is there for about four months when Rita's mother dies. During this period the family encounters all kinds of situations, including family conflicts over end-of-life decisions and staff/patient/family cross-cultural misunderstandings, etc. Below I recount problems over the sale of the family home, beginning at the point of the Hospital death of Rita's mother in the mid-1990s.]

Rita: We think Mom died of loneliness...
Marg: Oh.
Rita: This is what we think happened and my mom--actually in 199_ on Mother's Day--she had a massive heart attack and actually she'd gone downhill on Friday and my brother visited her and he noticed she was really withdrawn and really quiet but he didn't know and he didn't phone anybody and the nurses stopped checking her blood and she was really subdued, and nobody did anything until Sunday. She'd actually had a heart attack on Friday but kept breathing somehow. Sunday morning they phone us: 'Your mother is in ICU not breathing.' So again they resuscitated her but it was too late, two days later, we went to see her in ICU and they said her heart is so damaged, it's so big, she's not going to make it because I said, 'Tell me the truth, Doctor.'
Marg: Yeah.
Rita: 'She's not going to make it.' She had maybe a day or two. So this was our Mother's Day present in 199_ [crying]. It's really hard because my mom was our favourite. My dad nobody liked, but my mom was our favourite.
Marg: Yeah.
Rita: So she hung on till Thursday but she never regained consciousness. On Sunday she may have squeezed our hand--if we asked her--very weakly, but we're not sure because she was very weak.

She never regained consciousness but they told us she probably was hearing everything, so be careful what you say, and I tried to go everyday as much as I could but I found I was crying the whole time I was there with her, and she had an Italian roommate who was very...but every time I visited my mom I couldn't really talk. I just said, 'Mom, I love you.' And then I cried for an hour but I'd hold her hand [crying]. It was very hard and on Thursday when I went, I knew she was dead already. I just had that feeling at four o'clock. I arrived at five and my sister said, 'She just died.'

Marg: Oh.

Rita: ...when I arrived and we found mama dead, unfortunately my sister said, 'Okay, now we can sell the house.' I don't know if I remember correctly but we had a big fight. My sister--within an hour of my mom dying--my sisters and I....My sister goes, 'Okay, now we can sell the house,' because by then my dad was in a home for four months and there was nobody in the house and we didn't know if we should rent it or what. I got the job of cleaning out the house, it took me twelve hours a day for seven days and nobody helped me. I was furious, and I had asked for help. I was very furious. I took away seven van fulls of junk just to the garbage--on my own, and everything else was sold real cheap, just to empty the house because they had to get it ready to rent and my husband and I cleaned it and we didn't get a penny for it: the gas, my time... We got nothing for it: cleaning products--but what can you do? You know, because when my...in that hour, my sister goes, 'Okay, now we can sell the house.' And I was just so mad. 'Mom only died an hour ago and all you are thinking about is money....'

[Sometime later...]

Rita: ...actually I was almost physically fighting with my sisters....

...And so I did not talk to my sisters for a year. We did make up--accidentally--[when] my husband handed me the phone and I thought it was somebody else so I did talk to my sister, and since then, we've been talking and another time my other sister--this is the one that I always expect a little bit more help from, because she drives...
Marg: This is the one I might...[interview]?
Rita: No, that one doesn't drive.
Marg: Okay.
Rita: It's always this one I expect more of and so she, one
day, said, 'You better write down what you do with his
money because there might be a thousand dollars more
and we won't know.'
Marg: Em.
Rita: I took that like, you know, a knife in my throat. I
now keep books, every single penny I try to get a
receipt, photocopy, cash, cheques, everything...he now
has four bank accounts, I keep track of everything, I
do his income tax, I keep photocopies of everything in
case somebody says, 'Okay, 25 cents is missing.' I'll
know, and I do that, it's a lot of headache and time-
consuming....
Marg: That's a lot of work for you.
Rita: A lot of work taking up 4, 5 boxes in my den, um,
month-end I've got the renters, fixing the house, who
to hire, who to do what, I always try to okay it with
them when possible but you can't for every 5 cents.
Marg: No.
Rita: There's leaves, there's snow, there's insurance,
there's roof...it needs a new roof or it needs a new
fridge. I didn't...never...I never wanted this
responsibility. Never....
Marg: Oh, really.
Rita: I hate it, I hate it and had I known this twenty years
ago, I would have never started looking after my dad
and being responsible. I would have somehow just not
seen my dad but you can't go back twenty years and say,
Hey, this is what it's going to be like, it's a full
time job. I actually haven't had a life
since about 1982.

...And so he's near my sisters so I said, 'Okay I'm
giving up my hands regarding visiting him.' Um, my
husband is the main caregiver. Any authority is
through my husband--but basically me, but because of
my health I cannot be involved as much, so I do
everything over the phone. So I'm in the computer that
I'm the only caregiver--or my husband--through this
phone number. Nobody else because everybody was giving
the nurses different instructions and the nurses were
getting upset because they didn't always agree with me,
or they'd already discussed it with me, so when he
moved to Site Y, I wrote again to all the uncles, this
time I put, 'Please, if there are any concerns, phone
me.'--in a way saying don't bother the nurses. So even
now my sisters shouldn't be bothering the nurses. It
should go through me because they don't like dealing
with five, six different people and each gives a
different instruction. So they're supposed to go through me....

...But the good thing about looking after my mom and dad, since 1982, is because I've got to spend time with him. I've seen his kindness did come through, ....and so I saw that side that my siblings haven't seen and I did get close to my dad and we've had some nice memories because he likes music, and I like music. He likes dancing. I like dancing. And he was able to tell me the same stories over and over again about the War, some of the things that he remembers or some of his....how he was abused from his mother, um, when he was newly married. He would tell me stories from his past and same old jokes, but I, I have these memories and so I've been able to heal. I think the others will be healing after the funeral whereas I've, I've kind of matured even though I've looked after him and it's been very stressful, in a way it kind of makes you realize you're not here forever and you better grab that happy moment while you can [crying]. So I think, in a way, I did gain as much as I lost and that's about it. I can go into more details next time. How am I doing?

Marg: Oh, you're doing fine [Laugh].
Rita: Shall I continue?
Marg: Maybe I'll just ask you one question and then we'll turn it off.
Rita: Okay.
Marg: I'm just wondering, have you seen, since you've been, uh--you're going to get me crying in a minute....

END OF TAPE

Discussion

Although there are many things that could be said about the above excerpts, what I want to stress is the style of narration Rita uses, which may be influenced by the oral culture of her parents. I also heard Rita tell versions of her story on occasions other than during our taped interview (See Angrosino, 1989) and what primarily struck me was the difference in tone.

In our interview, Rita's presentation is theatrical--replete with surprising plots, characters, quotations, climaxes, and
imagery gleaned from diverse sources. She heaps images one upon another. And I was reminded of Shakespeare's *King Lear* in which there is a feeble, old patriarch who has competitive daughters, as well as Hollywood's classic Mafia parody, *Prizzi's Honor*, in which the heroine is suddenly pinned to a wall by a thrown knife to the throat.

I am not suggesting that Rita's stories are untrue, but rather I want to underscore Rita's use of dramatic flare to persuade listeners of the hardships she has experienced, her dominant position in the family as the eldest daughter, and her agency in relationship to the health care system. To me, her words constitute a political statement which encodes various messages, such as "I have suffered, and continue to suffer--unjustly." And, "I am powerful. I am the boss, and people should listen to me."

To some listeners Rita's words may be interpreted as melodrama, and their veracity thereby challenged. Her presentation, in other words, may either convince listeners of her suffering or they may unintentionally subvert her message.

The following is a portion of my fieldnotes taken after showing Rita the transcript of our taped interview:

*November 30, 1997*

Today I headed over to Rita's. I called her at about 1:15 pm and told her that I planned to walk over. I told her that I'd be there at 2:30 pm.... Rita took two full hours to read and correct the transcript. She was crying during the reading too. She commented that she wanted a copy of the transcript because it is, 'the story of my life,' and 'like my autobiography.' Later she said, 'This could even be a movie.' One of the reasons she wants a copy is to give to her sisters. It could be like a
'Christmas present', she said. She thinks that this would tell them what it was like for her, what she's been through, and set the record straight....

This means that people treat these transcripts as real. To them, this is their life story. This is their biography or autobiography—not just a version of it. They are also sure of the facts they report, and do not question whether their memories are accurate or not. These are their memories, and they are real and true....

...Rita told me that she was going to underline the part about her father crying. She said that this is because this was the only time he had cried in his life.

The words of both Rita and I contribute to a performance in that, "Performance is in a sense an element in every action..." (Finnegan, 1992: 91). As we talk, we are both reflecting and constructing ourselves, to ourselves, to each other, and to various implied audiences. From Rita's emic or insider viewpoint, her words are faithful to the experiences she describes. She makes this clear to me. I stand outside her subjectivity, however. Not in an objective position, but in a position of intersubjectivity. It is from this position of emotional and psychological overlap that I interpret her words, as well as those of all the other participants in my study and my own fieldnotes. For the moment I interpret them as possessing dramatic elements, although what I want to emphasize is how social researchers often take a strictly etic perspective by standing outside suffering and reporting it from a distance, apolitical, and removed from their own lives.

I do not wish to single out Rita. If I have done so, it is because her stories are so vivid, captivating, and illustrative of the point I am trying to make: that although eldercare
narratives are based on experience and real suffering, they are nonetheless still only mediated accounts of those experiences.

Narratives are interpretations of events which blend fact and subjectivity, but they are always spoken in specific social and political contexts. Rather than asking if they are true, therefore, we should closely examine the social processes involved in their production and usage, and the images and texts narrators are responding to when they speak. This will allow us to better understand how the lived experiences associated with, say, growing up, discrimination and caregiving are narratively given meaning, and also how these meanings--particularly when attached to self-representation--can have political purchase.

Self-representation is fraught with all kinds of problems, especially for women, and especially for those women who are deemed to be non-mainstream. This is because there is no language available to adequately convey women's experiences. For example, Leigh Gilmore (1994) stresses how women's autobiographical productions or autobiographies have been influenced by, but are different from, traditional, male-centred autobiography which does not problematize the subject position or the pronoun I. Gilmore (1994:42) says:

I offer the term autobiographies to describe those elements of self-representation which are not bound by a philosophical definition of the self derived from Augustine, not content with the literary history of autobiography, those elements that instead mark a location in a text where self-invention, self-discovery, and self-representation emerge within the technologies of autobiography--namely, those legalistic, literary, social and ecclesiastical discourses of truth and identity through which the subject of autobiography is produced. Autobiographics, as a
description of self-representation and as a reading practice, is concerned with interruptions and eruptions, with resistance and contradiction as strategies of self-representation.

Although I agree with Gilmore, what I want to stress too, is how, as an academic, and a human being, I must create and read with suffering in mind in order to do justice to the stories and self-representations I have witnessed (Green, 1998:6). My goal, therefore, is to somehow use the academic language of the dissertation to represent the language learned during fieldwork (See Green, 1998). Of immediate concern, then, is how to present Rita's eldercare narrative (and those of other caregivers I spoke with) in ways which acknowledge contradictions, interruptions, and eruptions, as well as its problematic I's--without undermining its message of true personal suffering and need.

CONCLUSIONS

In this chapter I went beyond the presentation of eldercare narratives as monologues produced by unitary speakers. I did this through explication of my own role in the recording and co-shaping of the narratives. I also described aspects of my positionality and how these affect my behaviour, perspectives, understandings, and how I am viewed by those people whom I interviewed. What I want to re-emphasize, however, is that the conversations and stories I have recorded are true in the sense that they are based on real people and real events. Sue's mother is a real person who was holding my hand. Emiko's husband did die. Rita's father is bedridden. These are all undeniable
facts. Furthermore, although we may never be able to capture events in an unmediated fashion, by paying close attention to the processes and contexts which constrain narrative production, we can begin to comprehend how people live and how they use narrative to transform their experiences into meaning-saturated productions.

One aspect of care I want readers to notice is the complexity of each situation. Rather than portray caregiving in terms of its usual metaphor, burden (Dorazio-Migliore, 1995; Kramer and Kipnis, 1995; Montgomery and Kamo, 1989), I portray caregiving as composed of a wide, intersecting array of rich colours and textures of feelings, thoughts, and activities.

In Chapter 6 which follows, the consequences of caregiving are emphasized. In Part I, I focus on health, well-being, and health care as three areas in which the influence of caring is particularly strong. Mainly what I am aiming to demonstrate is how thoroughly caregiving affects individual lives. Then, in Part II, I present a detailed case narrative in order to ground my study more firmly and to underscore the complexity of each individual case.
Notes

1In a recent study of the incidence of poverty among seniors in Canada which explores the impact of gender, ethnicity and race, Brotman (1998:182) describes how "time period of immigration" has a significant effect on poverty rates. She also notes, "it takes between 10 and 20 years for recent arrivals to Canada to reach a level of economic prosperity equal to that of the Canadian population in general." Noteworthy as these statistics are, however, they mislead because they only describe averages. Some recent immigrants to British Columbia are wealthy, while some never catch up. Martin Spigelman Research Associates (1998:1-2) note: "The province's riches and opportunities have bypassed some immigrants and refugees just as they have bypassed so many Canadian-born people. For some, poverty has transformed their dreams into nightmares. Their expectations remain unfulfilled. And the province has lost the opportunities which they offered."
CHAPTER 6 - ONGOING ENDINGS: EFFECTS OF CAREGIVING

Any live, competent, and dispassionate observation from any position, from any viewpoint, always retains its value and its meaning. The one-sided and limited nature of a viewpoint (the position of the observer) can always be corrected, augmented, transformed (transferred) with the help of like observations from others' viewpoints. Bare viewpoints (without living and new observations) are fruitless. (M.M. Bakhtin, 1986)

In Part I of this chapter, I discuss the effects of caregiving in three areas: health, well-being, and health care. These topics appear in the eldercare narratives as central elements and I use them here to suggest the broad spectrum of effects produced by caregiving. The narratives also demonstrate that individuals--no matter who they are--are always affected by their caring work. No individuals or groups simply provide care without thought, effort, energy, and emotion.

In Part II, I focus on the narratives of one participant in the context of a series of researcher/participant interactions. This expanded case is presented in greater detail because it summarizes and opens for scrutiny many of the issues discussed in earlier chapters and in Part I--plus, it suggests some new complexities. Through caregiving, Audrey has expended resources, thought, effort, energy, time, and emotion. Audrey's case-story explains how her health and well-being have been negatively affected, and how the allocation of home care is inadequate to meet her needs--even though she receives the maximum allowable home care support.
PART I.

Social interactions are important sites of struggle and creativity. From these locations ideologies buried in hegemonic ideas and practices are glimpsed, hinted at, or openly discussed, then negotiated, accepted, or rejected. As sites of interaction, the narratives, in a sense, are enactments, repositories and exemplars of values and ideas, as well as sites from which action is negotiated and initiated. Here again, I have also selected examples which seem to offer opportunities for learning and growth and for observing some of the processes just discussed.

HEALTH

The caregivers I interviewed speak about their own medical conditions, which they say are connected to caregiving in a variety of ways. For example, tears rolled down Cathy's cheeks during our entire interview while she revealed her inability to attend support group meetings because of her emotional vulnerability and her fear of sobbing in public. Her father who has Alzheimer's Disease was recently placed in a care facility and her mother is also sickly and frail. She portrays caregiving both verbally and non-verbally as something which negatively affects her emotional stability, personal well-being, and susceptibility to ill-health.

Cathy is in her 40s, but over 40% of the participants I spoke with are seniors, 65 years of age or over. When I ask 80-year-old Emiko how she managed to cope with everything over the last few years, including the death of her husband, she replies:
Well, this is what I thought to myself this summer: 

_Gee, it's a wonder I'm not sick in bed._

But, it did come out eventually. I went for my physical in December and he [the doctor] said, 'Oh. You've got high blood pressure! And it's really bad.' And then I thought, 'Ooh!' And then I knew right away that it finally came out. And so I started getting just one pill in December, and I go to the doctor to get checked every month. And I just went yesterday, and he said, 'Oh!' He said, 'It's coming down.' He said, 'That's a good sign.' So this is all stress, isn't it?

In this statement Emiko reveals her theory of illness causation: sickness is connected to stress. It is an entity which is stored within the body, and something which "finally came out" in the form of hypertension. Caregiving engenders stress, and thereby initiates a process which can cause sickness or even kill.

In the case of Tara who is a young-looking 45, stress--together with inter-generational, cultural, and personal conflict--has led to a highly debilitating, stigmatizing chronic health problem, and its complications. Tara's mother was born in Canada, but returned to Japan during the War. There she met and married Tara's father (who is now aged 80). The family returned to Canada in the 1950s when Tara was 7 years old. Then, eventually, Tara's mother and father separated, after which Tara went to live with "an all-Canadian, totally non-Japanese" foster family.

Later, Tara had to learn to see her father through "Japanese eyes," rather than through her own "Canadian eyes." She looked after her Dad at home for more than 5 years, but now visits his care facility, bringing Japanese food and so on, 2 or 3 times a week.
During her years of home caregiving she gave up paid employment, experienced financial difficulties, and had to change residence. Caring for her father also had consequences for other family members, namely her husband and two nephews. Furthermore, during this period Tara developed sicknesses which still leave her feeling tired, weak, and vulnerable. She says, 

I realized I couldn't work and look after him, so I quit my work completely. And then financially it was quite hard. And it was also the time when I was just starting to get to know my father again after not seeing him for years and years. So that was also hard as far as just getting to know him again--and not liking what I was getting to know [laughs].

Tara remembers her father's drinking and her fear. With the help of professional counselling, however, she notes:

I was able to kind of understand him a little bit more, and about his life, how he was raised and....but I had to go through a lot of changes myself. Like I started having panic attacks. Severe panic attacks. I thought I was having like a nervous breakdown. And then I started getting really fatigued and I kept getting flu's and colds constantly, and so a lot of this time I didn't realize they were panic attacks. I thought, Ooh! What's happening to me? [laughing].... And it was after I put my father in a home that I started seeing a doctor.

Maria, a second-generation woman of Italian ancestry, also told me that she gets depressed and sometimes takes antidepressant medication, drinks a lot of coffee, and smokes. She views her current caregiving, with a live-in father-in-law, and visits to her own parents (one of whom is in a nursing home), as frustrating in the extreme. She describes her depression as follows, using a foil to minimize its severity but emphasize its genesis:
I have a friend...she's a very, very severe case of manic depressiveness...I mean she hears voices, and, y'know, hallucinates, the whole 9 yards...attempted suicide numerous times. Her whole life is black. Like she sees nothing but black. They can't figure out why she's like this. She can't remember any abuse or anything that would maybe set her off. But with me, I know what gets me. It's just a matter of me trying to deal with it.

Like I say, Well, okay, this, this, this, and this get me down. So if I could change this, this, this, and this, then that would be better. But I can't change this, this, this, and this. Do you see what I'm saying?

In this narrative Maria suggests that there is nothing she can do to change her situation.

With a life-threatening disability, however, Mike has had to make some changes. He is a second generation man of Italian background and another senior caregiver. Like about 2/3 of the participants in my study, the person he cares for resides in an institution. Mike is nearly 80 years old, and he developed a heart condition during his wife's sickness and subsequent placement. In the early 1990s he underwent heart surgery, and now the stresses of caring, as well as frustrations at the "care home," are perceived as potential sources of danger. Mike says,

Since my heart surgery, I can't lift anything. I didn't have any heart attack, but the opening of the aorta valve is usually about an inch in diameter, but it was down to about that size of hole [demonstrates with his fingers]. And when I went to see the doctor....he said, "You're lucky you're still walking. You're supposed to be dead!" What a heckuva thing to say! [Laughs]

....It's hard on my nerves. With the valve in there and the bypass, I should be calm, y'know? I can't do any lifting. They leave my wife until I get there....then I call the nurse. I say, 'I'm going to fix her up now in that chair, and you're going to help me do it, because I can't do any lifting. You're going to sit her straight
...no pillows on the sides because you guys have been putting so many pillows in there, she can't move.'

Mike's frustrations now stem from trying to get the staff to take care of his wife as he feels she should be cared for.

Mona, like Mike, is another senior who cares for a spouse at the extended-care facility in which he now spends his days and nights. Mona cared for him at home until a second stroke left him severely disabled and it was then that daily visits to the facility began. A few months ago, however, stresses took their toll, and Mona had to slow down. She recounts developing a "nervous illness" which prevented her from doing certain things and which required her to cut back caregiving too. Now, she only goes to the facility 5 days a week, and shares her husband's care with a paid helper. In the excerpt below, Mona reveals the importance of place—as well as friends, food, and respite:

I have a friend who used to be a nurses' aide. She and her husband more or less looked after me when I had this nervous illness. They took me to the doctors. And they live maybe 7 or 8 miles from me, but they came all the way down to my place to pick me up and take me to the doctors, and then to the pharmacy—and for about a whole week. Two, three times a week she would come with fresh fruits and vegetables and things like that. Wasn't that nice? We've become real good friends. So we socialize with them, and then my son and I took them out to a Chinese restaurant [laughs]. And we asked them to order what they liked. And that kind of a thing would kind of make me alive again.

...At one time I was even scared to go to a mall. There's just the one bus stop. Ten minutes is all it takes. And yet I was afraid to go in there just to buy a pair of panty hose.... That's how bad I was...but I didn't mind going shopping where I am, you know? There are a lot of stores there. That's my area....I didn't mind going down there. I go down just for a walk and get away from everything. I used to do that, but usually I love going to malls, but I just couldn't do it anymore.
I cancelled all my dental appointments and my eye doctors, but that's all done now--except for the dentist. I keep putting that at the very end [laughs].

So I'm almost back to normal.

According to Lorraine, caregiving is risky. Throughout her narrative images of mental and physical illness--as well as death itself--keep popping into our conversation. Together we construct the following story when I ask Lorraine about any negative aspects of caregiving:

Lorraine: Jim used to go swimming once a week. Ben [a paid support worker] would take him and take him in the water and let him float and stuff which was lovely for him. And there was a man there that took his wife every week and oh, it was pathetic, just pathetic, and... It's very sad, you know. Now he's.... What happens to people, Margaret: the caregiver often goes before the patient.

Marg: Yeah, I've heard that before.

Lorraine: The doctor told me that. He said if I didn't quit, I was really heading for a breakdown. I mean just in the last couple of years, not the first five. But finally, you know, even though you're a fighter and you're strong and everything, there's no way out of it. You can work all day, you can do everything you're supposed to do: it's all there in the morning. So what's the negative aspects? There's no end to it. [laughs]

In the various transcripts, there are countless references to the passage of time. In Lorraine's narratives time figures prominently. She talks about her years and years of caregiving, the time she has spent organizing meals and outings and its "all day," never-ending nature. Furthermore, this precedes Lorraine's reference to "breakdown" and death.

In all of the above examples--of Emiko, Tara, Maria, Mike, Mona and Lorraine--poor health is spoken of as a consequence (or potential consequence) of caregiving. Each caregiver believes
that the effect of caregiving on health is negative and significant and some caregivers suggest that it can even kill—with the caregiver dying before the care-receiver.

**WELL-BEING**

Many of the women and men from all three ethnocultural groups mention guilt or feelings of unease as motivations, as experiences, and as consequences of caregiving. They also describe their attempts to overcome these painful feelings by engaging in certain behaviours such as doing volunteer caring work or providing regular visits to care facilities. In describing these activities, some people remarked that they are able to redeem themselves or to make up for past behaviour which is deemed somehow inadequate. I interpret their behaviours as attempts to provide a new basis for thinking about themselves as moral individuals. In a sense they seem to be reinventing themselves through caregiving, and through narrative, as valuable, and valued, people.

The reasons people feel guilty seem varied and complex. In her narrative about forgiveness, Tara reveals how she felt guilty and inadequate, even though it was her father who was abusive! Theresa, in telling the story of the two mothers, suggests that the coincidence of the two deaths is "a message" spelling out her mistake, while she stresses her so-called guilt complex. Others imply that although they provide continuously more care, it is never enough, and it never ends, and that this may be the source of their feelings of guilt and tension.
Describing her caregiving as "the worst time of my life," Theresa blends guilt with a kind of bitterness. Early in the narrative she recounts how her mother-in-law, Franco's mother, in contrast to her own mother, never attempted to do things for herself. Part of this she attributes to class. That is, according to Theresa, her mother-in-law was either from an upper class peasant family back in Italy or had pretensions of being upper class (she is not sure which it was). She describes her mother-in-law as being showy and theatrical, wearing lots of gold jewelry, haughty. She says with contempt that as a young woman her mother-in-law dramatically wanted to "throw herself into Burrard Inlet" when she first came to Vancouver. This was because she was so miserable here. Unlike Theresa's family, Franco's mother came from a more Southerly region of Italy, Calabria, whereas Theresa's family was from a more Central region northeast of Rome. This is significant because people of Italian background often identify themselves, or are identified by other Italians, in terms of paese or place and certain behaviours are said to be typically found among people from that location. This includes region and province of Italy, not to mention city, town and village.

