"YOU CAN'T JUST LET HEALTH CARE HAPPEN": UNPAID CAREGIVING OF BRAIN INJURED SPOUSES IN A CONTEXT OF MARKETIZATION IN BRITISH COLUMBIA

by

Jennie Haw
B.Sc., University of British Columbia, 1995
B.S.W., University of British Columbia, 1999

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Name: Jennie Haw

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Examining Committee:

Chair: **Dr. Wendy Chan**
Associate Professor of Sociology

_____

Dr. Arlene McLaren
Senior Supervisor
Professor of Sociology

_____

Dr. Jane Pulkingham
Supervisor
Associate Professor of Sociology

_____

Dr. Deborah O'Connor
External Examiner
Associate Professor, School of Social Work and Family Studies
University of British Columbia

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ABSTRACT

Drawing on feminist approaches, this thesis utilizes in-depth interviews to examine unpaid caregiving of a brain injured spouse in a context of health care marketization in BC. In this context of decreasing public support and cuts to services, this study focuses on caregiving practices which emerge at gaps in health services at three sites: the hospital, accessing rehabilitation, and the community. Caregivers provide direct care in hospitals in response to inadequate healthcare, construct their spouses as "deserving" of scarce rehabilitation services, and provide care in the community with limited supports. Caregivers' advocacy care work is critical for gaining access to services and those with greater resources are better positioned to provide advocacy and other forms of care. Overall, gender influences the discourses caregivers draw upon to describe their caregiving practices. I conclude with a discussion of policy considerations which address some of the effects of marketization on unpaid caregiving.

Keywords: unpaid caregiving; gender; health care; policy

Subject Terms: Caregivers – Canada; Women – Canada – Social conditions; Canada – Health policy; Health care reform – Canada – British Columbia; Medical care – Canada

to my family

and the caregivers who shared their stories with me

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CHAPTER 1: INTRODUCTION

Introduction to the Study

This thesis is an exploratory examination of the unpaid caregiving practices of individuals caring for an adult family member with an acquired brain injury. My interest in this topic stems from my own personal experiences as a caregiver to my father who has severe brain injuries from a motor vehicle accident. Beginning from the place of my own personal experiences my interest grew to consider how caregiving is situated and practiced within a specific health care context for a diverse group of caregivers. Caregiving, or care work, covers a wide range of activities such as bathing and feeding to advocacy and emotional care. Unpaid caregiving is an important policy issue because of the growing numbers of people who require care in the community given an aging population and increasing numbers of people surviving injuries. Although unpaid caregiving is often very isolating and goes unseen, as inter-dependent members of a society it is an important issue for everyone since we will all give and/or receive care at times throughout our lives.

Currently in BC, unpaid caregiving is situated within a political and policy context based on the principles of neoliberalism, restructuring, and the marketization of health care services. By "marketization" of health care I refer to the increased reliance on the market for the provision of health services through privatization and cuts to publicly funded services, as well as the adoption of consumer and market logic in the administration of public health services. The result is a health care system focused on budgetary concerns which relies on stringent interpretations of eligibility criteria for services and measures outcomes in narrow quantitative terms. Formal health care services are therefore less able to meet the needs of care receivers and provide flexible support for caregivers. In addition, the BC health care system has not adequately funded the shift to caregiving in the community, whereby the responsibility and costs of care have been downloaded silently onto the shoulders of women and families. In this context of marketization and shift from public (shared) to private (individual) costs,

caregivers with greater resources are better positioned to provide long term unpaid care for their family members. An acquired brain injury is a particularly challenging disability for caregivers in this health care context given the often highly debilitating cognitive and physical impairments for those living with a brain injury and the long duration of care work required of caregivers.

Informed by feminist caregiving literature, this thesis specifically examines how unpaid gendered caregiving unfolds in practices as they interact with health care structures in this context of marketization in BC. I use the term "health care structures" broadly to include all forms of health care institutions, workers and professionals, and policies. By focusing on caregiving to a family member with a brain injury I am able to contribute to the body of feminist caregiving literature in two ways. First, grounding my analysis in a particular injury provides a level of specificity that is absent in much feminist caregiving literature. Second, because of the diversity in terms of severity of the brain injury and time of injury, brain injuries can provide a broad perspective on the type of caregiving practiced and variability amongst the caregivers. My sample of 6 participants includes 5 female caregivers and 1 male caregiver. The participants vary in terms of their age, ethnicity, economic resources, and gender. Brain injuries, therefore, while providing a specific (though not singular) grounding for caregiving practices and analytical examination also provide an opportunity to explore and include the experiences of diverse caregivers.

Lastly, I chose to focus on caregiving of a brain injured family member because this is what I know. In my own challenges in providing care and finding services for my father I was often frustrated by what I understood as a lack of options and health services available for rehabilitation and long term care. In spite of these challenges, I consider my father, and our family, to be one of the "lucky" ones. My father had the resources of private insurance (ICBC) and the benefits of professional employment at the time of his injury, and as his caregivers, my sisters and I had the resources of employment, physical health, education, and each other to share the caregiving responsibility. Even with these resources, caregiving was and continues to be a challenge. The marketization of health care only increases the caregiving challenges for individuals and creates greater disparity in accessing health services and supports between those who have resources and those who do not.

What is an Acquired Brain Injury?

An acquired brain injury[1] (ABI) is an injury to the brain that occurs post-birth and is not related to a congenital or degenerative disease (Lower Mainland Brain Injury Association Website). Acquired brain injuries can result from traumatic causes such as an external force to the brain (commonly categorized as a traumatic brain injury, TBI) or non-traumatic causes, such as a stroke or brain tumour. With advancements in medical technology, people are surviving acquired brain injuries in increasing numbers (Webb, 1998). Determining incidence and prevalence rates for acquired brain injuries is difficult given the lack of adequate documentation; however, extrapolating from statistical data in the United States, the Provincial document, *Guidelines for Planning Brain Injury Services and Supports in British Columbia* (BC Ministry of Health Services and Ministry of Health Planning, 2002), estimates that BC has an incidence rate of 7,800 to 14,000 new cases of an acquired brain injury each year. Of these acquired brain injuries the document estimates that about 6,000 new cases of traumatic brain injuries occur each year, with a 20% mortality rate leaving 4,800 new surviving TBI cases annually. The authors estimate that 1,432 to 1,862 of those with a traumatic brain injury will require rehabilitation services. These numbers do not include non-traumatic cases and therefore are underestimates of all ABI cases that will require rehabilitation. The authors point out that while these numbers may not appear to be high given the approximately 4 million people currently living in BC, brain injuries are nonetheless significant because of the high level of health care services and caregiving that survivors require following a brain injury.

Clinically, the severity of brain injuries ranges from mild to severe. In the hospital setting the severity is measured by physicians using the Glasgow Coma Scale, a standardized test used to measure brain impairment using eye opening, verbal response, and motor response. A Glasgow Coma Scale score of 13-15 indicates a "mild" brain injury; a score of 9-12 indicates a "moderate" brain injury; and a score of 3-8 indicates a "severe" brain injury (Glossary of Brain Injury Terms Website). The effects of a brain injury are extremely diverse and can range from mild to severe cognitive and physical impairments.

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[1] I use the terms "brain injury" and "acquired brain injury" interchangeably throughout this thesis.

Research Questions

To explore unpaid caregiving practices of an acquired brain injury in the context of health care marketization, I address the following questions in this thesis: What are the daily caregiving practices of unpaid caregivers to a brain injured family member in the current health care context in BC? How do these caregiving practices interact with health care structures? How do caregivers, through the discourse of their caregiving practices, negotiate for and access health care services?

Limitations of the Study

There are several limitations to this thesis. First, although my aim is to examine a diverse group of caregivers, I recognize that there is sample bias given that everyone who agreed to participate has the time and resources to enable them to do so. Also, all the caregivers in this thesis is a spouse (5 wives and 1 husband) to their care receiver which reduces the diversity in the familial relationship between the caregiver and care receiver. Second, this thesis only considers the interactions between caregiving practices and health structures from the perspective of the caregivers and not health care providers or care receivers. Lastly, this is an exploratory study and while I discuss health care policies and services generally I do not focus on a specific health care policy or service.

Outline of Chapters

The outline of the chapters in this thesis is as follows. In Chapter 2 I discuss contemporary feminist approaches which provide the theoretical framework for this thesis. I begin this chapter with a focus on debates within contemporary feminist approaches and follow this with a discussion of conceptualizations of care and forms of caregiving practices. In Chapter 3 I review the brain injury and caregiving literature and identify some of the limitations of the gender blind and individualistic approach of this body of literature. To address these limitations, I turn to a review of the feminist literature which focuses on caregiving, gender and policy. I discuss feminist research which debates the complex relationship between the state and state policies and women; how policies, with underlying gendered assumptions, construct the caregiver in specific ways; and the gendered effects of caregiving. Lastly, I turn to a review of the

literature that focuses on the interaction of caregiving (and care receiving) practices and health structures at the micro level. I focus on studies which illustrate the active practices of caregivers (and care receivers) in contesting and transforming dominant constraining health care discourses and examine the complex interactions between private and public care. In Chapter 4 I discuss the social, political and economic context of unpaid caregiving in BC. I focus on the principles of neoliberalism, restructuring and marketization underlying the health care system and provide a socio-historical overview of the health care system in Canada. I demonstrate how these principles, evidenced through cutbacks and privatization, decrease access to health services and result in downloading costs and responsibility of long term care to women and families.

I begin Chapter 5 with a discussion of feminist and qualitative methodology and follow this with an outline of the research and analysis methods used in this thesis. In Chapter 6 I present and discuss my analysis of the data. I illustrate how caregiving practices emerge at gaps in health care service at three sites: in the hospital, in accessing rehabilitation services, and in the community. I demonstrate the importance of advocacy care work in the current context of health care services in BC and discuss how those with greater resources are better positioned to access health resources and provide care. I also illustrate how gender influences the discourses caregivers draw on to articulate their caregiving practices given the gendered context of care. Lastly, in Chapter 7 I conclude with a discussion of the policy considerations that emerged from the data and analysis which address some of the effects of the marketization of health care on unpaid caregiving and propose areas for future research.

CHAPTER 2: THEORETICAL CONSIDERATIONS

Introduction

The critical study of caregiving emerged with the rise of second wave feminism and feminist scholars during the 1960s and 1970s. Beginning with this early period of critical caregiving research, feminist theories have contributed to understanding the gendered and engendering nature of care work. Drawing on the contribution of feminist thought to caregiving research I apply contemporary feminist approaches to this thesis. Specifically I focus on intersectionality and feminist post-structuralism[2] since they are most relevant to this particular study. Contemporary feminist scholars apply the term "intersectionality" differently and conceptualize the relationship between intersectionality and feminist post-structural approaches in different ways. On the one hand, Mann & Huffman (2005) refer to intersectionality theory as largely synonymous with Black feminist theory and therefore conceptualize intersectionality theory and post-structural feminist approaches as two distinct streams within what is commonly referred to as "third wave feminism". On the other hand, McCall (2005) uses the term intersectionality more broadly, as a general paradigmatic shift from the singular "gender" approach of previous feminisms. McCall (2005) argues that within intersectionality there are those in the Black feminist or identity politics stream and those in the post-structural stream. I have organized my discussion according to the approach by Mann & Huffman (2005) for two reasons: first, the term "intersectionality" arose in Black feminist writing and remains closely associated with this particular stream of feminist theory; and second, by organizing intersectionality and post-structural feminist approaches as two separate streams I am able to present some of the ongoing debates regarding the differences and similarities in these two approaches with greater heuristic clarity. In this chapter I outline some of the critiques of earlier feminist theories from which contemporary feminist approaches arose; discuss some of the ongoing debates and tensions within

contemporary feminisms; and provide the ontological, epistemological and methodological approach of this thesis. Following this theoretical discussion I provide an overview of feminist debates regarding conceptualizations of care and caregiving practices.

Contemporary Feminist Approaches

Intersectionality Theory

Intersectionality theory emerged in the 1980s as a critique of the white, heterosexist, and middle class assumptions of second wave feminism[3] (Mann & Huffman, 2005; McCall, 2005). While second wave feminisms (liberal, radical, and Marxist[4]) varied, they largely reflected the concerns and experiences of a single group of women – White, heterosexual, middle class women – as the experiences of all women.

Black feminists and women of colour in the United States began to critique the homogenizing assumptions of mainstream feminists in the late 1980s and early 1990s which dealt only with gender oppression at the exclusion of other dimensions of oppression such as race, class, and sexual preference (for example, Crenshaw, 1991; Hill Collins, 2000). They argued that women of colour and poor women experienced oppression at the intersections of their gender and race or gender and class differently than White, middle class women.

Hill Collins (2000) defines intersectionality as referring to "particular forms of intersecting oppressions, for example, intersections of race and gender, or of sexuality and nation. Intersectional paradigms remind us that oppression cannot be reduced to one fundamental type, and that oppressions work together in producing injustice." (p. 18). McCall (2005) argues that rooted in the ideas of Marxist or socialist feminism, intersectionality is focused on emancipation and structural oppression. However, as

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[2] There is ongoing theoretical debate amongst feminist scholars regarding categorizing, organizing and labelling feminist theories and I do not argue that these are the only two streams of contemporary feminist approaches; however, I limit my discussion to these for the purposes of this thesis.