In the following lines Theresa compares the two mothers:

Franco's mother was totally different [from my mother] in that she was more helpless. She wanted everybody to do things for her. She was like that in her younger years too. I vowed I would never be like that. There is just no way. Her daughter used to do her ironing. I--with five children I raised just about all by myself because my husband was so busy. I used to cut the grass, make bread, wash, iron, didn't drive, shop, take the kids to dentists, music, cut
the lawn, did everything! And yet we were going down there, to do her work too.

She was just that kind of person. When my husband's father passed away, it was just unreal. So I learned a lot from that. You learn from negative things just like you do from positive things. In fact, I think probably the negative things help you more.

Theresa also told me that some of the people at the care facility at which she volunteers remind her of her mother-in-law. She says, "There are humble and not-so-humble senior citizens."

In creating an eldercare narrative about her mother-in-law, Theresa uses a recurring theme of tension and stress to suggest how awful these years were. She says:

...tensions were building up so bad that we decided, with the three children, that we'd take turns. A month here, a month there, but then as the days grew towards the end of a month.... It was just too hard on her and it was too hard on me. I think it was harder on all of us. Then on the last day her suitcase would be put by the door....

So I thought in working with the seniors at the facility that I could make up a little bit for my shortcomings. I don't know whether it's guilt. Maybe I wasn't capable of handling that, I don't know, but it's pretty difficult when you've got somebody who is so helpless and doesn't have to be. It's hard to do things for them. Whereas here...they really need help and I'll bend over backwards for them all the time. They are so much easier to work with.

Theresa certainly describes a need to make up for perceived inadequacies or wrongdoings. She felt guilty when, on the last day, "her suitcase would be put by the door." This was viewed as a dramatic act whereby the mother-in-law silently (yet symbolically) indicated her displeasure and feelings of rejection.

Theresa's putative sins include: keeping her mother and mother-in-law apart; not understanding, as well as rejecting her
mother-in-law; feeling anger at her mother; and placing her mother-in-law in a care facility. Emotions, such as bitterness, anger, blame, and satisfaction all mingle with the need to atone or make amends, and Theresa is not the only caregiver who describes these feelings, although others may use very different words.

**THE HEALTH CARE SYSTEM**

One of the effects of caregiving is greater familiarity with the health care system. In the present interviews, this sometimes, although not inevitably, leads to the narration of stories of criticism and disdain. Some stories, however, are stories of praise and appreciation. For example, John says that he does not refer to himself as a caregiver because this would detract from the nurses who "really care" and others I interviewed also express their admiration and gratefulness for the work of the nurses, aides, therapists, etc.

In the following example, however, an angry caregiver tells a story which contains some damning messages. She faults health care professionals, but implicates the whole system too:

*Linda:* ...it was just really hard for her when you're used to having your own home and your own routines and nobody telling you what to do. It is, for some people, I mean it is very, very hard to go and be in a place where there are people bossing you around and, you know, sort of telling you when you're going to have a bath and, um, she just didn't adjust well and so when people are like that, it is sometimes hard on the people that are looking after them and some people were better than others at dealing with this lady who was very weak and she looked stronger than she was--and because she sort of could think and talk--she seemed more able than she was, and so we ended up having a
real problem with her there...

*Marg:* This was a different facility than the one she's in?
*Linda:* A different facility than where she is now.
*Marg:* Oh, okay.
*Linda:* This was a previous one, yeah, and she would call for help because she was too dizzy, part of the problem is her medication makes her dizzy. And she was too dizzy to go to the bathroom by herself, but she couldn't always get someone to come and help her, and so she would try to go by herself and one time she fell and when she called for them to come, they wouldn't come. And she was stuck between the bed and the dresser and, um, for quite a long time, and then when the aide finally came she had a fit.
*Marg:* Gee.
*Linda:* And called, you know, and they had about five of them there making sure there was nothing broken so that was one situation and so they put a big thing on that if Mom needed to go to the bathroom that she would be taken and that there should be two of them to make sure she didn't fall. Well, that was before the shift change. And when the shift change happened, it wasn't carried on, so she fell again.
*Marg:* Gee.
*Linda:* And, so anyhow then things kind of settled down for a couple of days and then somebody else...there's always these different people, you know. You couldn't just say, 'Well, it was him or her.' Just a variety of not quite getting there and this one lady was mad at Mom and Mom often felt like they were mad at her, even when they were probably just impatient but, anyhow, she was...she didn't hurt her but she was really unkind to her, so we kind of had this family conference over the phone. I mean Mom would phone us and tell us what was going on and we would go and visit and the staff were always really nice, you know, and friendly to us and you'd say, 'Well, have you been having any problems? Was she...?' 'Oh, everything's okay.' You know, so I think they didn't write things down that they didn't want written down. Anyhow, it got kind of out of control and the three of us had a big long conference call and my brother wrote a letter to the Director.
*Marg:* Oh yeah?
*Linda:* And Mom...immediately moves were put into place so that Mom would be moved to a different location in the facility where there was more...where the people needed more care so that there wouldn't be a staffing problem.
Also the place did a...they had a...workshop on elder abuse or...
*Marg:* For the staff?
*Linda:* Yeah, for the staff...that grew out of our concerns,
because we figured our Mom could talk. There were other people that were much more nasty and crotchety than Mom who didn't make sense, and we figured if she was being treated that way and they knew she could tell on them, then there were other people that might have not been having a very good time too, and I mean they didn't hit her or anything, it was just.... They were, maybe they were understaffed, maybe they were this, maybe they were that. We don't know but we figured there was no excuse.

Yeah.

Linda: So anyhow when she was moved over there, they were geared for somebody who needed more assistance... a slightly different attitude on the part of some of the staff. I guess they choose people to work in different places. Where my dad was, where the people needed all kinds of care and some residents were totally unreasonable, they had excellent staff. I never saw anything that ever made me raise my eyebrows at all and so anyhow once she got there, it was much nicer...

Linda's narrative raises some critical issues regarding care facilities, including issues of communication, control, and staffing. Such issues were frequently raised by other caregivers I spoke with as well. For example, communication between staff and families, and between staff and care-recipients, was described as an emotionally-charged problem area by disgruntled family members on several occasions. Using similar words, several caregivers said they feared staff retaliation if they complained about anything. Staffing continuity, shift changes, turnover, holidays and understaffing were major areas of concern. Toilet problems, such as not being taken to the bathroom frequently enough, falling while trying to get to the bathroom, being left in the bathroom for long periods and having to wear diapers against one's will (instead of being taken to the washroom) were also viewed as highly important. These are all
significant, crucial and correctible matters although structural
issues and budget allocations currently constrain action.

Linda’s narrative underscores the positions of risk occupied
by residents in long-term care. Care-recipients are often
physically, mentally, and/or emotionally frail. They may be
receiving medication that affects their abilities. As well, they
are vulnerable to intimidation and control, ageism and elder
abuse. Furthermore, as restructuring of the health care system
continues apace and our populations age, these kinds of problems
will only become more common. Additionally, due to the
intersection of factors such as gender, race/ethnicity and class
certain individuals may be treated differently than others, or
some staff members may be perceived negatively by caregivers.

All such problems strongly affect the life-satisfaction
of residents as well as the well-being of informal caregivers who
often spend long hours at care facilities or otherwise struggle
to ensure the safety and well-being of their institutionalized
loved ones.

PART II.

Each large and creative verbal whole is a very complex
and multi-faceted system of relations. With a creative
attitude toward language, there are no voiceless words
that belong to no one. Each word contains voices that are
sometimes infinitely distant, unnamed, almost impersonal
(voices of lexical shadings, of styles, and so forth),
almost undetectable, and voices resounding nearby and
simultaneously. (M. Bakhtin, 1986)

Here, I present an extended example in order to further
illustrate some of the issues discussed in Part I of this
chapter, as well as material presented in previous chapters. This extended excerpt is a story which I feel must be told because it exemplifies what caregivers (and care-recipients) face, in terms of the complex intersection of multiple oppressions and multiple problems. It also demonstrates the intricate ways in which meanings in personal narratives are negotiated and remain open to subsequent reformulations and modifications.

The interview is with Audrey who has been a caregiver to her 86-year-old mother for more than 10 years. She is the caregiver, described in Chapter 4, who says she never decided to become a caregiver, but that like getting married, "One day it happens."

In my analysis, I suggest how the eldercare narrative and my interpretations are informed by preliminary and subsequent discussions, fieldnotes, Audrey's letter, her visit to drop off the transcript, and even my dream in which I literally become Audrey and she becomes me. In other words, this case-story is meant to demonstrate how extra-transcriptual materials, including my own reflexivity or self-consciousness as present in reflection, writing, discussion, and even dreams, have shaped my analyses of Audrey's narrative and those of other participants.

The story that follows is really the processual account of an interview. That is, this full story not only includes excerpts from a co-constructed eldercare narrative, but it spotlights information from my fieldnotes in which I reflexively record my thoughts and feelings before, during and after contacts.
with the participant. As such it offers a view of the ideas and feelings that inform my interpretations.

The Story of Audrey's Interview

FIELDNOTES

October 3, 1997

Just received a phone call from A., a Japanese woman who was referred to me by B. I probably spoke to her for about 10 minutes. She is willing to be interviewed. She said she is caring for her mother in her mother's home. She went to a final meeting, before patients go home, of some kind of stroke club. She said she was scheduled to talk there, but nobody wanted to listen to her. She hoped she would not have the same experience with me. When I told her it was hard to believe that no one wanted to listen to her, and asked her why, she said that it was because she didn't just talk positively about caregiving. She told the group that it was fraught with difficulties, and that they did not want to hear that. Instead they wanted to hear that with a positive, right attitude, then caregiving would be alright. A., however, believes that other things are also needed. When I said to A., 'So you've been through quite a bit...?' She responded by saying, 'Well, it's been a learning experience.' She said, 'They say that God never gives you anything you can't handle'...but she thinks that caregiving can be really difficult....

Her mother was in her seventies when she had her stroke, and reactions to her by the doctors (and other professionals) were very poor. She said that because her mother was old and Asian, she was considered to be dumb. A. said that basically Asians are considered to be dumb. It was like being in school and being thought dumb because you ask a "stupid question." I told her that I would love to talk to her and to record some of these ideas....

A. also told me that it was fortunate that her mother was in a wheelchair, because if a person wasn't in a wheelchair, then they were likely to cut back on hours. She also said that the professionals that are sent out (the Assessors?) should be at least 50 years of age. She said that the 30-year-olds are simply interested in careers, and do not have the empathy that comes with age. They don't think that the person might need a little extra care.

This should be an exceptional interview. I feel as though A. can really help me to understand some of the problems faced by caregivers who are non-mainstream, and I feel as though I should
show her lots of respect and empathy. I also think J. is right that I should stop referring to people as "Japanese," and instead just call them Canadian, and see how they identify themselves. A. called her mother "Asian."

In this regard, I'm going back to the first line of this notation. I referred to A. as "Japanese," but in this perhaps I am stressing too much her "Japaneseness," her exoticness, instead of seeing the similarities, in her being just a Canadian (who happens to have some Japanese ancestry).

A. also told me that she takes her mother to an exercise class three days per week; a stroke recovery club once a week; and once a week to some other function. So basically every weekday.

October 8, 1997

Tonight I went to visit Audrey... She and her mother were both born in Canada. Her grandmother came to Canada around 1900, so the mother told us. And her grandfather also came about that time as well. Audrey asked me if my family had a hard time when they first came over. I said that I didn't think it was that bad, but that my grandfather [who came in 1912] was here 7 years before he had enough money to send for my grandmother and my dad, so....

My interview with Audrey was very interesting. I got to her house at about 7:55 pm. She had made it clear on the phone that she would see me from 8 pm until 9 pm. At first I wondered if I had the right place. A handsome young man with jet black hair opened the door and then two little kids said hello to me. I thought Audrey had said that she would do the interview in the basement because she didn't want to upset her mother (who lives with her), but instead she ushered me into her kitchen. I sat down at the table and she immediately began talking. I quickly got her to sign the consent form and turned on the recorder. She introduced me to her mother who was in a wheelchair. The whole place was sort of messy. Clean, but messy. There were things all over the place. Little knick-knacks and pictures, papers, and in the living room the two little ones eventually went to sleep on the sofa bed.

I liked Audrey right away. She was an excellent person to talk with. She is exceptionally bright and articulate, and not afraid to say what she thinks. She wore a t-shirt and slacks, and had short grey-black hair. She also took long looks at me, seeming to gaze deeply into my very soul. I think she was trying to see whether or not I understood what she was saying.

During the interview there were all kinds of interruptions: people wandering in and out of the kitchen; the cat had to be put
out; people commenting about something being said; kids crying, etc. Finally, it was almost 9 o'clock. I didn't want to outstay my welcome. I noticed, by the way, that although I was quite nervous about going there, that as the interview progressed, I relaxed greatly. Anyway, when there was an interruption (a phone call, I think) around 9 pm, I thought this might be a good time to stop the interview. It wasn't really over though...

[A short while later, several relatives turned up whom she introduced me to, and who commented on caregiving in general.]

Audrey was very interested in what I was doing. After the interview she questioned me about my findings so far. We had quite a good discussion. It seems to me that a lot of our discussion centred on how awful care facilities were. She told me that what her mom most objected to were the nights. Her mom told her how awful it was to be in a dark room all by herself all night long. And, that the more you call for the nurse, the less attention you get.

...Audrey said that she thought women encouraged the belief that they were the best caregivers, so that they had something they could do and be good at! She described it as, "doing a number on themselves."

At one point Audrey commented to me, "Aren't you glad you stayed for tea!"

....Audrey also told me that there should be "drop in" respite so that someone can, at short notice, because of a crisis or whatever, drop off the care-recipient for say, 24 hours. Now, she understands that respite must be arranged quite a few days in advance, and the usual respite time, perhaps the required respite time, is two or three days. I suggested that it also cost about $25 per day, and Audrey immediately quoted a figure of $23.50.

Audrey doubted that caregivers would ever be paid for their work. It was also suggested that possibly things were worse now for women [than they were 10 years ago]. Audrey told me that she would not have been able to survive had her husband not died and she had not sold the house. She moved in with her mother, sold her own house, and has been living on the money from her house for the last ten years...

I was at Audrey's place until about 10:45 or 10:50. I mentioned as I left that she had a busy household. She told me that her mother's place was always like that, that her mom even kept her sons' girlfriends. Altogether I was there almost 3 hours.
THE INTERVIEW - October 8, 1997

[Audrey starts talking immediately and I barely have time to get the consent form signed and turn on the tape-recorder. The following excerpts appear below in the order in which they occur in the interview although much has been omitted in between.]

TRANSCRIPT - Excerpts selected to show the complexity of content and context, as well as the wide range of topics discussed.

AUDREY

Her home: Lots of noise in background: bird, kids, etc.

TAPE RECORDER TURNED ON

Audrey: ...I believe he's the Administrator at ________, that's a Japanese neighbourhood house.

Marg: Oh yeah.

Audrey: He said that it is a misconception that the Japanese from Japan, or the Japanese in Japan, necessarily look after their elders. That is not true. That it has been his experience that the Japanese here in Canada are more likely to look after their parents than in Japan, because in Japan the ultimate in life is to have money and to have a good position; they dress nice and here we're not economically driven as much. In fact, probably not as much as the Chinese, the Filipinos... I don't think we are as economically driven as Canadians. And I don't know if that has to do with we are used to having a good life and....?

Marg: I don't know.

Audrey: Anyway, I never decided to become a caregiver, it's just like getting married: one day it happens [laughs].

Marg: Yeah, maybe you could tell me a little bit about your own life and then how you got into caregiving...

Audrey: My husband and I were married for 30 years, and I have two sons and a daughter, and he died a month after she had her stroke, and because that freed me as a wife, I ended up becoming a caregiver and it is her fault that I'm a caregiver because she wouldn't stay in the facility.

Marg: Oh.

Audrey: I think that if she didn't fight so hard not to be there, I wouldn't have brought her home. So it had nothing to do with my, my moral obligation, all of those honourable things, it's just that she wouldn't stay there! She was at Site W for three months and because she was so determined to come home, I felt the need for her to do something about her physical abilities before she came home because I used to bring her home every
weekend from about the first month because she absolutely didn't want to be there, she fought, she struggled, did whatever she needed to do to get the hell out of there!

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Audrey: I am of the firm belief that they need to get more of the people--that are at home being cared for--out swimming because it is....it keeps them mobile. I mean, unless she goes swimming, she sits in that chair.

...You know, they [caregivers] want to believe that if you're positive that everything is going to be A-Okay and it's not. I think for myself it was the hardest thing I've ever done in my life. The hardest thing. And I don't know, I have my friend here that I work with, walk with, her husband has since died, but she said that she found it so stressful that she used to go to the park and cry and wonder what did she ever do that she had to put up with this man who was angry at her because he couldn't walk and if she went bowling he was mad that she doesn't stay home, she doesn't stay home with him; how dare she walk around or be, or be smiling because he can't walk.

Marg: Wow.

Audrey: And so when you have this daily grind, hour after hour, day after day, it's very, because all of a sudden you're mowing the lawn, you're cooking, you're looking after the money, and you have to live with them 24 hours a day--and right now the government doesn't make it easy for you to be a caregiver because if they see anywhere, anywhere at all that they could take your hours away to save money, they do. I mean it's really tackling it backwards because the less help they give you at home, the sooner you're going to burnout--but... even though we have a woman Minister...[Laughs]

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Audrey: ...and that's something we were talking about. I was talking about it with a friend of mine who has a 78-year-old husband, and he has had a stroke and he has--but I don't know if he has diabetes or something--but...something happened to his finger that they had to cut it off, and they sewed it any old how, and then when the doctor removed the dressing because it had stuck, he tore some of the skin off, and it hasn't healed properly so they left a couple more stitches in and he wrapped it so roughly that she ended up going to Emergency shortly after they got home. And it was her feeling that because he is so old, it doesn't matter, and I'm afraid
that is the way I feel our family doctor treats my mom because she has been getting dizzy spells, and...

Marg: Oh, wow.

Audrey: Oh, well, you know: just listen to her heart and if it's beating regularly, it's okay. Not dealing with her fright each time it happens. I think very definitely, not just men but women, you know; I think they talk about it in that Seniors' Newspaper [The Independent Senior]....They call it ageism....

...if they treated anybody else the way they treat seniors...there would be a loud hue and cry, and so two years before mom had her stroke the medication bothered her, and because my father was retired, the doctor pooh-poohed it and said, 'Oh well...you have nothing else to do but complain about whatever.' And it was the day before her stroke that she phoned, and said, 'You know, the doctor says it's not my imagination; I am reacting to all the medication that they're giving me.'

Marg: Oh, no...

I had a similar experience with my mother: the doctor told me she was lonely and that's why she was complaining, and then we found out she had cancer, and she wasn't just.... It wasn't just loneliness; she was physically....

Audrey: Are you a Registered Nurse?
Marg: No. I don't have a nursing background...

Audrey: ...Oh, I thought that you were...

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Audrey: So that's the other thing that they don't listen to: my father was in the hospital for over a year before he died, and he went into the hospital just a few months after my husband died.... They did surgery on his liver, and for over a year he kept saying that he, you know, he doesn't 'feel well,' even though he was doing his exercises in bed and doing all the things that....

Marg: Yeah.

Audrey: And we should have realized, as his family, that he was not, wasn't the kind of person to be complaining, that he prided himself in being physically fit and strong, and yet for months before he died he complained, and when they did the autopsy he was totally ridden of cancer.

Marg: Ooh.

Audrey: They said it was their impression that, that they didn't get all the cancer, that it had been doing its work for the months and months he was being held, uh, in a holding bay to go to a facility.

Marg: Oh really?
Audrey: So that was kind of something if I had to do it over again, that I would listen to my common sense instead of listening to the....
Gives you a lot of faith! [Laugh]

Marg: Yeah. Yeah.

Audrey: That's why I asked you if you were a Nurse.

Marg: No. No.

Audrey: But it's...my mother has an 86-year-old sister, and I said to her--and she's very together except that she forgets dates....but she does all her own yard work, all her own cooking, all her... And she burnt a pot twice in one week and I said, 'Julie, you better be careful because if you are 30 and you burn a pot, nobody thinks anything; but if you are 86 and you burn a pot they'll put you in an old folks' home.' And that happened to a Co-ordinator of my mother's Stroke Club. They set the house on fire. If that had been a senior, she would have been in a home so fast....

Marg: Wow.

Audrey: She would. Is that not right?

Marg: Yeah, I agree with you. The other thing I've heard is that doctors spend less time with older people. They have done a study where they have actually clocked it and....

Audrey: That's true....a number of times....I've complained to the doctor about her getting dizzy. Her blood pressure is fine; it has to be the medication, and so over the 10 years I've looked after her, I've taken it upon myself to gradually cut back and cut back so that from 80 milligrams, she's down to 10 and now she's been having dizzy spells more regularly and that's been the problem with her medication throughout--the same medication--is that she gets dizzy and it's gone away before because I've reduced what I give her, on my own, and not telling the doctor until she had a couple of good visits and her blood pressure has been fine. But he still doesn't look at his records and think!

Marg: You also mentioned I think on the phone that it, um, because your mother is Asian, that might be a factor, do you think?

Audrey: Oh yeah.

Marg: Could you talk about that a little bit more, or...?

Audrey: Well, when she was at the Care Facility, they just presumed, because she is Asian, that she can't read and write, and they were giving her ABC blocks--which she ended up firing at the therapist.

Marg: Oh, really?

Audrey: And more recently, we were at the Community Centre.... The Stroke Club gave us a storage cupboard, and we were there late one evening putting all our stuff from underneath the table into the cupboard, and they had two ladies from the University who were teaching new
Canadians English. And they didn't have anyone so they chose to speak to my mother, and even though she was sitting there reading a scandal sheet, they presumed that she can't read and write, and they were giving her a Dick-and-Jane-type book and saying, 'Why don't you read this to me?'

...[Laughing]...But that happens a lot and we have a Chinese lady who is very articulate and if she weren't Chinese, they would not think anything; but because she is Chinese and articulate, they think: 'Wow. She's a rarity!'  [Laughs]

Marg: Great. So, I mean, I see that basically as racism. Would you agree?

Audrey: ...I don't know if you would necessarily call it racism. I think by the same token if, like my mother when she was at [Site Y], she had a very stout therapist and if you saw her you would not think that she was a professional. And yet she inspired my mother and created that faith in herself to believe that...'I will walk.' And yet if you looked at her and you saw someone else that had a nice suit on and had their hair done. That is not racism, that is just visual [laughs] discrimination.

Marg: Yeah. Well, stereotypes, I guess.

Audrey: Stereotypes.

Marg: ...I don't know if your mother is an immigrant, or...?

Audrey: No.

Marg: Was she born in Canada?

Audrey: She's second generation.

Marg: Oh yeah.

Audrey: It is just the last two or three years that she sees herself as Japanese.

Marg: Oh really?

Audrey: Yeah, and she seems to want to gravitate toward, uh, the Japanese Community centre where...

Marg: Wow.

Audrey: ...it has never been something she wanted before, but for whatever reason--Maybe because the Japanese Community centre is small?--but it is the only group thing she goes to that they have almost one-on-one volunteers on. And her every need...is looked after while she's there and they each make a point of making that person feel like they are normal...that they don't have to sit there and look stupid or wish that they could be swallowed up somewhere.

Marg: Oh that's really nice.

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Marg: Do you mind if I ask you a little bit more about your own life? Did you grow up in this part of Vancouver?

Audrey: No, I grew up in Central Canada.

Marg: Oh did you? Oh, that's interesting.

Audrey: My parents went to Central Canada during the War.

Marg: Oh, did they? So were they out on the Coast here, and then they were...

Audrey: Yes. My father was a fisherman so.... He was one of the few that they didn't take his boat or his house because he sold them.

Marg: Oh.

Audrey: [Laughing] Didn't get much for it but.... He called it 'beating the bastards at their own game.' [Laughing]

Marg: Em.

Audrey: But he lost a lot. Cause he lost his livelihood and he already had a boat and the house paid for when the... when the War came.

Marg: Did he?

Audrey: Yeah, so. He always felt that there was no fair way for the government to compensate....

I think that there are just as terrible things going on now only they haven't defined it because I think that whole exercise was just, uh, men's greed for another's goods, plain and simple.

Marg: Man's greed for another's goods?

Audrey: Yeah. The fishermen, especially on the Coast, the Japanese worked well together and they had a strong co-op and they were very successful. And it was a good way to get what didn't belong to them for nothing.

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Audrey: I think my parents would have preferred I married Japanese, but they were in business all the time we were growing up and being in business meant that you can't be seen to be patronizing just your own people because then...[Laughs]. So we don't--my mother's children--don't speak Japanese. I don't speak Japanese. I understand Japanese, but I don't really speak it. It wasn't something that was encouraged.

Marg: Do you refer to yourself as Japanese Canadian or...?

Audrey: No, I don't.

Marg: You don't.

Audrey: No, I don't see myself as Japanese.

Marg: Okay.

Audrey: And I know that because I'm born here and because I don't have anything to do with the Japanese Community as such, when I met some Chinese people--when they were doing that Walkathon for AIDS or something, there was a whole bunch of Chinese people, mom and I were down at Stanley Park watching all these Chinese people
[wondering] what's going on--and I approached one of them who was sitting on a bench and I said, 'Are these all Chinese people? What are they doing? How come? Are they just from Vancouver here?' because [laughing] there were thousands of them.

Marg: Oh, really? Oh.
Audrey: And she asked me what nationality I was and I said, 'Well I'm born here.' And she said, 'But what is your racial origin?' When I said 'Japanese' they said, 'Oh no, you can't be, you don't even seem Japanese.'
Marg: Oh is that right? Oh. They must have had some stereotypes of Japanese people or something?
Audrey: Em. Yeah, probably, I don't know.
Marg: No, I get that sometimes because when people hear my last name, which is very Italian and then they meet me, they say, 'Oh you, you don't look Italian and you don't speak Italian.'
Audrey: Are you Italian?
Marg: Well, my father was Italian but my mother was English.
Audrey: But was what?
Marg: Was English.
Audrey: Oh.
Marg: Yeah, so...
Audrey: That's a strange mixture.
Marg: [Laughing] I guess.
Audrey: That's a strange mixture.
Marg: I don't know; I guess so. [Laugh]
Audrey: [Laugh]

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Marg: ...Oh here it is, 'In your opinion is caring for your mother meaningful work?'
Audrey: You know, I can't honestly answer that.
Marg: Okay.
Audrey: Ah, let's see, because in one sense yes, I want to do it because it's my mother and I wouldn't want her to be in a facility. I don't think there is any reason for anybody to live if they are in a facility and I honestly feel that for myself if I have to go to a facility, just let me die.
Marg: Really?
Audrey: Yeah. For what? You're going to look at the same old vacant or semi-vacant faces and...
Marg: Yeah. Yeah.
Audrey: What for? What quality is there in living in a facility? Sure you're dry and clean and warm, and...so what? That's not living.

Uh, but on the other hand, I spent ten years of my life doing just that, and nothing more. So, uh, and because of the way funding is for government, it's hard to go to work and have your own life.
Marg: Yeah.
Audrey: You can't. I tried for 14 months to do both. I went to work at night and came home at 3 o'clock in the morning and at that time I had a homemaker for 3 nights, but then it meant that I had also in the daytime to do my work so then I would try and use my sister and my three sons and my girlfriend to stay with mom on the nights I worked, but they don't make it easy, you know. They give...the maximum I had access to, as a fully handicapped person, was 120 hours. Well, that's 8 hours 3 times a week. It's not... They should do a proper job or not at all.
Marg: Yeah, and you weren't able to pay for someone to come in?
Audrey: No, no.
Marg: Were, were you a nurse?
Audrey: No, I used to work in a bank.
Marg: Oh did you, okay.
Audrey: And, I don't know, we had a different lady today and it's probably an unfair way to judge somebody but today my mother goes swimming, a lady came at 8 o'clock and all she did from 8 to 10 is get my mother's clothes on, cover the bed--because she didn't make it, she covered it--made toast, served her coffee, and then she sat and watched TV until Handi-Dart came.
Marg: Oh.
Audrey: [And]...you hardly ever get a Canadian-born homemaker.
Marg: I don't know why.
Audrey: Hardly ever. I'm sure that there are a lot of Canadians out of work. I have friends my age who can't get work, and it is not because they are harder workers. I used to believe that immigrants were harder workers until I worked at the Bank...
Marg: Oh yeah.
Audrey: And I think I was the only Canadian.
Marg: Wow.

END OF TAPE
Dear Marquerite,

I don't really know how studies like yours can ever alleviate the burden caregivers bear.

There are many who are caregiving who should not be, I'm sure.

Certainly in the first half of my eleven years of caregiving the information I have now could have at least helped me to better understand why my mother, as an elderly stroker, was behaving so angrily. Neither she nor I understood our own or each others' behaviour.

Government cannot possibly financially help us because caregivers' needs are so many and varied. More money should be spent on information sharing early in caregiving.

But if we could have access to information from past caregivers or caregivers period, for us, from people dealing with stroke, how much cheaper and beneficial it would have been.

You have to have "BEEN THERE!"

Thanks for listening,

Audrey.
November 19, 1991

Audrey called yesterday. Sounded a little indignant. She wanted to know what had happened to me. I told her that I wasn't quite finished with her transcript and she told me to call her when it was ready.

...Audrey [was concerned about] when I was going to see her because December will be a busy month for her.... It totally took me by surprise, so I fumbled around for some answers when talking to her. I'm now wondering when I should go over there, and also when I should see the other interviewees. Tonight I spent a long time, hours, fixing up the tape that the typist made of Audrey's interview. There were all kinds of mistakes.

November 21, 1997

Tonight I went to see Audrey as arranged by phone. The house was all dark. Then I saw a man coming along the side of the house, and I heard voices from behind the house. I recognized the man as one of Audrey's sons. I called hello to him, and asked if his mom was at home. He told me to wait a minute then called out to his mom, loudly, several times. Then I saw Audrey and her friend, Debbie. They were just about to go out for a walk.

The first thing she said was, "Oh, did we arrange for you to come over tonight?" or something quite close to that. I said, "Yes." and she apologized. I told her that it was alright and that I'd come back again another time. She seemed to feel badly, and although she offered no excuse, except that she had forgotten, her friend said she had too many appointments, too many people to see.

Audrey then didn't know what to do; she seemed prepared to forget her walk and go into the house with me, but I suggested that maybe she'd like to take the transcript and read it, and then get back to me, which she said that she'd do. She also said that she'd write some comments on it, so that should prove to be interesting.

Audrey tried to introduce me to her friend, but her friend reminded her that she had been present the night I had interviewed her.

Audrey seemed kind of confused. I wonder if she is getting stressed out with all the confusion at her home?
January 9, 1998

Today called Audrey. She seemed quite nice on the phone. Said she hadn't got around to the text, but that it was "in the pile." She also told me to talk to B. about more participants because B. knew a lot of people and was very involved "in the community." Audrey said that her and her mom had been sick on and off with the flu. She goes to the B. Stroke Club because of a difference in philosophy between the folks at the A. Stroke Club and herself....

March 22, 1998

In the afternoon, Audrey dropped off her transcript [with no written comments on it] with a nice hand-written letter attached. [See above] In the car was her mother, and what looked like another older lady. She wouldn't come in, but she did invite me to go to B. on Thursday morning around 10am to the Stroke Club there in order to meet an Italian woman who..., "loves to talk." Audrey said that this woman is "very burdened." When I said, "Is she?" Audrey said, "Well, you know Italian women, they're so subservient." This is an interesting comment. The same thing was said to me recently about "Japanese women"!

Audrey also told me that she had nearly had to put her mother into a "nursing home." This is because both she and her mother had bad bouts of flu which lasted for weeks. This is a bad year for flu.... [One nursing home which I was supposed to visit during this period told me to stay away because they had an outbreak of flu among the residents which was serious, and I believe there was a quarantine in place for a few days.]

Audrey also would like me to speak at her Stroke Club some day and I told her I would love to, after I analyze my results.

March 26, 1998

Today I went to the B. School Stroke Club.... I met Francesca....the lady that Audrey said was very burdened.

Anyhow Audrey was surprised to see me there. She didn't think I would come. Her mom, Lana, sat next to me. She wouldn't say much. Then [all of a sudden] she started talking! I wasn't quite sure how to take [some of what she said]...but I was glad she talked to me....

I was amazed that the Stroke Club receives no funding from the government. They seem to be doing such good work! Audrey also told me that the city had cut out funding to Mental Health too....
One thing I want to write down before I forget: I called M. before I left to tell her I'd be going out for awhile, and to ask her if she knew where B. School was. She told me... Then she mentioned that both [her siblings] had gone there. And I remembered then that [some of my relatives must have gone there too]. Anyway, as I walked up to the School, I got this sense of seeing it in the old days. I could almost see my dad running around the fields like the kids were today--only 70-odd years ago! It gave me the strangest feeling of nostalgia and longing. I remember my Aunt C. saying when she was in Italy that she cried at just about everything. It was that feeling of loss. But it wasn't just my dad. That was probably the strongest feeling. But it was that things have changed so much. The neighbourhood. The buildings. The streets. Everything. And I had this feeling of understanding why people put so much value on tradition and memory. These are aspects of the past that have just melted away...and I think this is probably somewhat of a universal theme: that people find their pasts and the pasts of their [own] communities fascinating. I remember in the [ethnographic] film, First Contact, how the New Guinea natives acted when they saw movies of themselves, old movies taken years and years previously, and how they watched them with such awe!

September 9, 1998

...the dream. I woke up in the middle of the night. I had been dreaming that Audrey was narrating a story over a film or a picture book [a kind of voice-over]. I was in the film. First of all I was huddled under some blankets (which I actually was). Then I sort of got up and was sitting on the side (or by the side) of a bed in which there was an older person. That is, I was the caregiver... That's about all I remember... I guess, however, it turns the tables on the caregivers--and Audrey, in particular...[in that she was narrating a story about me, and not vice-versa, and I myself had become a caregiver].

DISCUSSION

I want to make several points here about the interpretation of Audrey's transcript. My presentation of the story of Audrey's interview represents an attempt to show: a) the ethnographic complexity of one interview, b) the numerous stories behind and within a single interview, c) the tenor of interaction, and
d) how much information and richness of detail would be missed in a thematic textual analysis alone.

One aspect overlooked would be the contexts of the narratives. Contexts are selective and dynamic processes which both affect and are shaped by individual actors (Personal Narratives Group, 1989:19). Here I am mainly thinking of the contexts of negotiation (over who will speak, what will be spoken of, when, where, and so on) and the position from which each participant speaks.

Canadian society has placed Audrey in the somewhat mutable, ambiguous position of: a Canadian of Japanese ancestry; a working-class woman; and a mature, unpaid, informal caregiver (who lives in Vancouver in the late 1990s).

I would likely be placed in the mutable, somewhat ambiguous position of: a Canadian woman of Anglo-Italian ancestry, a middle-class woman, and a mature graduate student/researcher (also living in Vancouver in the late 1990s).

Although we are both women, we speak from different locations which have been constructed over time. As women we have been diversely imagined due to our perceived racial/ethno-cultural affiliations, which are strongly related to notions of class and status. Audrey gave examples of how her mother, because she is perceived as Asian, old, female and disabled, is sometimes also perceived as stupid and illiterate. When Audrey's mother did not respond to some of my questions, I wondered if she could hear and understand me, or whether she was hostile to this
white, middle-class researcher who had entered her home to talk about her care, without her permission, only her daughter's. I am also guilty of not listening during the interview, or, as passing over as inconsequential the information that Audrey's grandparents came to Canada in 1900. This is when I thoughtlessly ask Audrey if her mother is an immigrant.

But although the above ethnographic material reveals power relations based on our structural inequalities, things are not quite as simple and dichotomous as readers might expect them to be. The equation Self-equals-Oppressor and Other-equals-Oppressed hides the degree to which our identities, position-alities, and subjectivities are also hybrid and overlapping. As well it glosses intra-cultural variation within both Othered and non-Othered groups.

As a researcher, I ask the questions within the interview, and as Good (1994:86) has noted:

The ethnographer is the questioner par excellence, and therefore assumes a position of power, one often confused with powers to heal or act on behalf of those questioned. I stand with the power of the University and the prestige of research behind me, or maybe I should say, within me as an embodied subject. Both Audrey and I are vividly aware that I retain the power to write, to have the so-called last word, by writing the dissertation. I am also merely a student, however. Furthermore, the University has lost much authority of late and has been attacked as an elitist institution lacking accountability and worse.² I think that Audrey probably sees me,
therefore, as having a prestigious but also somewhat contemptible and ineffectual knowledge/power connection, as is suggested in our interview and again in her letter. She treats me with ambivalence, at least at first, and doubts that my research will have an impact, although she hopes it will. Later, however, she invites me to speak at her Stroke Club.

From the beginning of the interview, before I have a chance to open my mouth, Audrey begins to speak. She seizes power, and positions herself as a Canadian caregiver of Japanese ancestry, distanced from Japanese caregivers in both Canada and Japan. She also distances herself (and a we-group I presume to be Canadians of Japanese ancestry) from Canadians of Chinese and Filipino ancestry and Canadians period (and this simply may be a shorthand for non-Othered Canadians). Her mother is also referred to as "Asian." But later in the interview she calls herself Canadian and says, "I do not see myself as Japanese." So there is ambivalence and inconsistency here. This, however, fits in with notions of race/ethnicity and class as emergent, fluid and situational processes, and with the notion of individual selves as flexible and also emergent in the ambivalent and confusing context of Canadian multiculturalism.

What I wish to highlight, however, are the stable patterns by which we recognize ourselves and by which we are recognized. A caregiver of Italian heritage explained that there are two perceived worlds: a so-called Canadian world and a non-Canadian one. But I think identity is more complex for Audrey. She is
also part of a variety of other worlds, or has been placed into these worlds (such as the Asian world, the world of the Orient, the world of caregiving, the world of women, and so on). At any rate, it makes sense from Audrey's viewpoint to place herself at arm's length from Canadians, Chinese, and Filipinos and to identify with her Japanese heritage in one breath, in order to emphasize their materialism [her perception]. Then to distance herself from the Japanese in Japan and Canada and call herself Canadian in order to interrupt Othering associated with being racialized and ethnicized as Japanese Canadian.

Another way Audrey interrupts Othering and stereotypes of the Japanese Woman may be through emphasizing how non-exotic, how normal, she and her family are. She uses down-to-earth language, talks about her mom reading a "scandal sheet," and she told me they travel once a year to Reno where her mom likes to stay up all night gambling.

Because Audrey speaks--and does not wait to be asked to speak--this disrupts my interviewing procedure. When I get a chance, therefore, I ask her to describe herself and her caregiving (in that order). She responds, however, with little information about herself per se (for example, where she was born, grew up, went to school, etc. or other kinds of things I expect to hear in a Western life history or autobiography). Instead Audrey skips to her marriage, followed almost immediately by the death of her husband. In other words, she interrupts my taken-for-granted authority to begin the interview, subverts my
attempt to structure content, ignores my request for personal information, compacts two huge chunks of her biography into a tiny paragraph (roughly her life between ages 0-20 and 20-50; 50 years of her life in one or two sentences!), refuses to defer talking about caregiving for a few minutes, and later continues speaking when I want to end the interview. What is important is for her to tell her story--her way: against biographical conventions and cultural representations/stereotypes!

All this demonstrates, I believe, Audrey's own sense of agency and authority (her contestation of hegemonic constructions and practices), which is evident over and over again during the interview. When I try to make connections with Audrey and try to make the interview more conversational by sharing my story, she turns the tables, and seems to become impatient with listening. She then asks me if I am a Nurse. I interpret this to be a question about where my loyalties lie and where she should position me viz-a-viz the health care system. Also interesting is her delayed explanation for asking this question which represents her re-assessment of my perceived position. Recall that she says, ironically: "Gives you a lot of faith!" Then, "That's why I asked you if you were a Nurse."

Audrey's resistance to ideological constructions of her race/ethnicity are also underscored later when she provokes me with the repeated comment that I am composed of a "strange mixture" (i.e. Anglo and Italian)--which may have been proffered in retaliation for years of racial slurs against people of Asian
descent (including those individuals who only have one parent or grandparent of Japanese ancestry, such as her children and grandchildren). Although I might have pursued in more depth what Audrey meant by the term "strange mixture," I felt defensive and embarrassed, and let her remarks pass without, I suppose, risking confrontation. No doubt this is based on my assumption that interviews should be conversational not confrontational. Perhaps this is also partly why I respond with, "I don't know," when Audrey wonders why there are not more Canadian-born homemakers. Another reason is that I did not want to launch a complex discussion of racial discrimination late in the interview and at that time of day. I did not want to have to explain my view: that people who are regarded as immigrants (regardless of educational and class affiliations) are channelled into certain types of work perceived as dirty or otherwise deemed to be unsuitable for white, Canadian workers. At the time I was uncertain what to respond, but in keeping with the avowed active and feminist nature of the interview, if I was given a chance to repeat my comment, I would try to give a more considered and candid opinion.

There are power differences between us due to our positionalities, but power differentials deriving from the intersection of gender, class, and race/ethnicity are not wholly determinant. Audrey resists the status quo by attempting to minimize inequalities. She puts me on the spot, makes embarrassing comments, cuts me off, requests personal information, takes
charge, asks questions, etc., all of which are transgressive undermining acts (During 1993:11) which seem designed to equalize us, put me in my place, and challenge Othering.

CONCLUSIONS

Ongoing endings, in a sense, have been the topic of this chapter. I identified the continuing results of caregiving (sometimes years of intimate, intense, difficult caregiving) in terms of health, well-being, and health care. The extended case-story of Audrey was presented to demonstrate many of these themes and, additionally, in order to tell the full story of one interview.

The negative results of caregiving are no doubt more pronounced under harsh material and social circumstances. Happily, most of the caregivers I encountered had at least a minimum of resources at their disposal. All had roofs over their heads, with many having attractive houses or condominiums. Nobody was homeless—a situation that would render at-home care and home care impossible. All the people I interviewed also spoke good to excellent English; in about 25 out of 30 cases English was a first language since most of the caregivers had been born in Canada. Almost all had finished high school, many had completed one or more university degrees, and several had worked in occupations requiring special skills or knowledge, such as nursing, teaching, accounting, and welding. Most also were knowledgeable about caregiving and could access sources of information and assistance. This is something that not all
caregivers can accomplish due to language and other barriers. In other words, materially, educationally, and informationally the people I interviewed were comparatively fortunate even though caregiving negatively affected employment, social activities, and health and well-being.

Having now presented various examples and excerpts from my data, the eldercare narratives, I proceed to Chapters 7 and 8 where I summarize what I have learned and set the stage for a discussion of implications in Chapter 9. In Chapter 7 I describe my journey of discovery during the dissertation research and writing, and I relate my findings to ongoing theoretical and methodological debates. In Chapter 8 I analyze health care system restructuring, using examples of discourse on home care as a focal point. Then in Chapter 9 I identify the value of my study, outline some of its limitations, and make suggestions for further research. The underlying goal of Chapters 7, 8 and 9 is to outline ways in which my findings might prove meaningful.
Notes

1This question is a clear example of active interviewing in which "the respondent," Audrey, is not viewed as a vessel waiting to be tapped, but is respected as co-producer of "an interpersonal drama with a developing plot" (Holstein and Gubrium, 1995:16). James Holstein and Jaber Gubrium (1995:17) note that:

In the conventional view of interviewing, the passive subject engages in a 'minimalist' version of interpretive practice, perceiving, storing, and reporting experience when properly asked. Our active conception of the interview, however, invests the subject with a substantial repertoire of interpretive methods and stock of experiential materials.

This is not to say that active interviewers merely coax their respondents into preferred responses to their questions. Rather, they converse with respondents in such a way that alternate considerations are brought into play. They may suggest orientations to, and linkages between, diverse aspects of respondents' experience, adumbrating--even inviting--interpretations that make use of particular resources, connections, and outlooks. Interviewers may explore incompletely articulated aspects of experience, encouraging respondents to develop topics in ways relevant to their own experience. The object is not to dictate interpretation but to provide an environment conducive to the production of the range and complexity of meanings that address relevant issues, and not be confined by pre-determined agendas.

In this specific instance, I offered my interpretation of stereotyping as racism in order to provoke a response. I wanted to know if Audrey's frame of reference and mine were similar, and whether she explicitly linked stereotyping and racism. I judged Audrey able to weigh my interpretation and to speak openly about her own views.

2I offer the following quotation as food for thought. In building on the work of Edward Said, Masao Miyoshi (1997:59) argues:

Those of us who are members of universities need to think of our own site of work. We know that today the university is actually a corporarian in style and substance. Professors are allowed to make nearly any assertion, for or against the state, for or against TNCs [Transnational Corporations], but the reason is not academic freedom. Corporatism is so effective that any criticism is at once reppossessed by converting disagreement into preagreement, and opposition into diversity. Flexibility and multiplicity are, however, merely apparent. The university maintains its authority through its system of hierarchy, reinforced by means of carefully graduated privilege and power. Academic elitism is no less pernicious than TNC ultra elitism in as much as
it satisfies the most vocal and inhibits the least, producing acquiescence in both.
CHAPTER 7 - EXPERIENCE AND KNOWLEDGE

We have worked to resist an easy and imperialist universalization of experience in order to recognize, salute, and give validity to positions of difference and to affinities rather than prescriptive identifications. (Julia Watson and Sidonie Smith, 1992)

In this Chapter I focus on what has been learned during the research and writing. My dissertation project has been a personal learning experience par excellence. It has also generated findings that hold significance for theory, methodology, policy, and practice.

I begin the Chapter with a learning narrative about my personal journey of discovery. Then, after summarizing and discussing conclusions from the data, I identify knowledge production in the areas of theory and methodology. (In Chapter 8 discussion continues along the same lines but centres on the Canadian health care system and home care.)

MY NARRATIVE/JOURNEY

When I first conceived of my project I thought in the following terms:

I noticed that the literature on eldercare, especially the empirical gerontological literature, largely ignored important aspects of care. For instance, eldercare was not always explicitly discussed as a women's issue nor in terms of women's work. Instead, it was sometimes glossed as family caregiving. Also the ethnic heterogeneity of caregivers was frequently
ignored, thus making the ethnocultural issues invisible and mainstream findings seem universally valid.

I therefore wanted to fill what I perceived to be a knowledge gap by examining gender and ethnicity, and explicating their relationship to caregiving. I viewed these as separate problems: that is, on the one hand, I asked: "How is gender related to caregiving?" And, on the other, "How is ethnicity related to caregiving?"

To answer these questions I constructed a research design based on the above ideas. I decided to look at caregiving among members of two different ethnic groups, which I named Italian-Canadians and Japanese-Canadians. A third group, Anglo-Canadians, was added a short while later as a kind of control group. Gender was viewed as underlying the entire project since I anticipated that in all three groups women would be over-represented, and that issues concerning gender and patriarchy, therefore, would naturally arise.

Shortly afterwards I applied for and obtained ethics approval from the University of British Columbia. I then began contacting organizations and individuals in order to find caregivers from each of the three groups. As well, I enrolled in a course designed for informal caregivers and I began participant/observation as a voluntary caregiver in a long-term care facility.

In my fieldnotes around this time, however, I began to have misgivings about the project. I began to wonder whether seeking
caregivers who were members of three ethnic groups, in effect, legitimized and pre-determined ethnicity as something separate, real (not constructed) and highly salient to people. I wondered: Have I concretized the existence of specific, static 'cultures'? Rather than viewing ethnicity as something variously contributing to identity, constructed, dynamic, emergent, and situational, had I reified ethnicity and culture and taken their existence and salience for granted?

I began to recognize that I had been thinking in terms of there being three unique ethnic groups, whose members could be easily identified by me, the staff of care facilities, community leaders, other caregivers, etc. I also thought that each individual I interviewed would be similarly linked to the ethnic group or ethnic community to which each belonged.

Through reflection and discussion I began to sense the extent of the problems: For one thing, I realized that ethnic groups were not discrete, homogenous groups, each with a discrete set of full-blooded members. The idea of a single ethnic community to which members were uniformly, similarly affiliated was also problematic. I was a living example of someone who shared a kinship to two of the groups in the study, but ambiguity characterized my identity and my relationship to these groups.

My heritage is part-Anglo and part-Italian. On the Anglo side, I am probably second generation, but I know little about my Anglo-Irish ancestors and this ethnicity has always been taken-for-granted. On the Italian side, I am second generation as
well. Growing up near my Italian grandparents, being married to a Sicilian Canadian now, and having a "double-barrelled Italian surname" (as someone once observed) gives my claim to Italian ethnicity more weight, but I was still, I thought, a marginal native.

Imagining that there are real, concrete Italian and Anglo communities in existence out there, however, posed more questions. If I was only a marginal native, what was I marginal to? The communities to which people feel attached were, I thought, imagined communities in the sense that the Italian community or the Anglo community can only be realized through a kind of Orientalism--through imagination and representation, or the re-presentation of earlier equally-imagined formulations which say more about the person doing the imagining and representing and his or her position and politics than about the community in question. That is, there are no presupposition-less representations.

Looking back, there were at least two epiphanies whereby the constructed nature of ethnicity was really brought home to me: one was when a certain professor (not of Japanese origin) questioned my use of the term Japanese Canadian community. My remembrance of our telephone conversation was that she faulted me because there was, she claimed, no community left (because it had been destroyed during the War years). Although she implied that the Japanese Canadian community had been a concrete community of individuals, the idea that there was no community left because
people had been dispersed, left an impression on me. I wondered, *What is a community? Can a community still exist if its members are scattered?*

Another epiphany occurred in an early interview when one of the caregivers I was about to interview, a person of Japanese ancestry, talked about her relationship to ethnicity. She said she was tired of hearing the term *Japanese-Canadian* because it separates people from other Canadians, as well as implying homogeneity of Canadians of Japanese heritage.

The term sits uncomfortably with her family because it introduces artificial distinctions and suggests lines of division within the family. Although her grandparents were born in Japan, she and her parents were born in Canada. Furthermore she is married to a white Canadian of Anglo-Saxon ancestry. Her children are also constantly being requested to say "what they are," such as Asian or White or Japanese. Recently a teacher suggested the term *Eurasian* to apply to one of this caregiver's children--implying a stronger kinship to both Europe and Asia than to Canada!--and this had been a source of distress and anger to both child and mother. She also told me that she knows no culture other than Canadian and said:

I believe in the melting pot. I believe that it shouldn't make any difference. But I also believe in the Canadian society. I believe that there is a Canadian culture. I do believe that it's something to be valued and that it is a wonderful thing to be Canadian without the hyphenation.