[3] Mann & Huffman (2005) discuss the limitations around the use of the unifying term "wave" to describe different moments within feminism. For example, they present the critique that characterizing and describing feminism according to "waves" tends to exclude marginal feminist voices from the dominant ideas characterizing a particular "wave". However, they use the term arguing that it is useful in characterizing the ebb and flow of mass feminist movements during a particular historical period.

[4] For a review of the earlier streams of feminism refer to Bryson (1992).

quoted by Hill Collins (2000) above, intersectionality theorists argue that oppressions cannot be separated from one another, are not additive, and emphasize the particular social location in which each person is located. Intersectionality theorists, then, have taken their critique of the narrow categorization of women put forward by second wave feminists and have responded by claiming that gender oppression must include other intersections of difference. In other words, different women and men occupy diverse and specific social positions depending on their unique intersections of gender, race, class, age, and sexual preference. Intersectionality theorists argue that people are categorized differently based on their social position and they argue for the use of *categories* in social science research and as a critical component of identity politics (Hill Collins, 2000; Mann & Huffman, 2005).

Feminist Post-Structural Approaches

Post-structural feminist approaches also emerged as a critique to the narrow definitions and homogenizing experiential claims of second wave feminists (Mann & Huffman, 2005). Informed by the work of post-structural theorists such as Foucault, post-structural feminist approaches dismantle and reject the notion of a unified structural basis of oppression. Instead these approaches view power as inherently relational, emanating from everywhere, and exercised by all individuals and institutions. Post-structural approaches do not assume a power hierarchy bound within an immutable structure (since power can be exercised in all ways and not necessarily top-down) and instead focus on the distinction between dominant discourses which are centred – therefore, central in shaping and structuring ideas and practices – and those discourses or voices on the margins. Individuals within these power relations are both limited by dominant discourses as well as have the agentic ability to transform dominant discourses. The emphasis in feminist post-structural approaches therefore is not in emancipation of the oppressed, but in transformation and in bringing marginal voices into the centre (Mann & Huffman, 2005). Intersectional theorists critique post-structural feminisms for "flattening" the power hierarchy (Hill Collins, cited in Mann & Huffman, 2005).

A second key difference between post-structural approaches and intersectionality is their positions on the use of *categories*. While intersectionality theorists argue for the usefulness of categories as a platform for political movement, post-structural feminists

dismantle categories by challenging their underlying homogenizing assumptions. Post-structural feminists have also deconstructed and challenged the meanings and definitions of the categories "woman/feminine" and "man/masculine" as socially constructed labels attached to dominant images and binary categories of sex and gender. I take the position that while these labels are socially constructed, they are embedded in social institutions and have pervasive influence in organizing social life and activities. For example, powerful discourses which reinforce socially constructed gender categories are evidenced in the disproportionate number of women who are unpaid caregivers relative to men. Therefore theorizing the position of women relative to men is central in the feminist literature on caregiving. As such while I recognize the socially constructed nature of these terms I maintain the use of the categories "woman" and "man" in this thesis. I agree with Neysmith (2000) who argues that while categories may be useful on a macro political level, they are less useful at the micro individual level. At the political level, the organization of "unpaid caregivers" as an identifiable category has certainly increased their visibility on the political and policy landscape. However, there is a constant tension between the tendency towards homogenization of this identifiable category of people and the real diversity amongst individual caregivers. For this particular study, while I focus on selecting a diverse group of caregivers I do not consider them as representing any particular category of caregiver, but rather as contributing to an understanding of the range of caregiving experiences in BC and centring marginal discourses.

Commonalities between Intersectionality and Feminist Post-Structural Approaches

As discussed there are ongoing debates between intersectionality and feminist post-structural approaches in terms of their conceptualizations of power and their use of categories. Mann & Huffman (2005) argue however that these two approaches share common ontological, epistemological, and methodological ground. Mann & Huffman (2005) suggest that both approaches emphasize "difference, deconstruction, and decentring." (p. 57). While intersectionality theorists use difference and emphasize categories to assert political rights based on their specific identities, post-structural feminists use differences to deconstruct categories (Mann & Huffman, 2005). According to Mann & Huffman (2005) ontologically both these approaches assume the social construction of knowledge and recognize that all knowledge producers and knowledge

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claims are partial. Both reject the idea of a meta-narrative or meta-theory and instead focus on understanding the specific and detailed context of what is studied. Epistemologically they both elevate, or bring to the centre, knowledge from sources that had previously been considered deficient or marginal vis-à-vis dominant sources or discourses. In this study, I bring diversely located, unpaid caregivers into the discourse on health care. Lastly, the methodological implication of socially constructed and partial knowledge is that the subjective position of the researcher is also involved in the data generation process and knowledge construction. Rather than aiming for an "objective" position the researcher acknowledges her role in the research process and aims to consider her own assumptions and subject position throughout the research process.

Discourse

As the two theoretical approaches – feminist intersectionality and post-structuralism – focus on the social construction of knowledge, they emphasize its discursive and shifting character. As with most concepts, the meaning of "discourse" has shifted and been debated within and between different disciplines and different streams of post-structural scholars. Because social science research uses the term "discourse" broadly, I review three definitions of discourse used by feminists and care theorists that are relevant to my research.

A large body of theoretical and empirical research considers how dominant and powerful discourses in society shape and organize individual lives and how these discourses are contested and transformed. Although the more extreme forms of post-structural or post-modern thought may deny the existence or role of a material reality, many feminist post-structural scholars challenge this. In her study of immigrant paid care workers, Solari (2006) for example, demonstrates how discourses are bound in a specific material reality. She argues that discourses are not language per se, but structures of statements that are based in a specific *material reality* and then taken up and reproduced by individual and institutional practices. Smith (2005) includes textual material in her discussion of discourse and pays particular attention to the *textually-mediated* discourse of institutions and their ability to regulate individual and institutional practices across time and space. Lastly, Neysmith (2000), writing about restructuring and care work, defines discourse as "not a thing or talk; it is performed and practiced... it refers to particular ways of talking and writing about, but also doing or performing, one's

practice" (p. 15). Neysmith (2000) emphasizes the performative or practice dimension of discourse; in other words, discourse refers also to the *practices* of how we conduct our everyday lives. Bringing these ideas together, I conceptualize discourse as including verbal, textual, and performative forms and as structured within a material reality.