This caregiver also suggested that I read the book, *The Japan we Never Knew* (Suzuki and Oiwa, 1996). In this book, the
authors discuss representations of Japan in the private imaginings of Canadians as well as in Canadian public discourse. The book chronicles a trip to Japan, made by David Suzuki and Keibo Oiwa who are two Canadians of Japanese heritage. Among other things it exposes the myth of Japan as a culturally-homogeneous nation. Oiwa (in Suzuki and Oiwa 1996:305) underlines this point when, at the end of their adventure, he says:

Our journey has come to an end. On the way, we encountered many remarkable individuals who showed us the unfamiliar faces of a complex society. Their unique ways of thinking and acting, their ethnic, cultural, historical, and ecological diversity, challenged our image of the Japanese monolith, a people all conforming to a single identity.

The point the caregiver was making, I believe, was that generally Canadians have constructed Japan as monolithic and that this spills over onto Canadians of Japanese ancestry who are denied heterogeneity and individuality, as well as full status as Canadians.

As a nation, and as academics, we deal awkwardly with diversity. We either focus on superficialities and create labels that divide and exclude, or we gloss over significant special needs and sensitivities by lumping people together into falsely corporate categories.

The Japan We Never Knew alerted me to various reasons why Canadians of Japanese heritage--like Canadians of Italian and Anglo heritage--are hardly homogeneous. Canadians of Japanese heritage are of various generations (and whether one is an Issei, Nisei, or Sansei is significant in many contexts). People may have come over to Canada recently, or near the turn of the
century, and I was told that whether one's marriage was arranged, based on exchanged photographs, or on pure choice (and romantic love) holds significance (and may also influence one's commitment to caregiving).

Furthermore, certain groups, such as Koreans and the aboriginal Ainu, have been ethnicized and racialized into Others in Japan. There are also marked geographical, political, social, religious, and ecological differences. For example, the authors of *The Japan We Never Knew* describe Okinawa and its unique role in World War II. And, of course, Hiroshima and Nagasaki are icons of the devastation of war and our capacity for treating each other with horrific inhumanity.

All such heterogeneity (which has been passed down to Canadians of Japanese descent)—not to mention differential experiences here in Canada—are compressed into terms such as, Japanese and Japanese Canadian, or even less informatively, Asian or Oriental.

Another complexity I began to comprehend was that ethnicity is not separate from race as separate from class as separate from gender, but that these characteristics intersect and intertwine in complicated, interesting, powerful and telling ways within individual lives and society. An individual experiences herself, for example, as a white, middle class woman (of a certain age, sexual orientation, etc.) and these identifications usually are experienced as inseparable. I experience myself as a whole
being. A particular characteristic such as whiteness, however, can be singled out (by self or another) as a personal badge or group identifier, or it can be used to unnoticeably endorse normalacy.

Adding further complexity is the fact that ethnicity and race, and other characteristics used to separate people, are to varying degrees fluid. In particular situations we call upon different aspects of ourselves or present ourselves in certain ways, just as during different historical periods, in specific geographical locations, and under certain circumstances, others call upon our putative gender or ethnic or racial differences in order to pursue their own agendas. The perceived gender or ethnicity or race of people ranges, therefore, from highly significant to inconsequential, depending on time, space, circumstance, and purpose.

Recently I was directed to the work of Frederick Barth. This helped me problematize the processes involved in creating and maintaining ethnicity. What Barth (1969) stresses are boundaries, rather than the cultural content upon which ethnicity is assumed to be based. This makes sense to me since culture is so dynamic and slippery.

Barth (1969:10-11) notes that generally four features are used to distinguish an ethnic group. Such a group is said to be:

...a population which:

1. is largely biologically self-perpetuating

2. shares fundamental cultural values, realized in overt unity in cultural forms
3. makes up a field of communication and interaction

4. has a membership which identifies itself, and is identified by others, as constituting a category distinguishable from other categories of the same order.

His quarrel with the above (Barth, 1969:11) is that:

...such a formulation prevents us from understanding the phenomenon of ethnic groups and their place in human society and culture. This is because it begs all the critical questions: while purporting to give an ideal type model of a recurring empirical form, it implies a preconceived view of what are the significant factors in the genesis, structure, and function of such groups.

Most critically, it allows us to assume that boundary maintenance is unproblematical and follows from the isolation which the itemized characteristics imply: racial difference, cultural difference, social separation and language barriers, spontaneous and organized enmity. This also limits the range of factors that we use to explain cultural diversity: we are led to imagine each group developing its cultural and social form in relative isolation, mainly in response to local ecologic factors, through a history of adaptation by invention and selective borrowing. This history has produced a world of separate peoples, each with their culture and each organized in a society which can legitimately be isolated for description as an island to itself.

With respect to culture, Barth (1969:11) regards cultural content as more of an implication or result which has been premised on the above view, "rather than a primary and definitional characteristic of ethnic group organization." His views are consistent with current depictions which stress the variability and fluidity of cultural factors, and they critique anthropological conceptions developed earlier in the century.

During my research, I also began to question the idea of a discrete self, one totally separable from non-self. But notions such as the relational self (supposedly typical of the female self) and the autonomous self (supposedly typical of the male
self) essentialize gender by omitting cross-cultural shaping of conceptions of personhood and they overlook cultural variation within communities, populations, and societies as well. Additionally, even when cultural factors are taken into account when examining conceptions of self, glaring gaps are left. If we describe any group of people as possessing a specific type of self, we omit discussion of complex patterns of human variation and similarity. We also avoid the processes involved in the production of human variation. We must, therefore, theorize a sophisticated view of self—one which takes account of various intersecting social and personal factors, positionality and lived experience, structure and subjectivity, and so on.

When I read work by Julia Watson and Sidonie Smith (1992), I began to get a better sense of the forces that influence self-construction. This was through their cogent discussion of self-representation in the context of de/colonization. They emphasize three main points. The first concerns contextualization. In particular, Watson and Smith stress that "the autobiographical subject" (and, therefore, ideas concerning the self) must be historicized. In traditional, hegemonic autobiography, all I's are congruent and, in addition, male. Watson and Smith (1992:xvii) write:

...all 'I's are rational, agentive, unitary. Thus the 'I' becomes Man, putatively a marker of the universal human subject whose essence remains outside the vagaries of history, effectually what Spivak has termed the 'straight white Christian man of property,' whose identity is deeply embedded in a specific history of privilege.
In opposition to Man as "putatively a marker of the universal human subject," Western eyes degrade the colonized other to:

... an amorphous, generalized collectivity. The colonized 'other' disappears into an anonymous,opaque collectivity of undifferentiated bodies. (Watson and Smith, 1992:xvii)

But I also discovered that it is not clearcut who the colonized are. For example, should the colonized be distinguished from immigrants, Canadian Native people, and women? Or, should the term include anyone who speaks from a position of oppression and "damage," remembering too, there are "colonies within colonies" and "oppressions within oppressions" (Watson and Smith 1992:xvi)?

Second, Watson and Smith, suggest that we reassess genre boundaries of autobiography to include both traditional autobiographies and those that "play with forms." Both continue to be produced but many are not recognized as autobiographical because they are "outlaw," hybrid forms.

Third, Watson and Smith discuss the function of autobiography. They argue that autobiography is a mixed blessing. On the one hand, it offers people a chance to speak of/for themselves and thereby opens a space for counterhegemonic narratives. But on the other, Watson and Smith (1992:xxi) say:

...the power of cultural forms to recolonize peoples cannot be underestimated. All of which is to suggest that the relationship of the colonial subject to autobiographical inscription is indeed troubled.

At any rate, I concluded that not only were more complex conceptualizations of the person and self needed, but more attention also had to be paid to speaking/writing practices that construct and inscribe selves. And what I began to seek was
another way of describing people that would allow for ambiguity and complexity. One that would accommodate the paradox, for example, that we are each separate and unique, yet part of us dwells within others, and others dwell within us. Each of us has our own subjectivity, but that subjectivity depends on sense-making processes that are social and dialogical. We actively and intersubjectively construct meanings through interaction and socially-developed symbol and communication systems like spoken and written language.

I also discovered Leigh Gilmore's insightful work on women's self-representation, which makes any simple reading of my data problematical. Gilmore (1994) develops the idea of autobiographies, a kind of writing/reading against traditional autobiography that is concerned with interruptions, eruptions, resistance and contradiction as "strategies of self-representation." Gilmore (1994:42) writes that:

A text's autobiographies consist in the following elements in self-representational writing, or writing that emphasizes the autobiographical I: an emphasis on writing itself as constitutive of autobiographical identity, discursive contradictions in the representation of identity (rather than unity), the name as a potential site of experimentation rather than contractual sign of identity, and the effects of the gendered connection of word and body. Autobiographies gives initial conceptual precedence to positioning the subject, to recognizing the shifting sands of identity on which theories of autobiography build, and to describing 'identity' and the networks of identification. An exploration of a text's autobiographies allows us to recognize that the I is multiply coded in a range of discourses: it is the site of multiple solicitations, multiple markings of 'identity', multiple figurations of agency. Thus, autobiographies avoids the terminal questions of genre and close delimitation and offers a way, instead, to ask: Where is the autobiographical? What constitutes its representation? The I, then, does not disappear into an
identity-less textual universe. Rather, the autobiographicality of the I in a variety of discourses is emphasized as a point of resistance in self-representation.

Gilmore's work is causing me to re-examine how I have interpreted meanings and questions of power within the narratives. What, for example do I and the interviewees mean when we use the word I? Where is the autobiographical in the eldercare narratives and in the dissertation itself? Does the use of I gloss fragmentation, which may be the inevitable result of our being sub-altern subjects? Sometimes we switch from using I to we, even in the same sentence. These kinds of switches seem now to be in need of explanation. Furthermore, at least two interviewees mention name changes. In one case, a woman who had "done some writing" years ago (possibly to do with Redress) said she had called herself a Japanese Canadian and used her Japanese-sounding name then because it was important to do so. Now, however, she thinks that this is "a bit too much." Another person, Sam, told me of his experience with naming. As a teenager, he had been confined at Hastings Park for a time. Later, he was separated from his parents, and shipped with about 15 other young men to a prison-camp in the Northern wilderness. An officer who was overseeing people of Japanese background told him his name was "unpronounceable," and since there was no Sam in his group, he would be one. Through these processes he was shamed and he felt objectified. This kind of thing happened to many others during the War, as well as before and after the War under various circumstances. Immigrants and refugees of
different nationalities have also had their very names—a core metonym for the person—stripped from them in the exercise of state authority. I also reflected on my name after reading Gilmore's book and although I have no horror stories to report in this connection, I did begin to see how it is also the potential site of identity experimentation and expression. For example, the spelling of my maiden name has been changed from D'Orazio, which was deemed too exotic-sounding, to the anglicized Dorazio, with an accompanying change in pronunciation. If I really wanted to stress my Italian heritage, then, I might begin spelling my name D'Orazio and begin pronouncing it differently.

These kinds of self-representations—I merged with we, recounting of how names have been used/imposed for political purposes, struggling with what to call oneself or against what one has been called—are not trivial. Like struggles over terms such as women, hyphenated identities, and racial designations, they penetrate to the core of a person's being, and demonstrate the intimate links between self and others.

During the process of conducting interviews, I also began to realize the extent to which caregivers' identities are being transformed through their intimate and emotion-drenched experiences. Caregiving could, I thought, alter the way individuals perceive themselves in relationship to others and the degree to which they feel separate and autonomous. At least some caregivers describe such a process of life restructuring, self-invention, and restoration of telos in their narratives.
(And through the experience of the research and writing, I was changing as well.)

It is also important to note, however, that "subjectivity is not, after all, an out-of-body experience" (Smith 1994:266). Instead, Sidonie Smith refers to the body as material, and questions what skin, as a borderland, has to do with autobiography. She claims that the body is fragmented into meaningful parts, and it is also a nexus of "skins and skeins of meaning" in which "the body of the text, the body of the narrator, the body of the narrated I, the cultural body, and the body politics" coalesce (Smith, 1994:267). Smith discusses women's autobiographical writing and how many earlier writers, such as Virginia Woolf, had to neutralize their gendered bodies and engage in a "repression of the body." Whereas, in contrast, she emphasizes how contemporary writers like Cherrie Moraga participate in "war over and with the body." She says:

Cherrie Moraga brings the autobiographical body out from under the processes of erasure, assuming her body as narrative point of departure: she discovers that the body functions as a lens through which she comes to see her complex cultural positioning as woman, lesbian, light-skinned Chicana. (Smith, 1994:281)

...Moraga writes a specific body, and its specific history of practices. She does not write the body of a homogenized woman....Moraga's specific body is 'female' and 'lesbian' and 'colored' and 'working class/poor.' It is positioned in and out of Chicano culture, in and out of Anglo culture. (Smith, 1994:282)

In short, Smith demonstrates that the body is indeed a complex site, a busy intersection, which cannot be ignored in any discussion of self-identity and self-representation.
Because eldercare experiences are directly centred on the bodies, including the minds and emotions, of both the care-receiver and the caregiver, the embodiment of selves was kept forefront in my thoughts. Self and other are not abstract, philosophical or psychological phenomena. They are tied to real flesh and blood people who live in points of time and space. This vivid realization occurred through my encounters with people whose lives and bodies had been irreparably changed (for some, to the point where they no longer lived in their own homes) by heart disease, stroke, osteoporosis, dementia, and the like. It also powerfully occurred through listening to graphic references to bodily functions, pain, and ageing--especially in articulation with places of caregiving, and an unstable health care system whose responses to the ageing body are blatantly inadequate. I was particularly struck by illness stories, which incorporated details of heroic and not-so-heroic attempts to solve an individual's social, ethical, and medical problems with pharmaceuticals and advanced technology. Furthermore, during the dissertation research and writing up I was also aware of my emotions and fears for my own ageing body, and those people I care about. This especially occurred when I visited institutions. Sometimes when I saw groups of seniors in wheelchairs, sad-looking, scared, with limbs drooping or mouths drooling, I was almost overcome (with sympathy, affection, guilt, and, perhaps most of all, fear). On those occasions, to say that
I was relieved and thankful to be able to walk back to my car and drive home is a real understatement.

At any rate, I realized over time that there were numerous complexities, substantive and methodological (only some of which I have mentioned here), in my endeavour to investigate how gender and ethnicity relate to caregiving. To simply pinpoint the gendered meanings being attached to caregiving in three specific ethnic groups and to explain any differences as cultural was, therefore, problematical to me.

It was then that I decided to showcase the shortcomings in my original, naive formulations of ethnicity and gender by identifying complexity itself as a problem. I thought I could do this by writing about the ways in which individual caregivers, from whatever backgrounds, are both similar and unique. That is, to look for both differences and similarities in their lives, experiences, and narratives. To find a third way.

I began to think about the origins of complexity, as well as its interplay with other factors. Two sources of complexity, amenable to examination, came to mind which both unite and divide caregivers. These are: 1) the particularities and sameness of personal experiences; and 2) the similar and differential incorporation into personal narratives of elements derived from public discourse.

Now I turn to what can be concluded from the material presented in previous chapters.
THE DATA: SUMMARY AND ANALYSIS OF FINDINGS

At this point, I summarize general conclusions from the analysis of narrative material collected for the dissertation, recalling material from previous chapters and introducing other brief illustrations. These examples are not meant to pit ethnocultural groups against one another, nor to be generally representative of particular groups.

My conclusions are described below under the heuristic headings: Individual Stories, Local/Global Entanglements, Multiple Functions, Multiple Authors, and Patterned Stories.

1. Individual Stories. Caregivers and their experiences are unique and their positioned eldercare narratives are complex, individual stories.

As reflected in their personal stories, as well as in my notes and memory, the caregivers I interviewed are unique, knowledgeable, complicated, and compelling individuals. They are also diverse. They range in age from 33 to over 80 years of age, and they have lived through all kinds experiences, from the everyday to the traumatic. The situations in which they now find themselves are also extremely diverse.

The material in Chapters 4, 5, and 6 attests to this heterogeneity, and I present some additional biographical material below to underscore this claim. The following statements occur just after I open the interview when I say to each participant: "What I'd like you to do is to tell me a about your life and then go on to tell me about your caregiving experience":

Lois
Okay. I am a Sansei which is a third generation Japanese in Canada. I was born in Central Canada and spent the majority of my life there up until I went to University. Then I married a chap from University....[and after we had our kids, we moved to B.C....]. My grandparents came to the Coast of B.C. when they were teenagers. Then my parents were born here. Our family links have been here well over 100 years. (See Appendix III for more of Lois' story).

Gail
Okay. Well I'm 50 years old. I'm the youngest of the four children that my Mom has. I have one brother who is the oldest and two sisters who are a little older than me. And I'm married. I'm a grandma. I've got kids of my own, and one daughter that belongs to my husband. And I belong to a Mennonite Brethren Church which is a big part of my life. And I have nieces and nephews that I like to see.... (See Appendix III)

Lucy
I'm one of three sisters. My first sister was born in Italy and then 6 years later, I was born here. And we lived with my Aunt and my Uncle, and then we moved into our home--our own home--which was just a few blocks away. And when I was about 6 years old I moved in with my Aunt who is my Dad's sister (this is the lady I looked after) and Uncle because they didn't have any children of their own. And he was married previously. He had 9 children from a previous marriage. So she came over here on proxy*, and was married that way, but she didn't know that he had these 9 children....Yeah, he told her that he was alone here in Canada. I don't know how many of his children were left there [at home when her Aunt came over from Italy]. I think there were four of them. (See Appendix III)

*They had not met each other prior to marrying, only written letters back and forth. Some "friends of the family" made the arrangements.

From these three statements, one can see how each woman, although roughly the same age and living in the same time and place, has a very different biography and tells her story in a distinctive form. In their opening statements, each caregiver appears to stress what is most important to her and how she wishes to be positioned.
Lois's story describes movement: from Japan to British Columbia, British Columbia to Central Canada, and back to British Columbia again. In a few short sentences, Lois also manages to stress her family's deep roots in Canada, her generational position (Sansei) with regard to all people of Japanese ancestry in Canada, her middle-class status and higher education and, simultaneously, her assimilation, partly achieved through marriage to a university-educated man who is not of Japanese ancestry (as indicated by the word "chap"). Her story begins with subtlety and tact. She knows I am aware of major injustices and deprivations people of Japanese descent have experienced in Canada, and particularly here in British Columbia. This is because previously, at our first meeting, Lois tutored me on some of these points.

Gail's beginning emphasizes family relationships. As a white Canadian, Gail does not need to mention her ethnicity or roots because few, if any, people ask her where she is from, how long she has been in Canada, or where her people come from. She is able to maintain her status without drawing attention to her ancestry. Instead, she positions herself in relation to her natal family (and its extensions to grandchildren, nieces and nephews) as well as to her marital family which is nuclear and blended.

Gail does not start by telling me where her parents were born either, that she is of Anglo ethnicity, white, nor how long her family has lived in British Columbia. This also may be
because, as anthropologists have noted, many people of Anglo
descent in countries such as Canada tend to view themselves as
being cultured but without being ethnic or having culture (in the
sense of possessing customs, beliefs and behaviours which are
noteworthy, interesting, and possibly exotic—like those
possessed by people designated as Other). In addition, we tend
to be blind to our own conceptual frameworks: our own lifeworlds,
and the categories upon which they are structured, are the real
world. In short, Gail has no need to stress her roots because,
by virtue of her whiteness and familiar accent, she automatically
would be regarded by most Canadians (and seemingly she regards
herself) as a native Canadian—and a real Canadian (Thobani,
1998).

Gail's lack of need to stress her roots seems especially
ture in the context of our conversation because we share certain
characteristics such as gender, whiteness, and class. These
characteristics, therefore, can be viewed by us as self-evident,
normal and taken-for-granted. They subsequently become virtually
invisible and then are allowed to fade into the silent background
of our talk. Only her affiliation (through her husband's roots)
with a Mennonite society are what she does consider to be
important, special, and interesting enough to describe.

Finally, Lucy presents a story about disruptions and
displacement which have had a strong influence on the way she
views and positions herself. Like Lois's narrative, her story
speaks of movements and hardships: immigration from Italy to
Canada, living with relatives before moving to her family's "own home," she herself being moved back into the home of her Aunt and Uncle, and then shifting back again to the family home. There are hints of economic insecurity while growing up, and home is something yearned for but hard to grasp. She also touches on the family as a site of patriarchal deceit, pragmatic arrangements, divided loyalties, and deep bonds of affection.

In each of the above stories it is also apparent that participants are responding to certain cultural representations and stereotypes--that is, basically to Othering. Like the other individuals of Japanese ancestry I interviewed, Lois emphasizes that her family roots in Canada are deep and of long duration. This seems to be a response to the common idea that all people of colour in Canada are recent immigrants. Although people of Asian descent have lived here in Vancouver since the early 1800s, true Canadians are often still assumed to be white.

Lucy, on the other hand, stresses her family's recent arrival in Canada (in the 1950s) and the hardships immigration involved. Perhaps this is because nowadays people of Italian ancestry do not appear to be treated as harshly as in the past. They are now considered to be white and almost mainstream, I think. In Burnaby, near where I live, there is a lot of evidence of Italianness. For example, at Confederation Park in nice weather men play bocce, there are regional Italian picnics in the summertime and conversation groups at the Recreation Centre. Furthermore, it almost seems to be a status-symbol to be of
Italian ancestry: there are a number of Italian businesses (restaurants, delicatessans, furniture stores, flower shops, for example), and quite a few Italian flags can be seen on cars, businesses, and sometimes on homes--especially around World Cup Soccer time. I have not noticed people of Asian ancestry displaying their ethnicity in this way in the neighbourhood. Furthermore since Lucy may perceive a kinship with me, due to my Italian ancestry, she may feel free to stress her family's relatively recent arrival in Canada and later in her story (see Appendix III), she even says, "I'm very proud to be Italian, very proud; and I would say I'm Italian Canadian." This statement is undoubtedly indirectly inspired by Canada's official policy of multiculturalism. It should be remembered however that such pride in Italianness or Italian-Canadianness was not appropriate earlier in the Century, nor would it have been something publically declared without risk of reprisal from Canadians of Anglo heritage--especially during World War II.

The above beginnings are not meant to suggest that every narrative coincides with either that of Lois, Gail, or Lucy or that every we-group member feels or thinks in a similar manner. I encountered a wide variety of stories, self-representations, and identifications within each group. What I am illustrating is how individuals variously identify and portray themselves in response to hegemonic representations.

It is clear that each caregiver is unique and uniquely positioned. Each personal narrative is an individualized
response to particular life experiences, an individual story. It is also a self-constituting rejoinder to one's perceived placement by others, and the constraints and boundaries one feels encircled by.

2. Local/Global Entanglements. Elder care experiences/narratives are tied to issues and trends which go beyond the local.

What I mean by the preceding statement is that stories about caregiving—as demonstrated in the material collected and presented in the dissertation—encompass a much broader range of topics, themes, plots, settings/contexts, and so forth, than merely instances of unembellished eldercare. Caregiving narratives are multiplex creations which unify and integrate biographical, historical, and geographical facts; emotional expressions; and are composed of self-representations, life histories, illness stories, conversations, performances, etc. These narratives illustrate, therefore, how the social is collapsed into the personal, and the global is collapsed into the local in complex interpenetrations (Marcus, 1995:102). Among other things, the eldercare narratives contain signposts to texts of biomedicine, health care, ethics, gender, class, work, family, immigration, evacuations, and discrimination. In other words, caregiving narratives reflect caregiving's linked personal, social, and interactional nature, and they are inextricably bound to multiple processes, social structures, and life practices.

To give a concrete example of the above and remind the reader of points raised previously, the following excerpt comes
from a woman/narrator who was introduced in Chapter 5. Parts of her story are re-introduced here in order to underline the cross-over, entwinement, and interpenetration of individual biography, with its emphasis on local, detailed events and meanings, and its larger-scale social, cultural, global and universal significance. Emiko's story demonstrates how narratives incorporate much more than the personal or simply caregiving per se:

Emiko

I knew that my husband had something because I know people say that when you get older you do silly things or you are forgetful, but the things he did were out of the ordinary. But his doctor--I didn't like his doctor--he got mad at me. He said, 'I'm his doctor. I know what's the matter with him.' And he wasn't very nice. He didn't like me to be there. He used to say, 'Well, why are you coming?' The reason I was going was because when he used to go by himself, I'd say: 'What did the doctor say?' But he couldn't remember, and so I decided to go with him, and the doctor didn't like that. I used to ask him questions, and he'd say, 'Why are you asking me this?' And I'd say, 'Because I want to know.' And he was nasty.

But, anyways, he refused to change doctors....But this doctor wasn't...he wasn't great. I didn't like him because he never dressed like a doctor. He was wearing sweatpants and running shoes...talked to my husband about martial arts and things like that, and he refused to listen to anything I had to say. As a matter of fact, he resented it very much.