Conceptualizations of Care

Having reviewed and highlighted some of the salient characteristics of contemporary feminist approaches, I turn now to a review of some of the key features of how care has been conceptualized and theorized. Feminist scholars involved in the initial caregiving studies of the 1970s sought to find a place for caregiving research within existing theoretical frameworks. Much of this research and analysis was framed by a conceptual division between the private (home) and public (market) arenas. The home as a private arena was largely excluded from social scientific research along with work that was associated with this private domain. To address this exclusion of women and women's work, the emphasis for early care theorists included the gendered division of caregiving labour in the home and its role in social reproduction (Graham, 1983); the gendered ideological and psychological association of caring with women (Gilligan, 1982; Graham, 1983); and the influence of gendered state policies on caregiving and women's labour market participation (Ungerson, 1983). Studies broke down the concept of "care" and conceptualized it as involving both an affective or "love" component and a practical or "labour" component – care work– (Graham, 1983) with an emphasis on the latter component by most feminist sociologists.

These early care studies have been criticized for focusing on the experiences of White, middle class, heterosexual women (Neysmith, 2000). Early care theorists themselves took up the critiques by Black feminists and expanded their examination of care work to include issues of race and class. For example, Graham (1991; 1993) argued that the concept of care that care theorists in the UK had been using – unpaid care provided to kin in the home – was too narrow and did not include the experiences of Black women or working class women who often worked as paid caregivers in the homes of more privileged White women. In light of this exclusion, Graham (1993) argues for the expansion of the concepts of caregiving and "woman" and rejects the notion of a unified homogenous feminist position on complex issues such as community care. Graham (1993) concludes that the feminist perspective on caregiving must

maintain a tension and complexity which recognizes the conflicted, competing, and often irresolvable positions that exist between women rather than aiming for one unified position.

Thomas (1993), on the other hand, argues for a unified concept of care in order to address previous forms of care that studies had excluded. In deconstructing how research conceptualized care, Thomas (1993) examines the work by Graham and Ungerson and argues that both of their concepts of care were partial and largely shaped by their particular research focus – social reproduction in the home for Graham and reduction of exploitation of women by policy for Ungerson. Thomas (1993) reviews how the research literature conceptualized care and identifies seven dimensions to the concept of care: 1) the social identity of the caregiver; 2) the social identity of the care receiver; 3) the interpersonal relationship between the caregiver and care receiver; 4) the nature of the care; 5) the social domain of the caring relationship; 6) the economic nature of the care relationship; and 7) the institutional setting where the care is delivered. A unified concept of care, Thomas (1993) argues, can include all forms of care work. She also concludes that the epistemological status of the concept of "care" is empirical rather than theoretical, similar to the concept of "housework".

Celia Davies (1995) also reviews the caregiving literature to examine how care theorists define the concept of care. In contrast to Thomas (1993), she argues for the use of different terms to describe different forms of care rather than a singular unified term. She distinguishes between "caregiving", "care work", and "professional care" based on the dimensions of remuneration and training. According to Davies (1995), "caregiving" refers to unpaid care provided by family or friends; "care work" refers to paid care provided by workers who have received little or no formal training (e.g. home support workers); and "professional care" refers to paid care provided by formally trained workers with established standards (e.g. nurses).

More recently, contemporary feminist researchers challenge the ways in which language constructs "caregiving" and "care work" knowledge. Litt (2004) argues for a "strategic imprecision" (Litt, 2004, p. 627, citing De Vault, 1999, p. 81) in describing or labeling women's work in the home. By adopting a strategy of imprecision and interchanging the terms, she argues that we can challenge our understanding of the complex activities that the labels represent. Litt (2004) argues this explicit imprecision is

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important considering the complex nature of care and the inadequacy in the terms used to describe it. For example, the terms "caregiving" and "care work" obscure the gendered nature of care and the emotional work also involved in providing care. In other words, while earlier feminist theorists made a distinction between the "labour" and "love" aspects of care, researchers now recognize the need to integrate both in theorizations of care. In this thesis, I take the position of Litt (2004) and use the terms "caregiving", "care work" and "caring" interchangeably.

Forms of Caregiving Practices

In addition to various theories of care, researchers have also considered the multiple practices involved in caregiving; in other words, what people do when they provide care. In her study of mothers caring for children with disabilities, Litt (2004) distinguishes between direct care work and advocacy care work. Direct care work "involves the interventions, routines, and patterns related to the actual care of the [person]" (Litt, 2004, p. 628). The rehabilitation and gerontology literatures generally refer to direct care work required to assist an individual in the Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Levine, Reinhard, Feinberg, Albert & Hart, 2003). ADLs include: bathing, dressing, using the toilet, transferring, continence, and feeding (Levine, et al., 2003). IADLs supplement ADLs and include: shopping, cooking meals, housework, laundry, money management, transportation, using the phone, and taking medication (Levine, et al., 2003). Levine, et al. (2003) argue that these conventional definitions of caregiving practices are insufficient in capturing the additional work, such as securing and coordinating health services, that caregivers do.

Litt (2004) defines this additional work as advocacy care work: "work that attempts to create resources, recapture resources that had been lost, and/or correct for problems in those services currently in hand" (Litt, 2004, p. 628). For the women in Litt's (2004) study, advocacy care work emerged in a context of diminishing state resources in the United States. According to Litt's (2004) definition, advocacy care work is broad and includes: pursuing and seeking out services; seeking out information and asking questions; and mediating between health care providers and the care receiver. In addition, Traustadottir (1991) includes political advocacy for caregivers and care receivers as care work. She argues that advocacy care work extends outward from

direct caregiving at the individual level to political activism at the community level (Traustadottir, 1991).

Lastly, a third form of caregiving practice that research has begun to emphasize as a dimension of care is emotion care work. While it was previously excluded from the "work" aspect of care, researchers now recognize emotions as work and include it as a form of care. Clarke (2005), in her study of fathers who provide care for their children with cancer, defines emotion care work as: observing others, dealing with stress, dealing with their own emotions, evaluating personal philosophy of life, and changing priorities. While I have distinguished between the different caregiving practices all three forms are inter-related and overlap. Caregivers often engage in multiple caregiving practices in order to complete a single task (Levine, et al., 2003).

CHAPTER 3: LITERATURE REVIEW

Introduction

In this chapter I begin with an overview of the caregiving and brain injury literature and follow this with a review of some of the major themes in diverse bodies of literature which present a critical perspective on caregiving, gender, and policy. I have organized the second part of this literature review around two levels: the macro scale of caregiving and policy and the micro scale of everyday caregiving practices. At the scale of caregiving and policy I review feminist policy literature that present critiques of general state policies and long term care policies. At the scale of everyday practices I draw from gerontology, mothering and disability, community care, and social geography literatures which examine caregiving practices and interactions between individuals (caregivers and care receivers) and health care structures.

Review of Caregiving and Brain Injury Literature

Epidemiological research in Canada indicates that the majority of people with traumatic brain injuries[5] are young males (age 18-49) and elderly males (age 75 and older) (Zygun, Laupland, Hader, Kortbeek, Findlay, Doig & Hameed, 2005), findings consistent with studies in the United States (Sinnarkaruppan & Williams, 2001) and the UK (Webb, 1998). Because brain injuries are gendered in their disproportionate impact on men than women and family members most often provide long term care, it is unsurprising that wives and mothers predominate as long term caregivers to family members with a brain injury (Sinnarkaruppan & Williams, 2001). The severity and effects of a brain injury are extremely diverse and can range from minor to profoundly debilitating cognitive and physical impairments. Florian & Katz (1991) argue that brain injuries are unique in that the combination of the resulting cognitive, physical, and social impairments is more severe than any of the individual impairments on their own.

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Acquired brain injuries also differ from other cognitive disorders and forms of dementia, such as Alzheimer's, because they tend to strike at younger ages and therefore caring for a person with a brain injury often requires a much longer period of intense care work (Grubbs, 2003). The combination of the complex care needs of brain injury survivors together with the extended timeline for care places a great deal of responsibility and pressures on family caregivers.

As a result, research on unpaid caregivers for brain injury survivors focuses largely on understanding the physical, social, and psychological effects of caring for a family member with a brain injury and in assessing objective and subjective caregiver burden. These studies generally concur that caring for a brain injured family member results in negative effects for the caregiver and family both in the short term and over time (Kolakowsky-Haynor, Miner & Kreutzer, 2001; Marsh, Kershel, Havell & Sleigh, 1998a; Marsh, Kershel, Havell & Sleigh, 1998b; Nabors, Seacat & Rosenthal, 2002). Researchers find that caregivers of brain injured family members report worse physical health than the general population (McPherson, Pentland & McNaughton, 2000), have more role changes than non-caregivers (Frosch, Gruber, Jones, Myers, Noel, Westerlund & Zavisin, 1997), report feelings of depression and anxiety (Marsh, et al., 1998a; Marsh, et al., 1998b), have less free time and increased financial pressures due to decreased or termination of employment in order to provide care following the brain injury (Wallace, Bogner, Corrigan, Clinchot, Mysiw & Fugate, 1998) and experience social withdrawal and isolation (Acorn, 1995). In general these studies identify negative effects; however, Machamer, Temkin & Dikmen (2002) consider both the positive and negative effects of caregiving and write that many caregivers report feeling happy that they are able to provide care and spend time with their brain injured family member. The authors are quick to point out however that feelings of happiness do not eliminate caregiver stress and burden. Knight, Devereux & Godfrey (1998) also report that caregivers' find their caregiving work as uplifting and consider their ability to face adversity as a positive effect of caregiving.

In examining the negative psychosocial effects, such as stress and anxiety, reported by caregivers, these studies consider the "subjective burden" felt in response to the "objective burdens" (such as changes in lifestyle and behaviours of the brain injury

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[5] Epidemiological studies focus on TBIs rather than ABIs because better hospital records are available for TBIs.

survivor) of caregiving (Katz, Kravitz & Grynbaum, 2005). Researchers find that perceived caregiver burden has the strongest positive correlation to behavioural and emotional changes in the brain injured survivor (such as depression, anger, rapid mood change, anxiety, and aggression) rather than physical changes of the injured or severity of the injury (Knight et al., 1998). Studies also indicate that perceived caregiver burden increases with greater unmet caregiver needs and that caregiver needs change and expand over time (Murray, Maslany & Jeffrey, 2006; Nabors, et al., 2002). In their review of studies of brain injury and caregiver burden, Sinnakaruppan & Williams (2001) report that caregivers' needs include (but are not limited to): detailed and specific health information regarding their brain injured family member and future prognosis, caregiver support and time for themselves (through respite or day programs for the brain injured person), financial and legal assistance and information, and to have hope of improvement. The most highly ranked needs across studies involve receiving information and most unmet needs are in the area of receiving emotional support. Interestingly, these studies also report that while caregiver needs expand (both in numbers and in type) over time these needs are less likely to be met as acute and community services retract over time (Murray, et al., 2006; Sinnarkaruppan & Williams, 2001). This results in greater unmet needs and increased burden in the long term for caregivers who are dealing with an injury that is characterized by its long term nature.

Few studies in this body of brain injury literature consider how demographic features of the caregiver such as race, gender, and socioeconomic status influence the effects, burdens, and needs of caregivers. The sample of participants in most of these studies is primarily White women. While many researchers outline the demographic profile of their participants, in most cases they do not provide further analysis involving these factors. Nabors, et al.'s (2002) study, which specifically examines how demographic features influence caregiver burden and family needs, is an exception. Their study includes the reports of Black and White American caregivers and shows that higher income levels are correlated with lower levels of caregiver burden, younger caregivers have more unmet needs than older caregivers, and greater unmet needs and lower levels of education are correlated with higher levels of burden. In regard to race, Nabors, et al. (2002) report that their sample of Black caregivers had lower levels of education than the White caregivers and whereas their sample of White caregivers was equally split between spouses and parents the Black caregivers were parents and other

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family relatives. While Nabors, et al. (2002) identify these differences they do not provide any further contextual examination of these differences.

Critique of Caregiving and Brain Injury Literature

A critical examination of the caregiving and brain injury literature exposes several limitations of these studies. First, methodologically, the vast majority of these studies are based on quantitative survey methods with a focus on generalizability. Many of the studies are based on mail out questionnaires using "standardized" scales as measures with relatively low return rates. These types of mail out surveys place limits on the type and form of information they generate, particularly when dealing with difficult and complex concepts such as "distress", "needs", and "functioning". Quantitative survey methods are less able than qualitative methods to address complex concepts and to capture meaning and process. Also, with the relatively low rate of return, mail out questionnaires have significant implications for sample bias. For example, given that most questionnaires are written in the dominant language (in most cases English) this excludes those who are less comfortable with reading and writing in English from participating.