In this excerpt there are direct quotations, indirect speech and echoes of other texts, cultural representations, and ideological formulations. Emiko does not come right out and say, "I was concerned about my husband and I felt hurt and angry when his male physician, a representative of Western biomedicine, treated me badly by discounting my views," but that is how I decode her primary message. She describes the experience of being in a losing power-struggle with the doctor over the diagnosis of her
husband's condition (or whether he was sick or simply suffering from old age) and her right to be involved in his care. The doctor seems to subscribe to a time-honoured, legally-protected doctor/patient dyadic relationship--and her husband refused to change physicians too. One aspect of Emiko's story which is poorly demonstrated above, however, is her style. This includes the way she assumes different voices and accents when she quotes the doctor and herself, and her pervasive tone of indignation.

The above excerpt points to Emiko's weak and ambivalent position relative to local/global fields of power (such as biomedicine). It also suggests how, as a female, her ability to influence males--indeed to be taken seriously and believed by a professional man and a patriarchal husband--is constrained. In this instance, her influence and credibility also may be further limited by her status as a minority, older woman of colour (who may also be perceived by the doctor to be an Asian immigrant).

Furthermore, as a caregiver exactly what are her rights and authority? She is neither doctor nor patient and, therefore, is neither fish nor fowl. She is outside the doctor/patient dyad--even though she has grave and heavy responsibilities, and even though she holds the key to her husband's well-being.

Emiko's dilemma, as revealed above, is the same one faced by almost all informal caregivers, as well as nurses and other health care personnel (including nurses' aides, activity workers, and physiotherapists) who are formal caregivers to elderly persons. Like Emiko, all caregivers (the majority of whom are
female) are positioned between doctors (the majority of whom are male) and patients. Physicians have professional privileges and authority and patients have rights which are enshrined in various rules and laws. It is nurses, however, who are in touch with the day-to-day problems faced by patients, monitor their conditions and progress, and administer medicines, therapy, and care. It is now well-documented that our health care system, Western biomedicine in general, and the Canadian society which they mirror, are marred by patriarchy, ageism, ethnic and racial discrimination, and classism (see Anderson, 1987; Bolaria and Dickinson, 1994; Burgess, 1996; Coburn, D'Arcy and Torrance, 1998; and Lock, 1993). It is also well-known that both formal and informal caregivers have less power and resources than they require to carry out their jobs.

In December 1998 nurses in British Columbia took job action. They went on strike to protest cutbacks and shortfalls. Emiko, on the other hand, tells me how her husband's doctor "was nasty" and resentful, and how his talk and dress were offensive. Therefore, in her own way, she presents a critique of the Canadian health care system and Western biomedicine, and like the British Columbia nurses, she also protests.

Emiko may be relieved to speak to me about her experiences, to put her grievances into words. She may also sense that through the interview, her words are being given an opportunity to survive beyond the moment, and possibly be heard by others. We both may hope that recording and reproducing our conversation
will help to promote social justice and change through wide readership. This could be accomplished if researchers, health care personnel, policy makers and others could listen responsively to caregivers' needs as expressed in their eldercare narratives.

The lesson learned from analysis of interview material, and from the above example of Emiko, is that caregivers' complex, expressive narratives present biographical information, but not biographical information alone. Emiko's narrative, like the others, is a window through which to glimpse her worldview and, in her case, those of the doctor, her husband--and mine, too.

3. **Multiple Authors.** **Eldercare narratives have multiple authors.**

What I stress in this section is my finding that so-called personal narratives are more than monological personal statements or statements made by single authors. Here I want to emphasize not only how eldercare narratives are co-produced in local situations which are experienced by two or more speakers interacting at the face-to-face level, but also how they are co-produced by addressees who are not physically present. These include individual readers and potential readers who observe and understand a particular dialogue and therefore become a party to it from a distance (Bakhtin, 1986:126). And, in addition, Bakhtin writes about other addressees such as "superaddressees" or "loophole addressees." Bakhtin (1986:126) says that:
...Any utterance always has an addressee (of various sorts, with varying degrees of proximity, concreteness, awareness, and so forth), whose responsive understanding the author of the speech work seeks and surpasses.... But in addition to this addressee (the second party), the author of the utterance, with a greater or lesser awareness, presupposes a higher superaddressee (third), whose absolutely just responsive understanding is presumed, either in some metaphysical distance or in distant historical time (the loophole addressee). In various ages and with various understandings of the world, this superaddressee and his ideally true responsive understanding assume various ideological expressions (God, absolute truth, the court of dispassionate human conscience, the people, the court of history, science, and so forth).

Furthermore, the eldercare narratives I presented in this and previous chapters are only portions of much longer chains of discourse--some recorded, some not--which have occurred between a participant and myself over a period of months or even years. Still more broadly, the narratives occur within great chains of diachronic and synchronic conversations and pronouncements, and within historically ongoing, and contemporary national and global discourses. What I am suggesting, therefore, is that much is encapsulated, substantiated and collapsed into the personal narrative, which is merely a current manifestation of these much larger dialogues.

Emiko's description of her interaction with her husband's doctor can be viewed with such dialogism, such "interaction of meanings" (Bakhtin, 1981:426) in mind. In one sense her narrative is a simple face-to-face reportage of events. Emiko shapes what she says for me as the particular, immediate listener. She is communicating a message to me. My responses, questions, and silences direct Emiko as to how to proceed by
allowing her to gauge the immediate reception of her words. If I was the doctor's wife, a male physician myself, or another woman of Japanese ancestry, however, she would not speak of her husband's doctor in quite the same way. Nor would my reactions as listener be the same; my responses would also substantially affect her and her story. But, in another sense, Emiko's narrative also constitutes a link in a chain of continuing critiques of Western medicine and colonialism, class privilege, sexism, racism, and so on. Her words form part of discourses which have long histories all over the world, are still with us, and which will continue far into the future.

Another conclusion I reach, therefore, is that the eldercare narratives are significantly co-authored and dialogical in a range of notable ways. Researchers, health care practitioners, policy-makers and others who listen to eldercare narratives, therefore, should learn to function dialogically and to listen actively to the narratives.

4. **Multiple Functions.** ElderCare narratives have multiple functions.

Bakhtin states that the major purpose of language is communication. If one agrees that stories can be told by self to other(s), and also by self to self, or by an aspect of the self to another aspect of the self (for example, in the Meadian sense of I and me), then multiple functions all make sense as communication. More specifically, eldercare narratives function
as an idiom through which to accomplish goals such as the following:

1) Express and communicate emotion;
2) Debate ideological issues;
3) Negotiate involvement in caring work;
4) Engage in complex thinking about themselves, caregiving, and care-recipients;
5) Engage in moral reasoning (and often receive affirmation of their efforts to do the right thing);
6) Profess deep caring;
7) Document suffering;
8) Give meaning to disturbing experiences and restore telos to lives;
9) Formulate plans for subsequent action; and
10) Present themselves as interesting people.

In the excerpt from Emiko's narrative, although other interpretations are certainly possible, the major function of her discourse seems clear to me: her discourse is a protest. She is protesting the treatment that she received from her spouse, plus the treatment she and her husband received from her husband's doctor. In another sense, Emiko is also representing herself, through narrative, as a caring, knowledgeable, and concerned person who looked out for her husband's welfare, despite his and his doctor's patriarchal disregard for her ideas.

My conclusion concerning function, therefore, is that eldercare narratives can be interpreted as performing various and multiple functions, although the overarching function is always communication.

5. Patterned Stories. Eldercare narratives tell the same story and different stories.

What I examine here are patterns in the material. That is, how the narrative material is: a) composed of similar narratives
telling the same story, and b) composed of unique narratives or different stories which, however, can be clustered as responses to particular cultural representations.

THE SAME STORY

Generally speaking, all eldercare narratives tell a similar story. This is the story of a loved one or family member who experiences illness, frailty, disability, or accident, how the caregiver handles his/her illness or accident, and the ensuing disruptions to his/her own and the care-receiver's life. The narratives vary in many ways, perhaps most noticeably in regards to tone and the extent to which the narrator's life remains in focus. Also important, of course, are what events occur, in what order, and how smoothly these go. However, all the eldercare narratives revolve around a central idea and activity: taking care of an older person and the balancing of various personal and collective goals that this caregiving entails.

To illustrate this with a concrete example, I want to briefly examine the concept of placement in a nursing home or care facility. Placement is a turning point, and it was talked about at great length by the participants I spoke with. They took pains to explain how the person they were caring for ended up in a care facility, their role in the proceedings, and that sort of thing. Each person made it crystal clear that the decision was difficult or at least necessary, often out of their hands, and not due to laziness, irresponsibility, or lack of caring.
In the narratives, placement in a nursing home acts like a dividing line, a borderline or border zone that separates life and time before and afterwards (if it has occurred). Placement is also described in different instances as a point in time, a process (see J. Cosbey, 1994), and also as a period of adjustment.

If the older person is being cared for at home, then going into a home may still be something discussed as a feared (or welcomed) potential happening--or it may be entirely dismissed as a possibility. Making placement a significant event or process, potentiality, or non-possibility against which stories are told, therefore, is an example of how eldercare narratives are all the same. They are all answers to the question of whether institutional care is a solution, or the best solution, to old age in the specific instance at hand.

Although there are other sources of consistency, such as caregivers' interactions with the same health care system, the discourse on nursing homes and long-term care facilities is part of a usual way of talking about older people and their care. It is part of the hegemonic discourse on ageing which concretizes, objectifies and narrows the ageing process and older persons and their needs--and the word placement signals the fact that older people can be set down anywhere regardless of will. In their narratives, individuals react--in one way or another--to this most disturbing of ideas. The narratives, in other words, tell
the same story of the attempt to balance personal needs (and
desires) with those of an older person who needs care.

When I reported my conclusion that caregivers describe
having the same experiences and basically tell the same story to
one of the people I interviewed who is also a nurse, she
responded quite happily by commenting that she had been saying
this all along. That is: that caregiving is caregiving!
Although the eldercare narratives ostensibly do tell the same
story, there are a number of sub-narratives, however, which still
require comment.

DIFFERENT STORIES

At a more specific level, each story is different, with
variations being traceable to social structural factors,
positionality and unique situations. Therefore a number of sub-
texts within the stories require explanation.

For example, one such sub-text has to do with gendered
caregiving in particular ethnocultural contexts. Caregivers are
all engaged in dialogue with previous discourse on the topic of
care. Also, all must deal with the same over-burdened health
care system. But it is my contention that those elements that
are included in eldercare narratives are reactions to socio-
cultural representations of caregiving and to statements made by
significant others, friends, acquaintances, strangers, co-
workers, professionals or in public forums that have touched
nerves, stimulated emotions or otherwise struck responsive
chords.
My point is that if a caregiver is, say, of Italian descent, he/she may take a special interest in, adopt a particular attitude towards, and be responsive to previous discourse relating to *Italianness*, such as *Italian-Canadians* and caregiving, *Italians* and ageing, and *the Italian Woman*. This seems reasonable given that such topics contribute to the meanings of identity and caregiving.

For similar reasons and others, the caregiver also may be attentive to representations of mainstream caregiving. That is, he/she may be sensitive and responsive to statements and attitudes purporting to apply universally, but which are only narrowly valid, if at all, and are partially or wholly inapplicable to his/her local situation. Particular caregivers, then, may answer representations of gender, ethnicity, caregiving, and so on, in the form of narrativized modifications, corrections, or partial or full endorsements of sociocultural representation and specific statements.

Do I subtly suggest what would constitute adequate answers to my questions or how I want stories to be told? Certainly I must. Even my gender, whiteness, middle-classness, name, speech, dress and gestures combine to influence who will agree to be interviewed, who will say what to me, and how comfortable each of us will feel talking to one another. In a similar manner, indirect addressees make their own expectations felt too.

Three examples follow which demonstrate that individuals variously respond to how caregiving and caregivers, as well as
we- and they-groups are, or have been, popularly portrayed or Orientalized (in and outside the interview situation):

Example 1. A woman of Italian descent responds to cultural representations (in an interview with a female researcher of Anglo/Italian ancestry):

Lina

...if ever I've not felt well, Fred will say, 'Well, go to bed.' You know, if you're not well, 'Go to bed.' Where a man, if they're not well, then we cater to them. We make them their food, look after them. Where some men can do that, but I know he couldn't. You know, if ever I really got sick it's just too bad.

...Well, yes, in a way [I think my Italian background figures into this]. I think we've been brought up with 'family first.' I think like when I look back on my mother and dad, and, say, my brothers and their wives, we've been brought up with, 'Our family comes first.' And you do what you can for them, and sometimes maybe somebody else will think, Well, gee, you're doing too much. You're spoiling them. But you do it through love. Something like that.

This woman's narrative negotiates answers to widely-held notions that Italian women spoil their children and menfolk, overly cater to males (who are self-centred and helpless), and that family is too all-important. Lina does not just refute or confirm these ideas in any simple manner however. Rather she explains why she does what she does, and how it relates to her upbringing (and that of her mother, father, brothers, sisters-in-law). Further, she expects me to understand how a sort of womanly love--or a kind of self-sacrifice (perhaps patterned on the example of the Madonna, but also an ideological theme widespread among non-Catholics)--justifies her actions. In this regard it is interesting to note the popularity of this idea of caring through love. For instance, on a recent cover of the B.C.
Caregiver (1997:1) two women, Janice Dockman and Anne Reimer, are shown with an award (presented by the Health Care Public Relations Association of Canada) for a winning video which was produced in Penticton. The title of the video is Care Out of Love.

The phrase "caring through love" and "care out of love" connote not just affection, however, but self-sacrifice and martyrdom. In the world context of female exploitation and oppression, therefore, it denotes the ideological suggestion that warm feelings are sufficient motive and payment for caregivers' often difficult and devastating unpaid caring labour.

Representations such as Lina's, I believe, also demonstrate our society's ambivalence toward family and family members. Many people yearn for close-knit, extended families, and for a return to family values. We also realize that families are difficult, however, and they pose problems of oppression and risk for individuals, especially women and children--particularly in today's corporate world where money and consumerism rule. As an example, a British Columbia survey found that 36% of women reported assault by a partner sometime during their lives. Furthermore, in 40% of violent spousal relationships, children witnessed acts of violence (British Columbia, 1996:95).

Like Lina, therefore, we seem to hold ambivalent feelings, not just towards an ideal family type, the Italian family--whose members are both close and distant--but also about all families
and how near, dear, and distant they really are, can, and should be in postmodern life.

Lina just may be expressing near-universally held sentiments which have been internalized from discourse about families, all kinds of families. If so, her words raise a general question: why do only some males respond in a caring fashion to women and other close relatives when they are in need of help? But Lina's words also enclose certain ideas about the Italian family, including how it should operate and how she should respond to her family as a good Italian Woman—ever caring, strong, hard-working, and so on. Lina says, "...sometimes maybe somebody else will think, Well, gee, you're doing too much. You're spoiling them." I interpret her reference to "somebody else" as essentially those addressees who have judged the actions of women in general, and women of Italian ancestry in particular, and who have thereby contributed to current sociocultural representations.

**Example 2. A woman of Anglo descent responds to sociocultural representations** (in an interview with a female researcher of Anglo/Italian ancestry):

A woman of Anglo descent who shares care with her sister, brother, as well as paid and volunteer workers in a care facility, appears to be responding to general sociocultural representations of non-ethnic caregiving. For example, she says in response to my question about whether or not she considers herself to be a caregiver:
Gail

Um, [laughs] I guess I do. I guess I do in the broad sense of the word in that if I weren't doing what I am doing, it would put more of a burden on my sister or on my brother or both of them, and if none of us did it, I think it would be basically abandoning our mother to the care of strangers. So I see that we do [act as caregivers] even though none of us have her actually in our homes. I think that care is more than just actually looking after the feeding and the clothing.

There are a number of things I want to point out about the above short quotation. First of all, Gail is answering an attempt in public discourse to narrow the general meaning of caregiver. Gail is ambivalent about using the word caregiver to describe herself (and her siblings), however, and she is not alone among the people I interviewed. Gail tries to view caregiving in the context of her siblings' contributions and initially she only supposes she is a caregiver "in the broad sense of the term." Later she says that she and her siblings are caregivers, although she comments, "even though none of us have her actually in our homes." No wonder Gail is uncertain and makes provisos. This is because caregiver has only recently entered the public discourse to describe relatives and friends who informally look after older people (in Britain the term is carer), and although the meaning of caregiver is still being negotiated, it is simultaneously being given a narrow, culturally-specific denotative meaning.

Second, while not complaining that caring is a burden to her, Gail nonetheless uses the burden metaphor which is commonly used to describe eldercare and can be traced back to early
Christianity and martyrdom (Dorazio-Migliore, 1995). Several aspects of burden come to mind including the way in which:

a) ordinary people sometimes talk about caregiving in everyday conversations; b) the public media describes elderly people vis-à-vis the health care and social service systems or society in general; and c) academics use the burden metaphor. And with regard to the latter, gerontologists have developed burden scales to measure caregiver burden. They have also developed techniques to measure different types of burden, such as perceived burden, felt burden, as well as objective and subjective burden (see Kramer and Kipnis, 1995; Pearlin et al, 1990; Zarit, Todd and Zarit, 1986).

Finally, the phrase, "basically abandoning our mother to the care of strangers," seems to be a common way of conceptualizing and describing a family who places an elderly person in a care facility. The connotation, and more colloquial term, is that the person is being dumped there.

Gail, then, is ambivalent about using the term caregiver. She also uses the term burden. And, in addition, two or three times Gail emphasizes that unlike some other residents whom she suggests are basically well (and perhaps have been dumped), her mother has a medical condition (chronic heart disease) which requires her to live in a facility. She explains how and why her mother became ill (through exhaustively looking after her father), how the family unsuccessfully tried to care for their mother at home, and then how Mother herself makes the decision to
move into a facility. Furthermore, the explanation is offered that although Mother lives in none of their homes, they still provide much support and advocacy and that "care is actually more than just looking after the feeding and the clothing."

This participant, then, is speaking to herself, me, any and all critics--perhaps even to God--responding to hegemonic ideas about care through challenge and acceptance. This includes responses to general questions concerning where care should be performed and by whom and, in effect, Gail is trying to persuade listeners that her actions are indeed justified. In her narrative, she is responding to sociocultural representations of caregiving as performed by individuals in particular settings, the word burden as an appropriate descriptive term, and Canadian families as being responsible for eldercare.

Example 3. A woman of Japanese ancestry responds to cultural representations (in an interview with a female researcher of Anglo/Italian ancestry):

Lois

My mother is an interesting individual because she is...was the caregiver, the central caregiver, in terms of the way the family sees her. Not just her own family but to her nieces and nephews as well. My mother was very much seen as the caregiver.

[Now, is that because she was the oldest daughter or something like that?]

Yes. I believe that probably had some impact, but by nature she is a very nurturing individual. And in many ways...she was very subservient but yet she was the one that instilled in my sisters and me the need for self-identity. And to seek our own professional identities as well--and equality, yet she has never lived in an equitable relationship....
[As an example]...she was always the peacekeeper within the family structure and through her strength of peacekeeping, she very much relayed to us [the importance of] strength of character...and she always would say, 'You can be whoever you want to be and you don't allow anybody else to tell you that you cannot be.'

Yes, very profound. Considering by example we saw her role model in a functional way. Somewhat in a dichotomous type of way.... Her interaction with the female versus the male was very different. It was very different but by the same token having been in Japan just recently and never been exposed to the Japanese culture in this way before, I did see how the women do have a tremendous amount of power within the home. But not externally. It is very confined...

[That's interesting because you'd think if they did have power in the home it would somehow flow out into the rest of society.]

The power is a very different type of power though....They do manage the house finances to start off with, but when the male enters the household, he expects to be catered to--and in point of fact in that being catered to, there is power.

I believe this excerpt shows how a well-educated Canadian woman of Japanese ancestry articulately answers sociocultural representations of Japanese women as weak, self-less, powerless nurturers. She stresses how her mother--and Japanese women in general--have been misrepresented or Orientalized. It was her mother who inspired her own struggle for personal and professional identity and equality, despite her own inequitable relationship. It was also her mother who was strong, and a nurturer, whose example taught her that power and strength can be obtained through caregiving. Although this woman acknowledges traditional rules regarding who should be a caregiver (such as the eldest daughter), she is not content to rest with this explanation. She also stresses the uniqueness of her mother, her
nurturing nature, and her individuality. Then in her following statement, she highlights those same traits in herself too.

Examples of responses from women of different ethnocultural backgrounds were presented in order to illustrate how caregivers create narrative to counter hegemonic representations in public discourse. It seems perfectly clear that these rejoinders are not cultural in the traditional sense of the word. Rather, they are responses to exclusionary practices, to derogatory homogenizing images, to the creation of boundaries, and to gendered and ethnocultural prejudices.

I also noticed no significant differences in the meanings applied to caregiving which might be deemed to be cultural. This may be because the caregivers were either born and raised in Canada or came here at a young age. I am not saying that no cultural differences exist (depending on how cultural is defined), but that any differences I found can be otherwise explained.

In fact, within the categories of gender and ethnicity set out in my research proposal, I found heterogeneity. Also despite similar intersections (of gender, race/ethnicity, and class), I found that differences in age, occupation, marital status, immigration history, personality, and caregiving situation produced considerable diversity! For example, contrast the following excerpts about growing up in Canada spoken by two caregivers of Italian origin: Rita and Lina (whose words are also presented earlier in the dissertation):
Rita

The language was too hard for them: different money, different laws, different customs... it was just too much for them and they just couldn't cope and so unfortunately violence was there which nowadays you wouldn't see, you know, there's help.... But in those days you didn't speak about it, and the poverty didn't help... and we had a lot of kids, I lost two brothers... and one miscarriage so my mom was always pregnant and because we were so poor my mom had to make noodles from scratch, make bread, buns, pizza from scratch, cookies from scratch. I remember her living in the kitchen 12 hours a day and I swore I wouldn't be like her, but, um, my dad was very outgoing so I take after him. I'm a people-person. I love music and I found by taking care of my dad all these years we've kind of become the same person.

Lina

I was born on C. Street. Right in the old homestead on C. Right in the house. With a midwife, an Italian midwife, a Mrs. M. That was in 1923.

I was blessed with real good parents, and two wonderful brothers. John, who was 11 years older than me, and Tony, who is 5 years younger. We were there all our lives, until I got married, and moved--next door.

It was a simple childhood, but a happy one, and there are so many little things I could tell you about our childhood: it was long. No TV's in those days. We didn't even have a radio. No fridges. And wood and coal stoves.

Although these two caregivers are both women and both of Italian background, Rita was born in Italy and came to Canada after the War. She is about 50 years old, rents an apartment, and looks after her father (with lots of help from her husband and siblings). Her father resides in a long-term care facility and is severely disabled. Rita suggests she has nearly become her father, an idea perhaps derived from popular psychology. She distances herself from her mother and, in effect, from the image of the Italian Woman, saying: "I swore I wouldn't be like her."
In contrast, Lina was born in Canada and her parents arrived here around the time of the first World War. She is in her mid-70's, seems financially secure (owns her own home), and takes care of her husband at home. She says nothing of poverty, either in Canada or in Italy, although she mentions that her family's assets were simple. Lina resents her husband's idleness, but still spends considerable time "in the kitchen" and she takes considerable pride in serving her extended family.

These women caregivers, despite similarities in gender, ethnic origin, and perhaps class, could not be more different. They are of different generations, and their present situations, life experiences, resources and worldviews diverge. Furthermore, their narratives mirror these differences--even though both women are responding to socio-cultural constructions of caregiving.

The individuals I interviewed discuss reasons for, experiences of, and effects of caregiving in roughly equivalent terms. They basically tell the same story, a story which cross-cuts traditionally-defined gender, race/ethnicity, and class divisions.

On the other hand, I also maintain that each caregiver's narrative is not only a unique creation, but that eldercare narratives are also negotiated rejoinders to specific and general socio-cultural representations.

DISCUSSION

At this juncture, I focus on how my findings can contribute to the development of critical personal narrative analysis for
use in interrupting Othering and thereby facilitating social justice.

None of us sees the entire picture. Bakhtin (1981:425) explains this as *krugozor* which has been glossed as one's conceptual or belief system, or conceptual horizon. In Russian it literally means "the circle of one's vision" (Bakhtin, 1981: 425). What this implies is that each of us has a unique but partial view of the world. Since no one is able to see behind himself or herself, one must obtain another's viewpoint in order to complete the circle, to fill in the blindspot(s). We must, therefore, talk to and interact with one another in order to close gaps in comprehension.

I want my work to have use-value in academic and practical worlds, so it would be convenient for me to either affirm that caregiving is caregiving no matter who performs it or to underscore multiple differences in caregiving and call for policies and practices which reflect either one or the other. But I am unwilling to sacrifice in-depth knowledge and complexity. Therefore I have looked for a third way of viewing patterns without losing sight of particularities,¹ and to show how various descriptions inter-illuminate one another to reveal eldercare as both an individual and a collective phenomenon.

My narrative/journey (or the portion included in this chapter) can be read as a series of epiphanies, or learning experiences, which shift the way I view the world. It can also be read as a narrative of decision-making which describes my
struggles over how—in terms of politics and poetics—best to represent women, race/ethnicity, class, difference, eldercare, caregivers, ageing, research, myself, and others.