Secondly, the caregiving and brain injury literature focuses primarily on the individual or individual family unit and lacks an examination of contextual and structural factors. The aim in many of these studies is to focus on the individual in order to build capacity within the individual and family unit. This reinforces the ideology that the individual caregiver or family is responsible for shouldering care work themselves with a shared public responsibility as only supplementary. Extensions outward from the family into the community for services – such as respite, community support groups, or day programs for people with brain injuries – are presented as means to strengthen or prolong the caregiver's ability to continue providing care. These studies generally preclude any debate regarding the role of the state in sharing the responsibility of care work and in addressing structural inequalities that differentially affect diverse caregivers. Discussions of the effects of caregiving or their ability to cope with the subjective and objective burdens of caregiving are undertaken with the absence of any consideration of the relationship between their caregiving and other forms of work and responsibilities in their lives and without consideration of larger social, political and economic factors.

Lastly, this body of literature generally lacks a critical gendered analysis of caregiving. While many studies report that the majority of caregivers in their sample are women (wives or mothers) they do not consider gender in their analysis. The absence of a gendered analysis is particularly noteworthy given that brain injuries occur more often in men than women and therefore result in more female caregivers. This critique is consistent with that of Hooyman & Gonyea (1995) who, in their review of caregiving literature, write that the majority of research on caregiving and disabilities does not consider gender as reflected in their choice of words and labels. The language used in caregiving and brain injury studies also reflects this gender blind approach in at least two ways. First, by having "the family" as the unit of analysis, this obfuscates and makes invisible the differences between family members in terms of their relative position in the family and the care work that they do. Feminists argue that the family is not a neutral, uniform unit, but is composed of power relations between members who are positioned differently within the family. In other words, using "the family" as the unit of analysis makes invisible the work of the mother or wife[6] who has had to disproportionately bear the cost of caregiving[7]. Secondly, by using gender neutral terms such as "spouse", "significant other", "relative" and "parent" rather than "wife", "husband" and "mother", gender is erased from the analytical landscape and makes invisible the care work done by women[8]. The literature on caregiving and brain injury does not consider the role of policy or power relations in organizing and mediating caregiving work. In order to address these gaps in the brain injury literature, I turn now to caregiving research which provides a critical and contextual analysis of caregiving work.

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[6] Here I refer only to "mother" and "wife" because research indicates that the majority of people with brain injuries are male and because the majority of respondents in the studies that I have reviewed are mothers or wives. I do this to emphasize the lack of gendered visibility in these studies and not to argue that no men provide care (or that no other person besides mothers and wives provide care) in the family.

[7] While I apply this feminist critique to this body of caregiving studies, I recognize that feminist caregiving literature has also neglected the minority voice of male caregivers. Therefore, I include a male caregiver, a husband, in this thesis in order to address this gap in the feminist literature.

[8] My critique of the use of these terms is in response to their use in maintaining a gender blind approach in caregiving research. I do not argue against using these terms entirely since they may be appropriate terms and used for brevity (e.g. I use the term "spouses" in the title of this thesis rather than "husbands and wives"), as long as the overall effect is not to erase gender from the analysis.

Review of Feminist Caregiving Literature

Caregiving and Policy

State policies and services play an important role in modern welfare states, such as Canada, by organizing many aspects of social life and by providing a means of indirect governance of the population (Garland, 1997). In other words, state policies are a means by which the state interacts with and organizes how caregivers conduct their everyday lives. In Canada, political and policy discussions are increasingly paying attention to unpaid caregiving, largely as a result of the current demographic trend towards an aging population and heightened political awareness of the long term care needs of this growing segment of the population. For example, caregivers were included in the 2002 Romanow Report on the Future of Health Care in Canada, a federal Minister of State for Families and Caregivers was announced in 2004, and Canadian policy makers are participating in national discussions around caregiving policy (Canadian Policy Research Networks Inc., 2005). While the inclusion of unpaid caregivers in policy matters is valuable in raising the visibility of caregivers, feminist researchers have also examined how this increased visibility in state policies also unfolds in gendered ways.

Feminist theorists have critiqued policy provisions and their distribution schemes in general for their gender bias (such as policies that attach social security benefits to labour force participation but not to domestic labour) and specifically have deconstructed and made visible the language and ideological assumptions underlying caregiving policies and their gendered implications. More generally, feminist theorists debate the contested relationship between women and the state. For example, theorists argue that while on the one hand, many women depend on state policies for economic security; on the other hand, these same state policies institutionalize women's poverty (Fraser, 1989). A similar tension also exists in the caregiving and policy literature. On the one hand, feminists argue that the state is withdrawing from its responsibility in providing long term care and press for greater state involvement (for e.g. Armstrong & Armstrong, 2004; Neysmith, 2000); while on the other hand, feminist researchers demonstrate how the state continues to regulate forms of caregiving by attaching benefits (e.g. economic benefits through tax credits) to fit certain models of a "caregiver" more than others thereby constructing caregivers in specific ways (Fincher, 1993; Heaton, 1999; Henderson & Forbat, 2002). In what follows I focus on how state policies construct the

unpaid caregiver. In the next chapter I discuss the historical shift in state withdrawal and its implications for caregiving.

State policies construct the unpaid caregiver as a subject through the creation of policies which deal specifically with the unpaid caregiver (Dean & Thompson, 1996; Heaton, 1999) and shape the caregiver in specific ways through underlying ideologies (Hooyman & Gonyea, 1995; Hooyman & Gonyea, 1999). Heaton (1999) applies a Foucauldian genealogical approach to trace the emergence of the unpaid caregiver in UK policy. She argues that unpaid caregiving became visible following a shift in meaning of "community care" from "care *in* the community" to "care *by* the community" with an extension of the medical gaze from the hospital to the larger community. In other words, the focus in meaning of "community care" shifted from the location of care to the identity of the caregiver. Dean & Thompson (1996) argue that the construction of the unpaid caregiver in community care policy also marks a shift from moralization to normalization as a form of personal regulation; providing long term care for family members is now constructed as the "normal" rather than the "moral" thing to do.

The idea of the "normal", or "natural", family is also promoted by the ideologies of familism and separate spheres which underlie community care policies (Hooyman & Gonyea, 1995). The ideology of familism is based on a two parent, heterosexual family model which assumes that one adult (normally the wife) is able and willing to provide free caregiving labour in the home. The ideology of familism constructs the "normal" family as autonomous and always the primary source of care. Therefore, according to this ideology, only when the family's resources are depleted should the state step in to provide temporary short-term assistance (Hooyman & Gonyea, 1995). Based on this model of the family, care policies do not generally provide economic provisions for caregivers since it is assumed that the main source of income is provided by a male breadwinner. The ideology of separate spheres organizes the private and public spheres of society and affirm women's role in the private/domestic sphere as "natural" caregivers while men's role is in the public marketplace (Hooyman & Gonyea, 1995). In addition to these ideological assumptions, Fincher (1993) adds that the state assumes a certain model of the caregiver based on life course/social norms and designs its policies according to this model. She argues that state policies, as they relate to social reproduction, intervene at specific times during the life course to normalize life transitions at specific points. Policies assume "caregivers" refer to women as mothers of

young children and wives in heterosexual couples and provide "rewards" through the provision of services and tax breaks to those who fit those models. These same policies "punish" those caregivers, such as women or men caring for dependent adults, who do not fit this "ideal" model through an absence of appropriate servces and tax breaks.

Caregiving, Gender, Class and Race

Many empirical studies indicate that unpaid caregiving to the frail elderly and dependent adults is gendered work. According to Morris' (2004) review of 45 home care studies, women provide more hours and more demanding forms of care than men, receive less hours of care than men, and experience more negative health effects and greater disruptions to their daily lives because of their care work than men. Men often provide care only if there is no other female family member to provide care and the type of care work that they do provide tends to follow traditional gender lines such as assisting with yard work or managing finances. Studies based on Canadian GSS 2002 data indicate that women provide more hours of care work per week than men to the elderly (Stobert & Cranswick, 2006), employed female caregivers provide higher intensity care work than their male counterparts, experience greater stress balancing their paid employment and care work, and are more likely to decrease their hours of employment because of care work (Pyper, 2006).

The economic costs associated with caregiving differ for women and men. While both women and men pay the direct costs of caregiving, such as purchasing medical supplies, women experience greater long term, or indirect costs of caregiving than men (Morris, 2004). These indirect costs are associated with women's diminished labour force participation and include loss of wages, benefits, and pensions as women reduce or leave their paid employment in order to provide care to a disabled family member (Hooyman & Gonyea, 1995; Morris, 2004). Caregiving is more likely to disrupt women's paid employment than men's and thereby increase women's economic insecurity (Morris, 2004).

While the emphasis in feminist caregiving research has been gender, feminist researchers have also considered differences in other dimensions such as socioeconomic status and ethnicity on caregiving work. In her study of mothers caring for children with disabilities, Traustadottir (1991) illustrates how differences in class, education and economic resources influenced how women spoke about their caregiving

work. Women from lower socioeconomic positions spoke of their caregiving work as "part of life" whereas women from higher socioeconomic positions spoke of their care work as "empowering" or "disruptive". Traustadottir (1991) argues that an attitude of passive acceptance expressed by women with lower economic and social resources is not because they care less about their children, but because it is one more challenge in their ongoing struggles to secure food, housing, and other basic necessities. Spitzer, Neufeld, Harrison, Hughes & Stewart (2003) examined the experiences of immigrant female, unpaid family caregivers specifically at the intersections of gender, care work, and migration/ethnicity. They suggest that immigrant women are responsible for transmitting cultural values and therefore less able to renegotiate their caregiving work in spite of disrupted family networks and increasing demands. The immigrant women in their study also had limited economic resources and therefore they combined paid work with their care work in order to contribute to the household income.

Caregiving Practices

The studies that I review in this section examine caregiving (and care receiving) practices at the micro level and are drawn from a broad range of literatures including gerontology, social geography, community care, and mothering and disability. Research on home care has considered the importance of place or space in caregiving. Wiles (2002) focuses on place, or location, as an integral feature in constructing the unpaid caregiver and caregiving experience. She highlights the importance of incorporating place and space in understanding care work and the caregiver's identities. "Those caring for an increasingly dependent, frail, or ill senior have to renegotiate their identities and activities in relation to place as the nature of the caregiving role changes" (Wiles, 2002, p. 1308). Caregiving in the home transforms the space from a "private" to a "public" arena when paid home care is brought in to provide care on private bodies in what is normally socially constructed to be private rooms (such as the bedroom or bathroom). When public health care services enter the private spaces of the home, these spaces become contested spaces as family caregivers negotiate time and space with paid workers. Wiles (2002) demonstrates how caregivers organize their daily routines, mobility, and space around the needs of the care receiver and how the mobility restrictions of the care receiver affects the caregiver's use of space and time. She illustrates how caregivers with more financial resources are better able to negotiate and

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find alternatives to enhance their mobility and routine. As care is brought into the home, the caregiver's identity is shaped by the work they do in the home and by the changing meanings of the spaces within the home.

Dyck, Kontos, Angus & McKeever (2005) also consider the changing meaning of place and space as health care restructuring brings long term care into the home space. In their study they illustrate, through the narratives of adult recipients of paid home care services, how meanings of home and body are negotiated and co-constructed through recipients' interactions with their paid caregivers. These interactions are an example of an interface between private individual practices and public health structures. The authors write that for these care recipients access to home care services is the result of their categorization as "in need" and "deserving" according to health care policies and professionals. Expert biomedical, or formal, knowledge enters into their experience of their home and body at points of physical and social vulnerability. For example, biomedical knowledge intersects with their private spaces when they need specific wound care following surgery or in limitations in their ability to be identified as someone other than "disabled". The narratives demonstrate how with increasing physical and social vulnerabilities centred in the home rather than in medical institutions private home space is transformed to public medical care space. In other words, this transformation increasingly blurs the boundary between the "private" and "public". This study highlights the interactive and co-construction of meaning which emerges through the caregiving and care receiving relationship and the agency of the care receivers in negotiating and contesting biomedical discourses of their body and home space.

Angus, Kontos, Dyck, McKeever & Poland (2005) conceptualize the home not only as a physical and social space, but also as a field with its own distinct logic, rules, and practices. For example, the authors describe how individuals apply a distinct logic and practices in the home to create a particular aesthetics by using decorative features, smell, and orderliness which are associated with a feeling of being "at home". The aesthetics of each home is associated with the particular social position of the people who live in the home. When paid home care services are brought into the private spaces of the home, the logic and practices of the health care field are transposed onto the domestic field and disrupt the aesthetics of the home. Angus, et al. (2005) consider how care receivers of long-term home care are positioned and active within this shifting field of the home negotiating the imposition of this new set of logics and rules. The

researchers argue that cutbacks in healthcare services leave more of the responsibility of negotiating the space onto the participants. How well participants are able to maintain order in the home according to domestic logics in spite of their disability and the imposition of health care logics depends on their economic resources and financial wealth. The negotiation of whose standards of cleanliness or how the house was maintained is done within power relations established through health care policies; most care receivers are in a weaker position because they are dependent on rationed state provided services. The transposition of logics and the negotiation between care receiver and worker result in a hybridity of home spaces and activities and logics in long term care.