I suggest that the methodology a researcher uses must include a reflexive component, and ideally one which delves deeply into the researcher's own position and autobiographies. It is in this way that readers as well as researchers themselves are able to comprehend how knowledge has been created and why it assumes the form it does.

Critical personal narrative analysis pays close attention to the uniqueness, situatedness, and complexity of each personal narrative, its entangled linkages with larger systems, matters of positionality, power, and co-production, patterns in a body of narratives, and last, but not least, a strong reflexive component to allow readers to place a text in its immediate context of production.

Turning to Chapter 8, I describe public discourses on caregiving and home care, and how these form part of the context in which caregivers tell their stories. Using ideas from Mikhail Bakhtin, Norman Fairclough, Ruth Wodak and others, I demonstrate that caregiving and home care are being shaped by emotionally-charged language within various political contexts.
Notes

1Other theorists have employed the term "third way" or a similar term. I use "third way" to signify my dissatisfaction with and rejection of: a) binary oppositional thinking and b) universalizing. I am interested in developing a way of talking about complexity which simultaneously allows discussion of both similarities and differences.
CHAPTER 8: HEALTH CARE/HOME CARE

Discursive practices may have major ideological effects: that is, they can help produce and reproduce unequal power relations between (for instance) social classes, women and men, and ethnic/cultural majorities and minorities through the ways in which they represent things and position people.

(Norman Fairclough and Ruth Wodak, 1997)

In this chapter, my goal is to identify dominant features of the public discourse on health care reform (and its underpinning ideologies and values). I employ Mikhail Bakhtin's notion of heteroglossia, as well as Norman Fairclough and Ruth Wodak's Critical Discourse Analysis (CDA) to examine this discourse in relationship to home care.

HETEROGLOSSIA

Bakhtin writes about the multiplicity of an era's languages and the hybridity of discourse. Some of Bakhtin's ideas are themselves responses (and challenges) to linguists who believe that the proper study of language involves identifying separate languages, isolating them from their contexts, then examining how they have evolved or how their separate structural elements function. Bakhtin counters the soundness of these strategies by emphasizing heteroglossia, a concept which includes the notion that languages are themselves heteroglot and that meanings are not simplistically referential but are always specific to the contexts in which they are uttered. The Glossary of The Dialogic Imagination (Bakhtin, 1981:428) defines heteroglossia as:
The base condition governing the operation of meaning in any utterance. It is that which insures the primacy of context over text. At any given time, in any given place, there will be a set of conditions--social, historical, meteorological, physiological--that will insure that a word uttered in that place and at that time will have a meaning different than it would have under any other conditions; all utterances are heteroglot in that they are functions of a matrix of forces practically impossible to recoup, and therefore impossible to resolve. Heteroglossia is as close a conceptualization as is possible of that locus where centripetal and centrifugal forces collide; as such, it is that which a systematic linguistics must always suppress.

In talking about historical resonances, Bakhtin (1981:291) notes that "these 'languages' of heteroglossia intersect each other in a variety of ways forming new socially-typifying 'languages.'" Bakhtin (1981:291) argues that:

...languages do not exclude each other, but rather intersect with each other in many different ways (the Ukrainian language, the language of the epic poem, of early Symbolism, of the student, of a particular generation of children, of the run-of-the-mill intellectual, of the Nietzschean and so on).

But despite heteroglossia, Bakhtin (1981:291-292) maintains that:

In actual fact, however, there does exist a common plane that methodologically justifies our juxtaposing them: all languages of heteroglossia, whatever the principle underlying them and making each unique, are specific points of view on the world, forms for conceptualizing the world in words, specific world views, each characterized by its own objects, meanings and values....

He also indicates that we can learn nothing about the social situation from "the naked corpse of the word." That is, from any word which is extracted from a context. Bakhtin (1981:292) says:

Discourse lives, as it were, beyond itself, in a living impulse toward the object; if we detach ourselves completely from this impulse all we have left is the naked corpse of the word, from which we can learn nothing at all about the social situation or the fate of a given word in life. To study the word as such, ignoring the impulse that reaches out beyond it, is just as senseless as to study
psychological experience outside the context of that real life toward which it was directed and by which it is determined.

What Bakhtin is stressing here is our need to study language in all its complexity and language in use in contexts. In my analysis of public discourse on health reform, I follow Bakhtin and take into account the contexts in which heteroglossic utterances, including the eldercare narratives, are spoken and written.

I also want to re-emphasize the political power of discourse. Norman Fairclough and Ruth Wodak (1997:258-284) note that it is useful to examine how diverse aspects of the world are being represented in language, as well as how social relations between people, and people's social and personal identities are discursively constituted. Stressing the reproductions and transformations that power-laden representations can accomplish, Fairclough and Wodak (1997:273) write that:

...every instance of language use makes its own small contribution to reproducing and/or transforming society and culture, including power relations. That is the power of discourse; that is why it is worth struggling over.

CHANGE, EFFICIENCY, AND EQUALITY

A brief, critical introduction to the Canadian health care system may help orient readers or focus attention on specific aspects of restructuring. Herbert Northcott (1994:66) names the several principles upon which Canadian Medicare was founded and adopted across the country by 1972 as follows:
(1) universality--coverage of all Canadians;
(2) comprehensiveness--a broad range of insured services;
(3) portability--coverage could be carried from one province to another; and
(4) public administration--the program was to be publically administered on a non-profit basis without the involvement of the private sector.

A fifth principle--accessibility--is often also listed, although accessibility (i.e., reasonable access to services) can be subsumed under the concept of universality. It would not make sense to make all Canadians eligible for benefits, and then to allow barriers such as excessive cost or distance to disenfranchise certain segments of the population. In short, universal coverage implies equal access to services [my emphasis].

In their bid to deal with ever-rising costs and complex concerns, particularly regarding the efficiencies of hospitals, the provincial government has decentralized health care through regionalization of health services and significantly decreased funding to acute care (See various publications of the Centre for Health Services and Policy Research, University of British Columbia). Appropriate levels of funding for self, community, and home care are planned (see, for example, Closer to Home: The Report of the B.C. Royal Commission on Health Care and Costs, British Columbia, 1991), but these have yet to materialize. Caregivers' invisible subsidies of unpaid work, therefore, are helping to finance these reorganizational shifts from hospital to home and community. In fact, although this is nothing new, they subsidize the entire health care system! The work of informal caregivers allows increased expenditures on items such as physician reimbursements, high-cost technology, pharmaceuticals, academic research, and various other aspects of clinical care, etc.
Here I focus on the contemporary situation. Cutbacks and restructuring have continued for many years now, to the point where multiple problems have been reported including bed shortages, long waiting lists, and surgery cancellations. Reports of crisis come from both dissatisfied nurses and disgruntled doctors. Nurses are especially critical of staff shortages, while doctors have been closing their offices to emphasize their dissatisfaction and to advertise system deficiencies.

Not all observers are totally pessimistic about the results of restructuring, however. Nancy Betkowski (1996:ix) sees a potential for "beneficial change" arising from the tension between efficiency and equality. She claims that:

These two major social challenges are mutually present in many aspects of today's society. The dialectic between them can at times create tensions that frustrate beneficial change, but it can also, at other times, produce a synergy that brings about tremendous beneficial change. But change is never easy. (Betkowski, 1996:ix)

Although others seem to agree that finding an efficiency/equality balance is the core debate, they voice nothing but gloom and doom. Instead of synergy, they see increasing chaos. The drive for efficiency is viewed in strictly negative terms, as worsening the plight of patients and people everywhere in the short- and long-run, with no saving graces. There are complaints that people are leaving hospitals "quicker and sicker" and being sent home without supporting resources in place. Furthermore, hanging over the entire debate is the threat of losing medicare. Many of these ideas were discussed at the 1998 Centre for Health Services

How Canadians purportedly feel about major health care issues is contained in a report entitled, Canada Health Action: Building on the Legacy (National Forum on Health, 1997). In this report, the authors claim that Canadians want to maintain their present system of health care. They value it highly, but are anxious about the future, about losing medicare.

Currently the federal government has slowed health care slashes. In its latest budget (Canada, Department of Finance, 1999), it even began putting money back into the system. Ottawa, however, is still trying to silence critics, allay fears and justify its de-socializing tactics--one of which is to wrest power from the provinces and thereby gain greater administrative control over how health care dollars are spent.

One way this is occurring is through the negotiation of a new set of ideas, rules, regulations, and standards (Canada, 1999; Hollander and Walker, 1998). In other words, Ottawa wants to become manager of a corporate health care system, rather than merely paymaster (Coburn, D'Arcy, and Torrance, 1998:457). And it appears to be doing this through the development of national programs such as homecare which it would itself manage.

The Centre on Aging Bulletin (University of Victoria, 1998), reports that at the recent National Conference on Home Care held in Halifax in March 1998, Ottawa's managerial role was widely recognized. The Centre on Aging Bulletin (University of
Victoria, 1998:12) states that:

The federal government was seen to be the logical leader to develop a national home care program by the participants. Federal communication with provincial, territorial and local governments would provide the opportunity to reach a consensus on roles and responsibilities in administration, delivery and funding of the program.

The national standardization of home care may benefit Canadian citizens in several ways. Denise Alcock et al (1998:297) cites the following motivations and potential results:

Consistency of care provider, standards, clinical guidelines and care mapping have been promoted in order to maximize the effects of care strategies, to contain costs and to track goal attainment. A description of the competencies (knowledge, skill and clinical judgement) required to provide the care would assist educators, recruiters and planners. Standards relating to recruitment, training and role are particularly needed for unregulated home care workers.

These authors also maintain that since home care often is provided by "for-profit" service agencies, whether privately or publically paid for (through government "contracted out" services) that:

...the establishment of reimbursement scales and competency standards for formal care providers would ensure that the element for competition [my emphasis] is quality of care rather than the price of services. (Alcock et al 1998:297)

Much of the above seems reasonable. In her address to the National Conference on Home Care cited above, Neena Chappell encourages the development of a national home care programme (University of Victoria, 1998:12) noting that a) Canadians desperately need a health care system rather than a medical care system; and b) that although an integrated care model needs to be
developed, home care funds should be protected from acute care funding.

Last year in an interview in *Maclean's* (March 9, 1998:54), federal Minister of Finance, Allan Rock, commented on Ottawa's policies and the present shortfall in community services and home care. In the interview he sidestepped various issues and his words are often opaque (See Appendix IV for a lengthy excerpt from this mixed-genre interview/conversation/political speech). Basically, Rock stressed efficiency and I illustrate several points suggested by the content, form and tone of his remarks. Afterwards I turn to other voices which contribute to current discourse on home care.

In the interview, Allan Rock walks a tightrope as he attempts to distance himself from "cabinet colleagues" and position himself closer to the public.

He both criticizes and applauds government efforts to systematize the health care system. But his message is basically about efficiency, not equality. It revolves around how to "modernize the system through home and community care [my emphasis]," that is, employing a rationalized home-care system to "save money." It is peppered with references to "standard definitions," "standard approaches," "common approaches," "standardized training" all rationalized in "a co-ordinated fashion" into "a properly developed home-care system."

The examples he chooses of home care include the training of "homecare workers," people who are "maintaining the house,"
someone dropping in with meals, or a nurse practitioner. The latter may be someone who will come into the home temporarily, when an individual is "recovering from acute care" [Freudian slip or a comment on iatrogenesis?].

Rock's examples cover a mixed bag of people and services, but he never seriously addresses fair compensation for family caregivers. What he does is set efficiency and quality of care in tension, while avoiding explicit references to cost containment, as in the statement:

Well, it's often said that these problems arise because of money. But maybe the better way of looking at it is: what kind of system do we want? And this gets us into the area of quality and standards.

Social justice and equity for informal caregivers directly (especially for the majority of caregivers who are variously-positioned women) are not important issues apparently to either Rock or seemingly the interviewers. There is no mention of whether individuals will be able to caregiving and still engage in paid work or whether those that cannot work will be compensated to allow the continuation of pre-care standards of living. No discussion of gender, class, or ethnicity and no discussion of problems surrounding equality of access to appropriate health services for women, the elderly, the poor, the homeless, rural Canadians, Native people, perceived ethnocultural groups (immigrants and refugees) and other minorities.

There is also no mention of other significant issues of equity that have a profound impact on caregiving either, such as whether businesses and other employers will be given incentives
to allow eldercare leaves.

In the interview transcript, we can definitely see discursive reproductions and transformations (Fairclough and Wodak 1997:273) being wrought. The world is being viewed and represented in a contestable way by Allan Rock. For instance, Rock tells us what health care is, and what medical progress has brought about. He says that:

Health care for people used to mean hospitals and doctors. But hospital stays are shorter now because of improved medical technology. It's possible to have abdominal surgery and come out the next day, whereas it used to be a two- or three-week stay. (Maclean's, March 9, 1998:54)

Rock is asserting, as common sense, that "health care" used to mean "hospitals and doctors." This initial premise, however, is a controversial statement. What time-period is he talking about? Even if correct, it is only true for a particular era after biomedicine gained hegemony. Listen to what one senior--who urges Canadians to fight for the survival of medicare--has to say:

My name is Ben Swankey and I'm now in my 95th year. I lived through the economic depression of the hungry thirties, and I'm a veteran of W.W.II. In those difficult years, life was hell for many people who couldn't pay for medicines or hospital bills and who had to mortgage or even lose their homes. (Independent Senior, March 1999:5)

In the era of which Mr. Swankey speaks, to many people "health care" of necessity meant self-, home-, and community-care, not expensive "hospitals and doctors"! In this connection, medical anthropologists have documented a whole range of informal folk and alternative traditions which pre-date the Western biomedical system and which continue today.
That medical/technological progress is the reason hospital stays are cut short is another highly contestable assertion. It only encompasses part of the story. The Minister skilfully avoids mentioning that cost containment policies and practices have themselves necessitated truncated hospital stays.

With regard to social relations between people, Rock characterizes people as consumers who are competitive and strictly self-interested. If they get the quality goods being sought, all will be well, and our one-tier medicare system will endure. If, on the other hand, they are unable to get what they want, a market for a "private parallel system" will develop. Not everyone would agree that individuals are this economically-driven even if Western economics bases its precepts on this assumption. But Rock tries to pass off the model as common-sensical.

Rock must construct himself in solidarity with ordinary Canadian people, his electorate. He does this by using the term we instead of one, and by distancing himself from the government of which he is a powerful representative. It is not surprising that it is murky who the two "we's" refer to in the line, "If we don't keep our part of the bargain we're jeopardizing support for medicare." Is he referring to himself and the federal government, or himself and the people?

Now I turn to some examples of discourse that fall on the other side of the dialectic: those stressing equality, not
efficiency. After "deliberations from 1993 to 1995 on the issue of informal caregiving," in September 1995 the Seniors Advisory Council (British Columbia, 1995:1) wrote that:

Informal caregiving ranges from occasional assistance with errands or household tasks to the demands of personal and/or nursing care. Providing care for one another continues to be a strong societal expectation and most people, at various times in their lives, provide care and are cared for themselves by loved ones (Chappell, 1992). However when care is required 24 hours a day, or when caregiving is prolonged for months and years, informal resources can be depleted and the burden can become overwhelming. This may result in the physical or emotional collapse of the caregiver and inadequate or even abusive care of the care recipient.

This excerpt contrasts sharply with Allan Rock's statements to Maclean's Board of Editors. It appears in a carefully-researched, carefully-prepared publication not an interview, although I can justify juxtaposing the two because they share common traits: each addresses health care/home care, and each presents a point of view and a specific worldview. Furthermore, each expresses "the speaker's attitude toward others' utterances and not just his attitude toward the object of his utterance" (Bakhtin, 1986:92).

The Seniors' Advisory Council's exceptional quotation, cites social scientific authority, is emotionally-charged, and makes an appeal for social justice. If the Minister's words gloss difference, the Council's words stress diversity. The Council's definition of caregiving is more inclusive than the Minister's. It contains images of a whole range of caregiving activities, suggests that caregiving is a period of time, stresses our mutual inter-dependence, and notes the existence of special
circumstances which require special considerations. The latter can lead to overwhelming hardship (here glossed as burden), and there is a vivid image of a collapsed caregiver and a neglected or even abused elder. The representation being presented here includes nearly everyone too. There is no distancing: "most people, at various times in their lives, provide care and are cared for themselves by loved ones" (p. 1). Basically, we are all caregivers and care-receivers!

At another point in the Council publication (British Columbia, 1995:4) readers are explicitly apprised of the Council's stand on equity and its policy recommendations. These are as follows:

Policies must address inequities among caregivers such as the disproportionate number of women who are caregivers and the special barriers to accessing services faced by caregivers who are members of multicultural, First Nations or geographically isolated communities.

The majority of informal caregivers are women, many of whom struggle to balance their caregiving responsibilities with paid employment and/or the care of small children. Caregiver policies need to respond to the concerns of women and to encourage men to become more involved in informal caregiving. Due to the sparse population base in rural areas, there are generally fewer caregiver and formal services available, and transportation to those services may also be difficult. Caregivers in First Nations or multicultural communities experience linguistic, cultural and political barriers to accessing support and formal services. These inequities will require special consideration in policy and program development.

Unlike Allan Rock's words, the preceding portion of the Council's presentation directly addresses inequities in three areas: gender, geographical isolation, and race/ethnicity. The report is written in straight-forward, matter-of-fact language which
engenders credibility and a sense of irrefutability. Little is said about efficiency and rationalization, but the main message is explicit: that new policies and practices must be just.

Metaphors which depict justice and fairness--without making shrill demands--are partly responsible for the tone of the report. Women "struggle" to "balance" their "responsibilities." There are "barriers" to accessing services and support. Women are "concerned" and men should be "encouraged" to take on caregiving, etc. There is no corporate aggression here, but rather a sense of quiet compassion, strength, and social consciousness.

The Seniors' Advisory Council is appointed by British Columbia's Minister of Health and Minister Responsible for Seniors and its mandate is to represent the concerns of seniors. Informal caregiving was adopted by the Council in 1991 as a significant issue of self-interest to seniors. As noted in their presentation, if the well-being of informal caregivers is achieved, then seniors are likely to be well cared for.

There is certainly evidence of hybridity and heteroglossia in the Report, however. There are quotations from academic studies, government reports, and the Report has a mixed journalistic, scientific, and academic style.

In the Summary of the Annual Health Policy Conference held in Vancouver, British Columbia in November 1998, Steven Lewis (1998:45) from the Health Services Utilization and Research Commission, Saskatoon, Saskatchewan, sums up aspects of the conference and makes the following remark:
...a major implicit message of the conference is that vocabulary counts a lot, and the vocabulary that sets the rules for discourse influences outcomes.

I agree with Steven Lewis--up to a point. But I also think we need to look at more than just vocabulary. Bakhtin (1981) makes it clear that vocabulary is only one component of the heteroglossia of language. There are professional languages, literary languages, poetic languages, genres, prose, languages infused with "a particular tendency" or "an individual personality," historical languages, and so on. He stresses the complexity and interpenetration of languages and he emphasizes how, in each language, each word, viewpoint, and metaphor, there are echoes of other languages and traces of worldviews.

In the above two examples--the Maclean's interview and the Report of the Seniors' Advisory Council--we see different languages and different worldviews. Both mix genres, content, form, and styles. They mix languages. One is hybridized through corporatism/instrumentalism/solidarity/efficiency/capitalism, while the other through humanitarianism/activism/equity/wisdom/socialism. Both are communicating messages derived from different positions in the world and from different worlds.

If the differences in languages reflect disparate world views, then the discourse on health care/home care has much more to do with values, ethics, and justice than initially might be realized. It is not just about individual words, therefore, not just vocabulary.
There are many more examples from the discourse on health care/home care that could be mentioned here. Quickly, I will add that Canada is not the only developed country dealing with an ageing population and rising health care costs, and therefore issues of efficiency and equality. Many countries are attempting to solve similar dilemmas, often with far fewer resources (for example, see Xu and Hu, 1996) and Andrew Twaddle (1996:637-654) notes that health reform seems to be underway around the world. In Canada, young people--especially women from poorer parts of the world--are being hired to perform caregiving for Canadian families who cannot or will not. As this trend increases, all kinds of cross-cultural and ethical issues may surface, just as has happened with the employment by Canadians of nannies from poor countries (Pratt, 1999).

SUMMARY

By caring for young, sick, disabled, and elderly people, and providing general household services, caregivers, who are mainly female and often themselves elderly and in compromised health, contribute more than their fair share to society. They quietly and invisibly subsidize our health care system, and therefore society in general. That is, they donate their work and thereby allow other individuals to freely pursue their own dreams and careers; engage in necessary full-time, paid work; live out their lives in dignity; or die comfortably at home. As a society we save tax dollars (theoretically at least) by expecting and encouraging a proportion of the population which is mostly women
to continue to caregive without just compensation. Furthermore, on a global scale, by continuing to work on a volunteer basis women around the world are kept oppressed. In effect, women say that our labour is not worth very much, when we say we only do it through/for love.

Of course, emotional considerations are important in caregiving. It could not be otherwise. Care without affection, I believe, is not true caring. Many of us also would agree that home and caring are things very close to the heart indeed. In the book, *Writing Home: A PEN Canada Anthology*, Margaret Atwood (1997:2) describes her 1940's childhood memory of a Toronto building:

The Home for Incurable Children was made of brownish-red brick, and it was grim. There was the sign with its name in big black letters, right on the lawn....

Once I'd managed to escape from childhood as far as high school, it still obsessed me. It was the name: I could see it contained a swarm of meanings. Did 'incurable children' mean those that could not be cured of being children? Was it childhood itself that was the disease? And 'home'—why call it a home, when everyone knew it wasn't a real home at all, but, like 'homes for the elderly,' the exact opposite? If such places really were homes, what a sinister and quicksand twist it gave the word!

And in the same volume, Timothy Findley (1997:67) offers this poignant view of home:

Our governments are withdrawing from us, leaving us as refugees are left, abandoned. Homeless. The very young and the greatly old, the sick and the needy have been the first to suffer. This is always so in desperate times. A person might imagine, here, that our governments have declared war on the people. The stringencies are all the same—loss of place and loss of hope; loss of security, loss of dignity. The roof that once was safely set above our heads has been blown away. Gone. Our home is not what it was, not what we intended, not what we created and shared. The arsonists
have come, and--God knows why--we seem to be powerless to prevent their fires.

Home is the centre of our lives. Only a fool--a determined, not a true, pessimist--would tell you otherwise. Home is not just people. Home is what people dream: a bed, a window, food, a blanket. Something, anything, kindly to remember. For horses, the smell of hay and other horses. For cows, the mother-smell of milk. For us, for humankind, a photograph of someone loved, the taste of marmalade, curry, wild rice, the scent of snow. In a trunk or in a suitcase, in a mind or in a memory, something carried everywhere. The permanence of nowhere, nowhere made somewhere, because you have it in your hand. I am here--and, with me, who I am.

What I argue in this chapter, therefore, is not that caregiving be stripped of its emotional meanings, even if this were possible. Rather, I am advocating that caregiving be recognized as hard work as well and that we make a commitment to assist those individuals who become caregivers. We can assist them by offering choices and support in their decisions to care, and by ensuring that all caregivers have universal access to a wide and flexible range of care-related resources and services including those concerned with language, information, meals, activities, housing, institutional care, home care, day care, and respite.
CHAPTER 9 - FINALIZATION

The meaning of work lies in its interpretation, and this is intersubjectively constructed. Further, the understanding that a person gives to their working is not simply determined by, and a reflection of, pre-existing cultural discourses. Individuals creatively use pre-existing understandings, variously accepting, manipulating and transforming them. (Douglas Ezzy, 1997)

First, let me summarize the main purpose, findings, and conclusions of the dissertation before I describe implications and limitations, as well as suggestions for further research.

SUMMARY OF PURPOSE, FINDINGS AND CONCLUSIONS

My original goal was to fill a gap in our knowledge of caregiving which existed because researchers have shown little interest in how the intersection of gender and ethnicity (in conjunction with other factors) affects caregiving in specific contexts. As an example, Kaden and McDaniel (1990:5) state that "there has been limited focus on gender in aging research" and they rightly identify caregiving and care-receiving as women's issues. But they themselves pay inadequate attention to race/ethnicity and its intersection with gender. To remedy such shortcomings, I conducted interviews with 30 Canadians of Italian, Anglo, and Japanese ancestry who live in the Lower Mainland of British Columbia, Canada. I wanted to discover what meanings were being given to caregiving, and also if these meanings varied along gender and ethnic lines. To do this I began to listen to, help to generate, and record the narratives people were composing about themselves and caregiving. One of my
major assumptions was that through the creative struggle of narrative production caregivers were attempting to provide their lives and experiences with meaning.

I discovered that the caregivers in my study produce both the same and different meanings through narrative. That is, despite differences in the positionalities of caregivers in terms of the intersections of gender, race/ethnicity and class (as well as type of sickness or disability, family size and composition, amount and kind of support, identity and relationship of the care-receiver, and so forth), the macro-narrative remains the same. This is a story in which the self is represented, eldercare is a central experience, and caregiving is presented as an entanglement of emotion and work. In a general sense, the eldercare narrative explains actions taken and explores the dilemmas of providing care.

All caregivers I talked with are engaged in emotional and physical work (which may also be financially draining). Their work is performed in conjunction with the same problem-fraught British Columbia health care system and at a moment in time when the work of women is generally undervalued. It is also performed while ambivalent perceptions of immigrants prevail, and racism and discrimination are prevalent. Furthermore, caregiving is performed while intrusive globalizing forces grow stronger, corporatism escalates, and conservative forces work to expand their spheres of influence.
In another sense, I found that each caregiver and narrative is distinctive. Each caregiver's life and circumstances are complex and unique. No two caregivers have identical histories, problems, issues, and concerns. For example, caring for a 90-year-old mother who has Alzheimer's Disease and a 60-year-old husband who has suffered a stroke are different experiences. And even if caregivers are similarly positioned and related to their respective care-recipients (who may be the same age and gender, have the same health problem, etc.) caregivers do not react identically and their narratives reflect this diversity.

Significantly, I found that individual narratives can be clustered together. Although each eldercare narrative is based on a caregiver's unique experiences, the eldercare narratives can be grouped together as linked responses which have been prompted by prominent public depictions of caregiving that vary along ethnocultural, gender, and/or class lines. ElderCare narratives, in other words, can be grouped to form an overlapping family of responses to particular cultural representations and constructions.

I also discovered that, as a researcher, how I am positioned in the world—in terms of experience and hierarchies of power, knowledge and status—not only affects what I perceive, but also affects how others perceive me. For instance, caregivers' perceptions of me influence how I can conduct my research and, in turn, these perceptions significantly influence what knowledge can be generated from the data.
I learned that not only do eldercare narratives describe experience, they also serve as the basis for what ought to be. Further, they are points of departure for the development of subsequent discourse, since there never is a concluding word on any topic due to the dialogical nature of communication. An example that occurred during my research demonstrates this ongoing feature of communication. A male caregiver stated that there was a qualitative difference between female and male caregiving. When I asked him whether men could become involved to the same extent as women, he emphatically told me, "I can't see that day." Then he explained (suggesting that he himself was typical of males) that this is because:

...anything that is caregiving is not in the realm of my interests whatsoever. I guess the bottom line is: I'd rather be doing something else....Anything!

A short while later I returned to the man's house with our interview transcript. To my surprise, he spontaneously revisited the topic of gender differences. He then described a delayed reaction. Gender differences in caregiving had been bothering him since we had talked. He wanted to make the following corrections to his statements: a) maybe other men felt differently; and, b) he could not see things dramatically changing within his own lifetime. Taken a step further, his corrections also affected how I subsequently interpreted our conversations and incorporated his words into the write-up.

Although eldercare narratives perform a variety of functions, their overall purpose is communication. Bakhtin
(1981:340) notes that we must pay attention to fundamental circumstances, saying that:

...In order to assess and divine the real meaning of others' words in everyday life, the following are surely of decisive significance: who precisely is speaking, and under what concrete circumstances?

I conclude, therefore, that initially we must look at who is speaking and his/her positionality. Who is telling the eldercare narrative and under what concrete circumstances?

I also conclude that narrative analysis should be a core component of the study of eldercare. There are numerous reasons for this. I agree with many observers, such as Byron Good, Arthur Kleinman, Arthur Frank, and Kathryn Montgomery Hunter, that personal narratives are important sites of meaning-making in the realms of sickness, disease, and medicine. And with Paul Atkinson, I believe that "[t]he narrative organization of health and illness, and of medical work, is unquestionable" (Atkinson 1997:340).

The brand of narrative analysis used in my research squarely addresses the crisis of representation. That is, it faces the difficulties of locating and describing ourselves and others--given the postmodern realization that all our descriptions are political, poetical and incomplete. Narrative analysis offers a complex solution: narratives are at once deemed to be personal statements and intersubjective constructions whose truths are hidden and partial.

Postmodern advocates of narrative analysis reject the notion that language is "a transparent medium, unambiguously reflecting
stable, singular meanings" (Riessman, 1993:4). These narrative analysts are not interested in content alone, but also form and context. They put forth questions such as: How is the narrative structured? Who are the addressees and what are their contributions to narrative production? Under what circumstances, and for what purposes, is the narrative being created? How is language being used to achieve particular results?

Another conclusion I reach is that we must study how larger issues and trends (such as global corporatism, patriarchy, biomedical dominance) are manifest in eldercare narratives and other personal narratives. The latter are not just personal, idiosyncratic, micro-level stories. The nature of their relationship to the cultural, social, national, and global are highly complex and addressees need to listen carefully for complicated connections.

We need to be sensitive to both similarities and differences in eldercare narratives. Differences and similarities in meaning are primarily contingent upon dialogical responses to cultural representations (and even to particular statements sometimes) as well as upon the positionalities of both caregiver and researcher. Bakhtin (1981:345) writes that:

...When thought begins to work in an independent, experimenting and discriminating way, what first occurs is a separation between internal persuasive discourse and authoritarian enforced discourse, along with a rejection of those congeries of discourses that do not matter to us, that do not touch us.

We need to examine, therefore, how eldercare narratives are an interplay of our own words ("internal persuasive discourse")
and the words of others (external authoritarian enforced discourse) (Bakhtin, 1981:345).

IMPLICATIONS

In this section, I summarize implications of my study, and present a set of practical/research/policy-relevant suggestions for listening to eldercare narratives.

What I want to stress is context. Although many of us may be fascinated by "a quick-moving tale, a thrilling plot, mystery, adventure, suspense" (New and Rosengarten 1991:1), when it comes to finding meaning in narratives of caregiving, sickness, and suffering, we need to broaden our interests. We need to consider what we are hearing from other perspectives--at the same time as remaining emotionally engaged--and directly examine how the narratives are being constructed, in what contexts, and why these stories are being told.

1. **Individual Stories.**

Listeners should appreciate the complexity of each life and each eldercare narrative. To the extent possible, each narrative should be listened to, interpreted, and analyzed as a whole. At least initially, each one should be listened to without making comparisons and contrasts.

In order to achieve the preceding ideal, it is essential that researchers use methodologies such as those of Dorothy Smith and Leigh Gilmore. These begin from, and, therefore, give...
priority to, a person's positioned, local experiences (rather than to social structure and organization).

2. **Local/Global Entanglements.**

Researchers and other listeners need to pay attention to the linkages between individual biographies and larger structures and spheres. If, for example, the global is complexly collapsed into the local (Marcus 1995:102), then we need to examine what this means, in particular instances, for the lives of individuals. For researchers, this surely means that we must examine micro and macro structures and forces in more complex ways. Rather than viewing the micro and macro as separable levels, these should be viewed as entwined and tangled in multifarious ways.

In my study, caregivers' lives reflect/reproduce/contest/construct/inscribe global patriarchy, hegemonic ageing, a turn to the Right, health care restructuring, multi-national corporate politics, technological escalations, the medicalization and individualization of caregiving, and so forth. Caregivers' lives are highly influenced by, and inseparable from, these forces, trends, policies, institutions, ideologies and their accompanying webs of significance and mystification.

3. **Multiple Authors.**

Researchers and other listeners should analyze eldercare narratives with attention to the manner in which they are co-produced and are dialogical, in order to better understand contextual factors.
Eldercare narratives are significantly co-authored and dialogical in a range of ways. Here I am not only referring to my own participation in co-construction as an interviewer. I am also referring to the fact that the narratives variously contain interactions of meanings and language with invisible others. Viewing personal narratives in this way alerts us to the wider and more public meanings of eldercare.

4. **Multiple Functions.**

Listeners should stay alert to the various possible functions narratives perform. Researchers and other listeners should also acknowledge their own role in the assignment of purpose, function and meaning to particular narratives.

Critical personal narrative analysis makes the assumption that despite a variety of functions, the major purpose of all language is communication (not classification of the world, for example). Communication can take place between the self and other(s) or between aspects of the self. Therefore, researchers should pay close attention to the ways in which all language (including that of personal narratives) functions as an idiom for the communication of statements and responses to previous statements.

5. **Patterned Stories.**

Listeners need to stay alert to the various ways in which narratives are the same and different. For instance, looking after an older person usually means balancing self-sacrifice and
altruism. It produces a mixture of emotions, and often requires heavy involvement with the health care system. Furthermore, eldercare narratives may be similar responses (in terms of content, form, contextual factors) to previous discourse on identity and caregiving. No rigid categories should be formulated into which experiences, personal narratives or the caregivers themselves are simply slotted.

Policy-makers should support programmes which help caregivers, such as immigrant women, who have special needs and who, therefore, require special assistance. This assistance might be in the form of extra resources, respite, home care, help with language or medical translations, etc. (See Happy, 1997 for further suggestions).

Caregivers have different needs depending on their resources and situations. With regard to gendered, ethnoculturally appropriate health and home care, my findings show that caregivers are sensitive to how we-groups are being represented and that caregiving and the meanings being given to it are not restricted to particular groups of people. Meanings cross-cut divisions based on gender, race/ethnicity and class. Ethical and other dilemmas are omnipresent. Due to the nature of caring itself, caregiving is a source of both stress and satisfaction for all individuals--female and male; Canadians of Anglo, Italian and Japanese ancestry; rich and poor; young and old.

In addition, however, there are also differences in the eldercare narratives I listened and responded to. These rest on
the present circumstances of caregiving, as well as on the
specific interpretations and meanings caregivers negotiate and
attach to their eldercare work.

Some caregivers are (or have been) in dire circumstances. They are caring for extremely sick or disabled older people with very little outside help, caring for more than one person (for example, two parents), have stressful relationships with other family members (such as husbands or siblings or children), or are elderly (several of my participants were in their 70s and 80s) and/or in poor health themselves, etc. Furthermore it made a difference where caregiving occurred. If it took place at home, caregiving often disrupted domestic life. If in a care facility, caregivers had to deal in an immediate way with the Canadian health care system, with institutional regulations, policies, procedures, and health care personnel. Various special circumstances, therefore, affect peoples' lives/narratives.

Also how caregiving is interpreted, represented, and constructed and what meanings are given to it is influenced by one's perceptions of self/other distinctions, and the inclusions, exclusions, and contradictions which have been experienced throughout life. Personal narratives about eldercare are basically idioms through which to communicate subjective meanings about self/other, and the nature of one's attachments and responsibilities.
POTENTIAL LIMITATIONS

Recall that the major purpose of my research is to answer the question: "What meanings are attached to eldercare in specific contexts (of gender and ethnicity)?"

One limitation of my dissertation is that interviews were conducted only with a small number of Canadian caregivers (those of Anglo, Italian, and Japanese ancestry) -- most of whom are middle-class women. Thus a large number of caregivers whose positions differ from those of the participants remain excluded. Not found in my study are caregivers who are:

a) homeless, very poor or rich, or upper class; b) of non-Anglo, non-Italian or non-Japanese ancestry; c) without available time or willingness; d) involved in eldercare situations but who remain unidentified as caregivers or primary caregivers.

Also largely excluded are care-receivers. While care-receivers are typically left out of caregiving studies, the opinions and stories of care-recipients would have provided a significant perspective on caregiving issues such as home care. In addition, although I spoke with several health care professionals or formal caregivers, I have chosen to focus on informal caregivers, their experiences, and their viewpoints. The voices in the dissertation, therefore, are in many ways selected. There are logistical, ethical, and theoretical reasons for my decisions in this regard, but the result is that the spotlight remains largely on informal caregivers.

I do not see my focus on particular, positioned individuals
as a true limitation of my work, however. Louis M. Smith (1994:286-305) discusses the so-called "biographical method" in qualitative research with which my study is affiliated. Smith (1994:298) notes that Howard Becker, a well-respected sociologist, argues that life history research is "part of a 'mosaic' of community and institutional investigations." Life history material and biographies are important as:

...'touchstones' for considering any abstract theory of person and community, and the testing of implicit assumptions about human beings in the larger sociological studies.

Moreover, social studies which focus on the individual are justified because:

...biography with a concern with the way a specific individual perceives and construes the world also moves the sociological interpreter toward the subject's perspective rather than the observer's point of view, a major issue labelled by the anthropologist Clifford Geertz as 'experience near' versus 'experience distant' conceptualizations. (Smith, 1994:298)

In my study, I seek such touchstones and experience near conceptualizations in order to support women and caregivers with rich, concrete portraits of their lives. An additional point is that these actual and close-up accounts may be more readily achieved by native researchers, such as myself, who are simultaneously engaged in auto-ethnography and thus seeking to learn about their own subjective experiences and ties to local communities. Moreover, feminists like myself, demand that individuals and their marginalized, counter-hegemonic narratives and outlaw discourses be showcased as critiques of universalized accounts which have systematically excluded a range of female
subjectivities. The Personal Narratives Group (1989:3) states that: "Traditionally, knowledge, truth, and reality have been constructed as if men's experiences were normative, as if being human meant being male." In any case, as the Personal Narratives Group (1989:4) goes on to tell us:

Listening to women's voices, studying women's writings, and learning from women's experiences have been crucial to the feminist reconstruction of our understanding of the world.

Therefore, I view my study as contributing experience near conceptualizations of participants' own perspectives and feelings, as well as to the feminist project of rendering audible diversely-positioned women's words above the noise of sociological theories, hegemonic narratives and totalizing discourses. For these reasons, I view the eldercare narratives I helped to generate as "primary documents" (Personal Narratives Group, 1989:4) and touchstones which ground generalizing abstractions in the actual lives of women.

A related but potentially more serious problem concerns the relationship between the "naked immediacy of experience" (Bakhtin, 1993:x) and narrative, between reality and stories, and between acts and accounts thereof. Here I am not referring to the very real problems involved in transforming spoken narratives into written texts, but rather to the ability of words to ever capture our raw experiences.

A few caregivers tried to reassure me that they were indeed telling the truth not just making up stories! For example, while the tape recorder was momentarily turned off, one participant
mentioned that 2/3 of the time she had been aware of the recording device. Therefore, at times she felt as if she was giving "a kind of a presentation," rather than engaging in a conversation or participating in an interview. When I turned the recorder back on she also added:

Yeah, it's not completely natural; it's not...the way I would talk if it was just us sitting here talking about family.

But that's the nature of the game, I guess, you know. I mean, I'm not making it up. It just comes across a little bit differently. But it doesn't make me uncomfortable, it's just different.

These are the interpretations that I embrace, therefore: that personal narratives are dialogical responses which provide up-close meanings of identity and life as experienced. They are close to, although not identical with, "the naked immediacy of experience" (Bakhtin, 1993:x). But in any case, they do reflect subjectivity and are subjectively-inspired responses.

This accords with Bakhtin's (1986:163) idea that the consciousness of speakers is always in the process of being monologized (Bakhtin, 1986:163). He explains that:

...Others' words become anonymous and are assimilated (in re-worked form, of course); consciousness is monologized. Primary dialogic relations to others' words are also obliterated--they are, as it were, taken in, absorbed into assimilated others' words (passing through the stage of 'one's own/others' words').

Whenever we experience anything, those experiences are already mediated. But we are always trying to put things into our own words, to represent whatever we feel and think.
In Toward a Philosophy of the Act, one of Bakhtin's goals is to perform the impossible task of focusing on the act itself, rather than on accounts of the act (Bakhtin, 1993:xii). In the Foreword, Michael Holquist (Bakhtin 1993:x) writes that:

...Bakhtin in this volume is seeking to get back to the naked immediacy of experience as it is felt from within the utmost particularity of a specific life, the molten lava of events as they happen. He seeks the sheer quality of happening in life before the magma of such experience cools, harding into igneous theories, or accounts of what has happened. And just as lava differs from the rock it will become, so the two states of lived experience, on the one hand, and systems for registering such experience on the other, are fundamentally different from each other.

The point I am making is that although narrative construction (selection of a beginning, events to describe, and endings, etc.) is a creative process that occurs when we transform the naked immediacy of experience into thoughts, descriptions, accounts, and theories, the caregiver quoted on page 285 is correct. She is not "just making up stories"; she is registering her experiences through narrative production.

Perhaps we can never really identify "the sheer quality of happening in life before the magma of such experience cools"—and I want to state this as a limitation of the study. But even if we are unable to grasp immediate experience per se, or even the objective truth of actual events, my study is still valid. This is because listening to personal narratives is one of the best ways we humans have of learning about another's subjectivity and experiences as these are given meaning and value through language. Instead of simplistic, homogenizing studies which leave out our individual humanity and the contexts in which we
live and speak, studies of personal narratives are able to demonstrate and validate our diversity, dignity and complexity under limitless circumstances.

FURTHER RESEARCH

I hope my dissertation suggests--and opens spaces for--numerous research projects. Here, I would like to discuss two which I believe are challenging and important. One focuses on the health and well-being of caregivers and the meaning of caregiving work, and the other centres on how active listening to presentations/re-presentations\(^2\) of identity and experience can be studied and encouraged.

1) Health and Caregiving Work

Following from my dissertation research, I think it is important to study the extent to which caregiving is affecting the health and well-being of caregivers. I also want to learn about any health-threatening risks in their work environments (that is, in both private homes and continuing-care facilities).

In addition to everyday care, such as feeding and washing, various medical and quasi-medical procedures are now being performed by informal caregivers. It has been noted (Canada, 1999:11) that:

> With hospital reforms such as consolidation, shorter lengths of hospital stays, day surgery, etc., the need for the provision of heavier acute care in the home and community has increased.

In private homes, for example, caregivers use portable lifts and transfer devices, administer intravenous fluids, and even perform
more complicated tasks such as hemo-dialysis. These activities may take place in small rooms and cramped spaces. They also require training and skills. Therefore, performing these procedures poses potential risks to the physical health and psychological well-being of caregivers (as well as care-receivers).

The public is becoming aware of such problems through media reports. For example, on June 25, 1999, The National (a Canadian Broadcasting Corporation's television news show), carried an item about the Quebec nurses' strike followed by a story about home care. It was introduced by Peter Mansbridge who said:

There is no quick end, however, to the struggle being faced by another group of people in the Canadian health care system. Governments call them informal caregivers, but you might call them mother, father, sister or brother. They take care of chronically ill members of their family, and today a study of more than 200 organizations trying to help them found that the home care system is under seige. (The National Online Transcripts 990605).

The story was based on a study conducted by Queen's University and commissioned by the Canadian Association Of Retired Persons. In the study's final report, governments are criticized for their lack of action. A caregiver who appeared on the show suggests that although caregivers have increased their care of others, they now have less time and energy to look after themselves. Therefore, their own health and well-being is beginning to deteriorate. She says that,

Sometimes at the end of the day, it will be 4:30 or five and I'll think 'I haven't even combed my hair or brushed my teeth today.' And that's just the way it goes.
Her words echo those heard on The National back in February (1999) when it was reported that:

Women in the 1990s seem to be looking after everyone but themselves and their hearts are paying for it...The problem is time....

It was claimed that women put themselves last in terms of their kids, parents, jobs, etc. and that women aged 45 to 70 are overweight, stressed, not seeing their doctors early enough--and it was emphasized that women's heart disease is on the rise.

When family caregivers work in care facilities and hospitals, there are other potential dangers too. When I attended the mandatory orientation session for volunteer workers at a local care facility, we were warned that health care institutions were dangerous places. We were taught how to wash our hands effectively in order to avoid infection. We were also told not to lift residents/patients, nor to feed them. This was partly due to union regulations, but it was additionally related to residents' risk of accidents, injuries, and choking, and our own risk of injuries. Furthermore, all caregivers face the possibility of violent attack (just as care-recipients are vulnerable to abuse). No matter where older persons are cared for, it seems, there are physical and psychological stresses placed on caregivers which threaten their health and well-being.

For these reasons, it is important to assess the extent to which caregivers are exposed to factors in their occupational settings which render them vulnerable to injury, disease, sickness, disability, and death. Of equal importance too, is the
degree to which caregivers view eldercare as safe and/or risky. Feelings of safety and vulnerability—especially when coupled with emotionally-charged work situations—can themselves contribute to ill-health.

Such a study would need to be interdisciplinary and would require the collection of both quantitative data (ideally with identified cases being matched to health records) and narrative accounts which would keep abstractions from straying from caregivers' lived experiences.

2) Active Listening and Responsive Understanding

A story is not like a road to follow...it's more like a house. You go inside and stay there for awhile, wandering back and forth, settling where you like and discovering how the room and corridors relate to each other, how the world outside is altered being viewed from these windows. And you the visitor, the reader, are altered as well by being in this enclosed space, whether it is ample or easy or full of crooked turns, or sparsely or opulently furnished. You can go back again and again, and the house, the story, always contains more than you saw the last time. It also has a sturdy sense of itself, of being built out of its own necessity, not just to shelter or beguile. To deliver a story like that, durable and freestanding, is what I'm always hoping for.

(Alice Munro, Selected Stories, 1996:xvi-xvii)

I want to suggest here that the study of how individuals read and listen to eldercare narratives is urgently needed. In the document, Provincial and Territorial Home Care Programs: A Synthesis for Canada (Canada, 1999:33), the authors note that:

There is increasing standardization within individual jurisdictions with respect to both the processing of demand (e.g. by a standardized assessment tool) and management of service information (e.g. by provincial information systems) in home care. British Columbia has gone a step further to implement management of a
single data bank for both home and institutional care using the same functional classification system.

What this means for British Columbians is that assessors and case managers are moving away from listening for differences, and closer to listening for similarities in caregiving and eldercare narratives. Narrow definitions, standardized assessment procedures, questionnaires, information systems, classification systems and single data banks may produce greater perceived control and efficiency. But this trend towards greater uniformity also means that caregivers/care-receivers whose situations fall outside a defined range will be deemed ineligible for services such as home care or be allowed only the minimum.

If personal narratives are presented in written form, as are the eldercare narratives in this dissertation, then we can enter the narratives as we would enter houses, spending time inside and entering as often as desired. If, on the other hand, we listen to narratives in fleeting (non-recorded) speech, we can only re-enter them through memory and we must find different ways of understanding these productions and our reactions to them.

Research is needed into how listening relates to time, and how it is a dialogical, active-not-passive endeavour, significantly dependent upon what listeners bring to each conversation.

Research could be conducted, for example, on delayed responses to particular statements (Bakhtin, 1986). Studies of literary texts suggest that there may be delayed responses to key symbols or touchstones, for example. More of Alice Munro's
I never wrote a story about the man and the horses. It doesn't work that way anyway. The scene which is the secret of the story may not seem to be close to what it's 'about.' For instance, the story 'Open Secrets' is 'about' a girl who disappears on an overnight camping trip, and the ripples set up in the community by her disappearance. There you have the central incident, the 'what happens' of the story. But the scene that I could not do without, the scene that seems to hold the most essential key to the story (but not necessarily to the plot), is the one in the back yard. The woman, the dog, the deranged man, the pump, the heat, the pain of the boil. I don't mean that these are things put into the story and that they seem to work well, I mean that they were there from the beginning and it was to an extent because of them that I was able to discover or invent the rest of the story.

What I am suggesting is that while reading or listening, readers may be so intent on listening for 'what happens' that the lasting effect of the story, the "secret of the story," only makes itself felt gradually as it outlives the intricacies of the plot.

In this connection, I also recollect words of Sherrill Grace (1994:189-203) who describes how powerful symbols can act as keys to autobiographical works and lives. Grace analyzes autobiography in Margaret Atwood's The Handmaid's Tale. She explains how Offred uses two autobiographical touchstones--community and games of Scrabble--to construct a narrative of her life that will "reconstruct her being across an all but unbridgeable, violent severing of time before and after the imposition of Gilead"
(Grace, 1994:196). Grace (1994:197) suggests that Atwood uses Scrabble as:

...an image of the text...in which one can see this autobiographical 'tale' as a Scrabble board on which we must also play. If we have trouble with the plotting of the narrative or the structure of the text, we can think of it as a Scrabble board which grows (one step, one letter, one word at a time) in a seemingly haphazard manner in several directions at once around the invented, constructed centre: OFFRED. And the combinations and permutations of that single word, that arbitrary combination of letters, are—if you stop to play with it—many.

Certainly Scrabble is a game which springs immediately to my mind when I think of *The Handmaid’s Tale*, even though much of the intricacies of the plot have faded from memory over the many years since reading the book.

As a final example of how we listen and react to what we hear, Bakhtin (1986:60-101) suggests that in addition to content, we must listen for the attitudes expressed within utterances and what meaning they have beyond the text/context. Bakhtin (1986:92) notes, that:

The expression of an utterance can never be fully understood or explained if its thematic content is all that is taken into account. The expression of an utterance always responds to a greater or lesser degree, that is, it expresses the speaker's attitude toward others' utterances and not just his attitude toward the object of his utterance.*

*Intonation is especially sensitive and always points beyond the context.

We must pay attention to these ways of reading and listening. That is, attention must be directed towards: a) integral details and nuances, such as essential scenes and symbols; b) the possibility of delayed responses; and c) expression and tone.
I look back at the stories people told me and I am struck by the selectivity of my memory and also, in rereading the transcripts and mulling over the stories months after the interviews, how the texts are still able to generate new interpretations.

During the interviews, reading, and all social interaction and communication, however, there are times when communication breaks down. Speakers and listeners cannot understand one another, or they misunderstand what is being said. Such instances may slip by virtually unnoticed or they may only register with a listener after much reflection—and perhaps only after an intervening event. For example, anthropologist Renato Rosaldo (1993) describes being able to empathize with "the rage in grief" that his informants felt, only several years later and only after experiencing the full weight of his wife's accidental death (which occurred during his initial fieldwork).

Although there may be various reasons why people fail to communicate, Johannes Fabian (1995:41-50) discusses two types of not-understanding/misunderstanding which pertain to listening. One arises from the misinterpretation of particular words or phrases and the other results from what he calls "the perils of context."

The first type of error concerns the researcher's assumptions concerning the meaning of particular words and phrases. For instance, while in a rural area of Lumumbashi/Zaire, one of Fabian's research participants referred to a "white
man" who had come to their area. Fabian assumed this referred to a person of male gender who had light-coloured skin. As it turned out, however, the speaker's phrase was ungendered and it made no reference whatsoever to skin colour. Instead, the speaker's associations were with Europe and America, and they were based solely on "origin, socioeconomic status, and political position." And sometime after the initial conversation, with more information at hand, Fabian figured out that the person being referred to was a female, African American researcher (Fabian, 1995:43).

To illustrate the second type of miscommunication, Fabian discusses a case which springs from the misinterpretation of context and the categorization of a meeting as a particular kind of speech event. Fabian assumed that "an interview is an interview," and it did not initially occur to him that his definition and the participant's were at odds. He describes a pre-arranged meeting about religion with a woman he calls, Mama Régine. During the interview, Mama Régine asks unanticipated questions such as "Do you pray?" and "Are you a Catholic?" Only reflexively does Fabian realize that a misunderstanding occurred regarding the intentions of the parties involved which, in turn, influence the interpretations they each make. The problem is that Fabian was there "to record information about charismatics" and he also failed to recognize Mama Régine's use of irony. Therefore, he considered many of her answers to be "dodges." Mama Régime, for her part, used the interview to compare and
contrast their different spiritual beliefs, as well as to
critique the local Catholic hierarchy. According to Fabian, Mama
Régine was engaged in, and attempting to engage Fabian in, a
"different genre" (or what Bakhtin likely would call a speech
genre): not research interview (traditionally defined) but
religious testimony.

Fabian (1995:41-50) thinks such mistakes, errors, and mis-/not-understandings are part and parcel of the process of
knowledge-creation. He stresses that knowledge production is a
struggle which occurs "through practices of interacting with, or
confronting, reality" and that not-knowing/not-understanding are
"dialectical negations" which are necessary conflicts by which we
create knowledge. Delayed responses and re-interpretations,
therefore, are entirely normal and should be expected; allowances
for them somehow should be built into our interpretative
frameworks.

Such ideas relate to how we listen, interpret and respond to
the speech of others. Some of the people I interviewed suggested
that our interview was an opportunity to visit, to express
frustrations, to recall the past, to confide in someone, to
experience healing, etc. One caregiver and I even prayed during
the interview. On my part, the interview was not only a method
of information-collecting, it was an opportunity to meet people,
to find out about three ethno-cultural groups, to explore my own
self and roots, and so on. Interviews, then, are hybrid events.
We must listen to the speech of others, therefore, taking into consideration the customary meaning of words and how these words are variously accented--sometimes with conventional meanings totally abandoned--to recognize how we dialogically create meaning, and to give ourselves time to develop understandings and responses. Furthermore, we must also attend to the intentions of individuals and how they are defined within particular contexts--since versions of eldercare narratives are fashioned for particular occasions, settings, and listeners/addressees (Angrosino, 1989; Bakhtin, 1986; Barker, 1989; Smith and Watson, 1996). In addition, we also must realize that all narratives contain the speech and ideas of others. For instance, Bakhtin (1981:345) says that, "In the everyday rounds of our consciousness, the internally persuasive word is half-ours and half-someone else's" and he adds:

...More than that, it enters into an intense interaction, a struggle with internally persuasive discourses. Our ideological development is just such an intense struggle within us for hegemony among various available verbal and ideological points of view, approaches, directions and values. The semantic structure of an internally persuasive discourse is not finite, it is open; in each of the new contexts that dialogize it, this discourse is able to reveal ever newer ways to mean. (Bakhtin, 1981:346)

The study of speech reception--of how we listen, what we bring to the listening situation, how we process words and narratives, how we create meaning from another's words and then formulate responses--all need to be studied in the context of listening to personal eldercare narratives with practical and policy implications in mind.
The potential of such studies to improve practice and policy is great. Julie Cruikshank (1992) shows us how the women she interviewed were living their lives with stories in mind; in a sense, they viewed themselves as characters in traditional, eternal plots. Cruikshank (1992:15) had to learn how to hear these various life stories which often involved complex plots with "a bewildering series of characters and events," as vehicles through which women explained some aspect of their unique lives, histories and lived experiences.

Cheryl Mattingly (1994:811-822) also makes concrete the idea that life is lived against the backdrop of traditional narratives. In her study of what she calls therapeutic emplotment, therapy (occupational therapy in her example) is lived as a plot to get back home. Therapeutic emplotment encompasses the notion that there is an underlying plot or "figure in time" which underpins treatment. In cases of acute illness or accident this is basically the story that the patient will improve through treatment, right attitude and hard work. It will not be easy; persistence in the face of adversity will be essential. If successful, however, the patient will eventually leave the hospital to resume a satisfactory outside life. Mattingly suggests that health care professionals should heed the manner in which healing narratives are dialogically-emploted through small, unanticipated interactions between the patient and professional. Furthermore, Mattingly (1994:811-822) convincingly argues that
prescribing a fixed treatment plan is antithetical to
dialogically emploting a therapeutic narrative.

These, then, are two examples of the kind of studies I hope
my dissertation will open space for: one example focuses on
caregivers' health and well-being, and the other on learning to
listen effectively, especially by paying attention to key
elements, the contexts of personal narratives, delayed responses,
and emploted lives and caregiving.

SOME FINAL WORDS

For Bakhtin (in 1993:xii) the gap between an act and its
meaning is something that must in every instance be achieved.
The way Bakhtin sees this occurring is through continuously
taking responsibility for one's own actions. Bakhtin (1993:95)
believes that each of us has "a non-alibi in Being" which can be
explicated as follows: "...I cannot be relieved of answerability
for the commission of an act by an alibi, that is, by claiming to
have been elsewhere than at the place of commission."

In the context of my dissertation, each of us is responsible
for listening or not-listening to the eldercare narratives of
caregivers and of finding ways to help them out. Just guessing
at caregivers' needs and offering our own solutions is not good
enough. It is imperative that we try to understand the meanings
that are being given to caregiving by diversely-positioned
individuals in a wide array of contexts, and to base our
assistance on what is meaningful to them.
We can no longer rely on common sense solutions since common sense in this complex, postmodern, multicultural world has become something relative, idiosyncratic, and messy. Universal common sense has no meaning; if we invoke the phrase, we merely show our ethnocentrism. Nor can we rely on the so-called Golden Rule which urges Christians to "Do unto others, as you would have them do unto you." This is because we are all different, and we all have special needs which are derived not just from general circumstances, but from specific situations arising from our distinctive positionalities in the world. So, to do unto others, as we would have them do unto us may very well be harmful, insulting, ethnocentric, and so on. Therefore, we all need to listen well--with our hearts, minds, souls, bodies, with everything we have--and then act wisely and responsibly on what we hear.

One of Joy Kogawa's (1977:19) poems suggests that if someone asks for bread, we should not--even if we think it tastes better--offer them cake. Kogawa writes:

she asked for bread
we offered cakes
and as she waited
the food
within her grasp
turned to stone
she asked for bread

Neither should caregivers be offered services that are not designed with their particular needs in mind. That is, we should not offer caregivers blanket programmes which are meant to serve average Canadians or ordinary Canadians or generic Canadians
(based on white, Anglo-Saxon, middle-class values)—since there are no such people. If we fail to listen to their disparate voices and needs, without paying attention to the diverse meanings being given to caregiving in local, material, gendered, ethnoculturally diverse contexts, then we indeed risk turning well-meaning assistance into burdens, and humble requests for assistance into meaningless phrases: bread to stone.

This dissertation is my interpretative attempt to listen to and report upon what meanings caregivers give to their lived experiences. The dissertation is also, in a way, an attempt to listen more carefully to the past and to those people who have shaped my own identity. Through the process of research and writing I hope I have become a wiser, better person and gained insight into how self and other overlap and sometimes disappear into one another. Although there can be no tidy divisions, now I have a greater appreciation of how all of our paths have been the same yet different—but, in any case, always entwined.
Notes

¹Bakhtin refers to the finalization of utterances. Bakhtin (1986:71-72) says that the change of speaking subjects creates rather clear-cut boundaries for utterances. Conclusions are another matter, however. Conclusions in the sense of being final words on a topic do not exist because there can always be rejoinders to every final statement.

²This is a distinction made by Sidonie Smith who suggests that although some aspect of autobiography is a re-presentation of previous presentations, there is an authentic, original presentation of identity as well.
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APPENDIX I - Profile of Participants
### PROFILE OF PARTICIPANTS

**N = 30**  
(24 Women; 6 Men)  

Age Range: 33 - 80+  
Mean: 59 (Approx.)

<table>
<thead>
<tr>
<th>PSEUDONYM</th>
<th>ANCESTRY</th>
<th>APPROX. AGE</th>
<th>MAIN CARE-RECEIVER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cathy</td>
<td>Anglo</td>
<td>43</td>
<td>Father</td>
</tr>
<tr>
<td>Doris</td>
<td>Anglo</td>
<td>69</td>
<td>Mother</td>
</tr>
<tr>
<td>Jane</td>
<td>Anglo</td>
<td>62</td>
<td>Mother</td>
</tr>
<tr>
<td>Joyce</td>
<td>Anglo</td>
<td>55</td>
<td>Mother</td>
</tr>
<tr>
<td>Gail</td>
<td>Anglo</td>
<td>50</td>
<td>Mother</td>
</tr>
<tr>
<td>Lorraine</td>
<td>Anglo</td>
<td>66</td>
<td>Husband</td>
</tr>
<tr>
<td>Sue</td>
<td>Anglo</td>
<td>63</td>
<td>Mother</td>
</tr>
<tr>
<td>Joanne</td>
<td>Italian</td>
<td>55</td>
<td>Parents</td>
</tr>
<tr>
<td>Julia</td>
<td>Italian</td>
<td>50</td>
<td>Parents</td>
</tr>
<tr>
<td>Lina</td>
<td>Italian</td>
<td>75</td>
<td>Husband</td>
</tr>
<tr>
<td>Lucy</td>
<td>Italian</td>
<td>40</td>
<td>Aunt (Mother)</td>
</tr>
<tr>
<td>Theresa</td>
<td>Italian</td>
<td>68</td>
<td>Mother-in-law</td>
</tr>
<tr>
<td>Nina</td>
<td>Italian</td>
<td>57</td>
<td>Mother</td>
</tr>
<tr>
<td>Rita</td>
<td>Italian</td>
<td>50</td>
<td>Father</td>
</tr>
<tr>
<td>Maria</td>
<td>Italian</td>
<td>55</td>
<td>Father-in-law</td>
</tr>
<tr>
<td>Audrey</td>
<td>Japanese</td>
<td>58</td>
<td>Mother</td>
</tr>
<tr>
<td>Brenda</td>
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<td>Mother</td>
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<td>Emiko</td>
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<td>80</td>
<td>Husband</td>
</tr>
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<td>55</td>
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<tr>
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<td>80</td>
<td>Husband</td>
</tr>
<tr>
<td>Tara</td>
<td>Japanese</td>
<td>45</td>
<td>Father</td>
</tr>
</tbody>
</table>

| Ed        | Anglo    | 65          | Mother              |
| John      | Anglo    | 33          | Mother              |
| Roy       | Anglo    | 58          | Mother              |
| Atilio    | Italian  | 50          | Mother              |
| Mike      | Italian  | 77          | Wife                |
| Sam       | Japanese | 78          | Wife                |
APPENDIX II - Joy, Lina and Joyce
Joy's Story:

Grandma Earned the Right to be Spoiled

So I guess this family of my grandparents, and Grandma now, is part of what's happening here with her illness and everything. It is probably much more traditional than it might be in Japan in some ways. I'm not sure. Y'know, it's kind of odd now because we've hung on to something that she brought with her when she was a teenager. And that's the only experience we have because none of us have been to Japan, so consequently we grew up in kind of an oddball Japanese culture that's now very old-fashioned. So, I guess that's my background....

But we figure at 99 she's earned it.... So, we'll sort of give her what she wants. And so we have been the last 2 or 3 weeks. Been here 24 hours a day. It's worked out quite well, but, y'know, the children are all in their 70s or 80s, or 79 is the oldest, I guess, and 65 is the youngest, and they're all a bit too old to be sitting up nights with her.

So as of last Sunday we have hired a babysitter from 11 at night until 7 in the morning.... So she stays the night and then we take over in the daytime, which will make more sense for us.

I mean she is very lucky, but she is very spoiled. But at the same time we thought she worked as a farmer and dragged these children half-way around the country, living on nothing for 70-odd years. She's earned the right to be spoiled, so we continue...

I think it's a natural thing to do. I can't imagine her dying by herself.... So I think for me this is the way it should be for Grandma too.... So, I think that's sort of our responsibility. At least that's the feel I get from everybody, and certainly my feeling is that she's been sort of the head of our household, and has really worked her buns off for the last 90 years or whatever--to get us where we are--and as a family, we're all...well, most of us are professional people; we started off scraping what we could eat, and I remember being put out on a farm and working for other farmers until we had our own property, and now of course, everybody's doing very well, and they're all successful. And she was a large part of that--because she held all of it together. So we have an obligation, I think. Not in a bad sense, but part of finishing my life with Grandma is to get her off somehow peacefully.... I think that's what all of them feel is that she's served them in some way for a long time, and so this would be their way of sending her off.
Lina's Story:

Fred Would Be Lost Without Me

I have no loved ones in the hospital, but I find I have now a husband who is maybe on the verge of Alzheimer's. It is slowly progressing, but I think he is, you know, handling it. And some days he's good; some days he isn't. He doesn't do any more driving; you have to repeat everything, and then he'll forget about it; but he'll remember things that happened years ago. And some days it can be quite frustrating, and it's something you have to be very patient with. But other than that, I mean he's in no pain--but just very forgetful, very forgetful....

I do consider myself to be a caregiver, I do. Sometimes I feel like his mother because I find that I have to do everything. Like he doesn't like to go to the bank anymore. Now he doesn't do any financial things at all. He knows how to deposit the money but he doesn't know how to take it out.... I really don't mind, but then sometimes you think, Well, maybe somebody should do something for me....

Mind you, he's very good in the morning. He gets up every morning and makes breakfast. But it's painful to watch him because he goes to the fridge I bet you six times to get six different things. Where a woman--especially a woman in the kitchen--we can gather all these things maybe at once. So now when he makes breakfast in the morning, I make sure I stay in bed until he's finished.

I had my mom with me for 10 years. Mind you, she wasn't all that much trouble. But you have no time to yourself. You know, this is what you miss, I think. As I get older I kind of feel sometimes I'd like a little time to myself.

Fred would be lost if there wasn't someone there to lead him around, or, I drive him everywhere and if he has to go to the doctor's, or even the other day now he had to go for a haircut and he couldn't remember how to get there, so I said, 'Well, I'll drive you there.' And the time before when he wanted to get a haircut, he asked me how to go there. And I told him, and he got to the corner and instead of going right he went left, so he got lost. So he came home and never did get a hair-cut that day....

I don't mind doing it. No, I don't mind doing it at all. Some days it can get frustrating, but as a rule I don't mind. I feel maybe that's my job [laughing]...
It takes patience, lots of patience. You've got to be a little bit humorous. Yeah, that really helps a lot, but I don't mind doing it.... The biggest thing I can't stand is when you are busy and you see them sitting there all day long watching television. But he enjoys his sports, so what can you say? We have a TV downstairs, but he won't go down there....

Oh, I'd like to be able to sit maybe for about 2 or 3 hours and do absolutely nothing. Sit and have a good book, and I have done that on a nice summer day. I've gone outside and sat and read a book but then I have neighbours that come over [laughing] and so I don't think I'm meant to do that because I have never sat outside without someone coming over....

Joyce's Story:

All These People Deserve The Best

...it's sad because all these people sure need someone to be there to see what's going on there. Or maybe I worry too much; I don't think so though.

...Over the 3 years that mom has been here, there have been a couple of people that I kind of just felt so sorry for that I've watched out for them a little, and because I didn't think things were really being done right, I have spoken up. But I've taken some of them outside, in summer, because a lot of them really don't get out. People with Alzheimer's Disease, it's actually their right to be taken out, and to have fresh air, and a change in scene, but actually some people aren't taken out much...

...Another thing that's heartbreaking: Mom shares the room with another lady who is non-verbal; she doesn't speak any more, but she loves to be spoken to and she will smile and make little sounds. But I've been in the room while they were doing the personal care, and feeding that lady, and getting her up into her wheelchair, and had observed that they had not even spoken one word to her. It's so terrible. And I've brought that up, and they are starting to talk with her more, and to other people. I brought that up in my mother's care conferences, that we have twice a year....I don't know whether people aren't aware that every person should be spoken to, even just to talk about the weather or the food they're eating, but that's something I learned, I guess, in working with children with special needs...But there are staff who actually didn't say one word in that whole time.... I wouldn't want to be that person.... They're people, not just a body, but that is changing.
....family members or friends need to really speak up and I don't think anyone thinks that I'm some terrible person because I do speak up, and I'm going to continue to...and I think that's how we're going to get better care and compassion for these people. It should be part of their training. I know some people who maybe they just aren't aware of some of these things. To me it's common sense, really, to speak to someone that you're caring for...

I get a lot of joy out of being here with my mom, and getting together with other residents who are here, and she deserves--and all these people deserve--the best in these last years of their lives. Although all my life I've been looking after children, mostly, I find this is just as meaningful.
APPENDIX III - Lois, Gail and Lucy
Lois

Okay. I am a Sansei which is a third generation Japanese in Canada. I was born in Central Canada and spent the majority of my life there up until I went to University. Then I married a chap from University....[and after we had our kids, we moved to B.C....]. My grandparents came to the Coast of B.C. when they were teenagers. Then my parents were born here. Our family links have been here well over 100 years.

...So they were a part of the War experience. They were evacuated to the Interior of B.C. They were part of that, and basically they lived in the East because after that evacuation, they were not allowed to come back to the Coast so a lot of Japanese moved to the East. So basically that's where we were born and bred--my brothers and sisters, and many cousins, so the extended family. But we were taught to assimilate into the Canadian culture. Basically we have no language except English. Japanese was spoken sporadically, like endearments. You know, how you use endearments in different languages? That was our basic exposure to the Japanese language...

Other than that, culturally we kept in touch only via food and certain activities. But there are certain basic family values that come out no matter what...

Certainly there was absolutely no question in our minds that it was a patriarchal family. That the men certainly had more dominance than the women. And that was interesting, especially since I believe I am a feminist and my sisters are too.

But my mother is an interesting individual because she is--was--the caregiver. The central caregiver--in terms of the way the family sees her--to not just her own family but to her nieces and nephews as well. My mother was very much seen as the caregiver.

I believe that [being the eldest daughter] probably had some impact, but by nature she is a very nurturing individual. And in many ways in her example--although she was very subservient--yet she was the one that instilled in my sisters and me the need for self-identity. And to seek our own professional identities as well, and equality too. Yet she has never lived in an equitable relationship herself.
Gail

Okay. Well I'm 50 years old. I'm the youngest of the four children that my Mom has. I have one brother who is the oldest and two sisters who are a little older than me. And I'm married. I'm a grandma. I've got kids of my own, and one daughter that belongs to my husband. And I belong to a Mennonite Brethren Church which is a big part of my life. And I have nieces and nephews that I like to see....

I grew up in Vancouver, and moved to the suburbs when I was 15. I graduated from school there and I went to College for a year and then I got married really young and had my four kids. And growing up in Vancouver was very different than it is now, you know. We used to go to Stanley Park for the whole day and Mom didn't worry about us. Rode our bikes out to the new mall....[laughs]

So we had lots of really free time. And I enjoyed school. I was in a choir in elementary school and high school, and at Church. So I had a pretty nice childhood and a pretty good life.

Lucy

I'm one of three sisters. My first sister was born in Italy and then 6 years later, I was born here. And we lived with my Aunt and my Uncle, and then we moved into our home--our own home--which was just a few blocks away. And when I was about 6 years old I moved in with my Aunt who is my Dad's sister (this is the lady that I looked after) and Uncle because they didn't have any children of their own. And he was married previously. He had 10 children from a previous marriage. So she came over here on proxy*, and was married that way, but she didn't know that he had these 10 children....Yeah, he told her that he was alone here in Canada. I don't know how many of his children were left there [at home when the Aunt came over from Italy]. I think there were four of them.

[You didn't grow up with them then?] No, not at all, they are all in their 70s--like my Uncle was quite a few years older than my Aunt. So they're the same age as my Aunt basically. She is 81 and so I grew up with her, and I lived with her for 17 years. So she is like my Mom. Yeah, my Dad and her are brother and sister.

My husband is Northern Italian. But I think my family is more traditional than his family. Like we're very traditional, whereas his family is Northern, and they're more Canadianized than we are.
Well, my parents...like we weren't allowed to go out. A very strict family....and we were not allowed to move out before we were married, that sort of thing....

Mike's family is more liberal. Like they are more Canadianized, where the kids could go out and do whatever they wanted and it was not a problem. But we were very traditional. We still go by the Italian traditions and that sort of thing.

I'm very proud to be Italian, very proud; and I would say I'm Italian Canadian.

My kids think that they're Italian too because both of their parents--my husband and I--are Italian. We were born here in Canada, so you're Canadian with an Italian nationality or tradition, you know? [laughs]

...my husband doesn't speak Italian or just very little. Like there is dialect from their hometown. Whereas I speak Italian [dialect] to my Mom and my Aunt, and I speak proper Italian too...because my parents didn't speak English. And my Mom still doesn't speak English very well and so we always just speak Italian.

*They had not met each other prior to marrying, only written letters back and forth. Some "friends of the family" made the arrangements.*
APPENDIX IV - Maclean's Conversation with Allan Rock

Maclean's: Do you think Canada can avoid a two-tiered health system?

Rock: I absolutely do. And I think the way we meet those who would have a private parallel system is to ensure there's never a market for it. We're very proud of our public health-care system, but we have to remember that it's not something that we can take for granted. Broad public support for the single-tier public health system isn't automatic; it will remain only as long as people can be confident they'll get the highest possible quality of care as and when it's needed. And I think that's part of a bargain governments have with the Canadian people. If we don't keep our part of the bargain we're jeopardizing support for medicare.

Maclean's: And are the federal and provincial governments keeping their side of the bargain?

Rock: I think both federal and provincial governments can do better. If you look at the pace of restructuring in some parts of the country, it has gone ahead quickly with hospital closings, for example. But governments haven't followed up with the reinvestment in community and home care where it's needed. Health care for people used to mean hospitals and doctors. But hospital stays are shorter now because of improved medical technology. It's possible to have abdominal surgery and come out the next day, whereas it used to be a two- or three-week stay. But when you come out you often need someone to change your dressing, to check your condition, to look after you in the home, at least for the period of your recuperation. The availability and quality of that care in Canada at the moment is uncertain.

Maclean's: The provinces who are responsible for delivering those services say they can't afford them.

Rock: Well, it's often said that these problems arise because of money. But maybe the better way of looking at it is: what kind of system do we want? And this gets us into the area of quality and standards. But, that being said, I have no doubt that we're going to have to modernize the system through home and community care....

Maclean's: What levers can Ottawa operate to encourage the province to improve home-care provisions?

Rock: Many provinces already have home care of one description or another, and a handful lead the way. As to what influence
Ottawa would have over the adoption of a standard approach to home and community care, I hope that is going to be worked out over the next 12 to 18 months. We will be developing some consensus about the importance of home and community care and how it might be furnished in accordance with standard definitions and common approaches. It has to be woven into the fabric of health insurance, just as physicians and hospital services are now. We also need an approach towards the quality of care. I see, for example, standardized training for homocare workers as an essential part of this. At the moment, that's not in place in many parts of this country....

Maclean's: When you talk of home care, what do you envision?

Rock: Home care could be anything from maintaining the house for an elderly person who is not able to do it, to someone who might drop in with meals, or a nurse practitioner coming by to take vital signs, right through to looking after someone who is recovering from acute care. And I should stress that I don't think home care can be looked at in isolation—it's tied into everything else. I can't imagine solving the home-care riddle without also resolving some of the pharmacare anomalies. You know if you're in the hospital in some parts of this country and you're taking chemotherapy, for example, you get the drug for nothing because it's covered by medicare. But if you'd rather be home during the course of your treatment, you have to pay, sometimes $2,000 per treatment. So I think all of these initiatives are connected.

Maclean's: How realistic is it to expect provincial co-operation on widespread changes to the health-care system?

Rock: In an area like home care I'm very optimistic. First, I think there's a broad and growing perception that it is needed. Second, many of the provinces have already started down that road. Third, acting in a co-ordinated fashion will give us an opportunity to make it a standard approach across the country. Fourth, there is the prospect of federal help in financing the plan. Finally, I think the provinces also acknowledge that with a properly developed home-care system they can save money in other parts of the health-care system.