Brotman (2002) examines the interaction between ethnic elderly care receivers and health care structures in a context of diminishing community care services in Ontario. She argues that with government cutbacks in health care funding to community care there is greater rationing and targeting of services. The result is a tightening of the criteria to determine who fits the categories of "need" and "risk" and allocating scarce resources to only those who meet the stringent interpretations of "in need" or "at risk". In this context, Brotman (2002) illustrates how case managers' (i.e. those who are 'gatekeepers' and assess eligibility for services) assumptions about family support in ethnic minority families leads them to provide less services to ethnic minority elderly women. While not written into institutional policy, mainstream cultural assumptions about greater family involvement in ethnic minority cultures play a role in workers' practices in providing fewer services to ethnic minority elderly women making them particularly vulnerable relative to non-ethnic women. Brotman (2002) argues that the care workers' belief in the "mythology of the extended kin network" (p. 37) for ethnic minority families place strong expectations on what these families "should" and "will" do. Because of this subtle expectation put on the families, primarily the female members, to provide extra care to their elderly, Brotman (2002) argues that care receivers are prompted by the health care system to construct themselves as "in need" in order to receive services. For example, case managers discuss how the elderly re-create themselves as "passive" or "dependent" in order to access services from the workers. In other words, care receivers and their family members transform their categories or identities to meet eligibility criteria in a context of diminishing state services.

Lastly, McKeever & Miller (2004) examine the caregiving practices of mothers of children with disabilities and their interactions with health care structures. In this article, the authors challenge the prevailing interpretations of the mothers' caregiving practices in the health care field as "difficult" or "demanding". McKeever & Miller (2004) argue that mothers of children with disabilities enter the health care field in a subordinate position vis-à-vis health professionals. As non-professionals in a highly stratified health care field family caregivers are often placed at the lowest rung of authority. Also, as caregivers of children with disabilities mothers are up against a powerful discourse in society which devalues individuals with disabilities. In this context, McKeever & Miller (2004) argue that the caregiving practices of these mothers should not be considered difficult or pathological, but interpreted as strategic responses to advocate for their children within a contentious health care field.

These studies expand our understanding of giving and receiving care at the micro level; however, there remain several gaps in this literature. First, while Wiles (2002) and Angus, et al. (2005) demonstrate how caregivers with greater financial resources are better positioned to adjust to their care work they do not consider how differences in resources influence the ability to access resources. Although Brotman (2002) and McKeever & Miller (2004) examine accessing health services they do not consider how differences amongst caregivers influence access to services. Secondly, there remains a need to increase the diversity of caregivers studied since many of these studies focus on the experiences of White, middle class women.

Conclusion

In sum, the brain injury and caregiving literature outlines the individual effects and long term challenges of caring for a family member with a brain injury. However, this body of literature neglects to consider caregiving within a critical perspective. A review of the feminist long term care literature provides a critical examination of caregiving, gender, and policy. It considers how ideological assumptions underlying policy and structural factors shape and construct the caregiver in specific ways and how these influence women and men differently. A review of the literature at the micro level of caregiving practices illustrates the dynamic nature of the caregiving and care receiving relationship. In addition to the daily activities of providing care, caregiving involves negotiations of space and time when care enters the home and of categories

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such as "disability", "in need", and "at risk" in accessing services. The studies also demonstrate how greater levels of caregiver (and care receiver) resources are increasingly important in a context of diminishing state funding. While the critical studies discussed above are informative, they do not have the specificity of dealing with a specific illness or disability and they are largely based on the caregiving practices and experiences of White women. I aim to address these gaps in this thesis by examining caregiving practices for a specific disability, an acquired brain injury, through the voices of diverse caregivers.

CHAPTER 4: THE SOCIAL, POLITICAL, AND ECONOMIC CONTEXT OF UNPAID CAREGIVING IN BC

Introduction

Unpaid caregiving in the home to dependent adults is practiced within a particular health care context. The health care system in BC is itself situated within a specific social, political, and economic context shaped by both global and local forces. In this chapter I provide an overview of the emergence of the universal health care system in Canada and discuss how contemporary large scale processes such as globalization and neoliberalism influence welfare state restructuring and health care structures which in turn shape the local context for unpaid caregiving. I begin this chapter by discussing neoliberalism and the restructuring of welfare states in general. I follow this with a discussion of the restructuring of the health care system in BC focusing on the marketization of health care including the adoption of neoliberal economic rationality in the administration of health care services.

The Welfare State, Neoliberalism and Restructuring

The term "welfare state" is applied to modern states which intervene "in civil society to alter social and market forces" (Orloff, 1993, p. 304). The welfare state introduced social welfare as a right of citizenship through greater federal regulation and explicit state involvement in the daily lives of individuals through state social provisions (Young, 1992 as cited in Brodie, 2002). In Canada, the period following WWII through to the mid-1970s has been dubbed the "golden years" of the welfare state (Armstrong & Armstrong, 2004). Following the devastation of the great depression and returning home from the war there was a ground swell of public support for the implementation of a public social safety net in order to provide protection and share the risks – of sickness, accident, or loss of employment, for example – amongst all Canadians. During this period, the increased visibility and active role of the state in providing services for its

citizens was evidenced in the implementation of universal health care, education, pension and family allowance.

Feminist scholars point out that even during this laudable period the principles of equality, universality, and rights of citizenship were based on the model of the full-time employed, independent male who was free from the responsibility of providing care, or "citizen the worker". Cast as dependent citizens, or "citizen the carer" who is primarily responsible for private domestic and care work, women were not equally entitled to full social citizenship rights as were men (Brodie, 2002; Fraser, 1989; Kingfisher, 2002; Young, 1989). Thus, state social provisions have (and continue to) impact the daily lives of women and men differently (Orloff, 1993). In addition to gender inequality, the citizenship rights or claims of entitlement were experienced differently by different women according to their social position based on dimensions such as race, class, and sexual orientation (Armstrong & Armstrong, 2004). Even within this problematic context, however, many feminist scholars agree that women fared better during the "golden years" of state provision prior to the aggressive adoption of neoliberal ideology and principles shaping current welfare state restructuring.

Neoliberalism is a constructed andocentric, ethnocentric paradigm based on the 17th Century political ideals of freedom, self-possession, market society and the minimalist state (Kingfisher, 2002). The association of neoliberalism with the minimalist state rests on its definitions of personhood as the rational, independent, possessive individual and its assumption that the market should remain outside the hands of the state (Kingfisher, 2002). The neoliberal paradigm not only assumes rational, independent personhood, but also reifies its cultural construction by asserting that the western independent individual is "natural". This naturalized image of the independent working male has as its counterpart the naturalized image of the woman working in the home. In order to maintain the force of these "naturalized" images, the neoliberal project relies heavily on the construction of particular subjectivities through political discourse (Kingfisher, 2002). Therefore, a social and political context is created which renders invisible the multiple forms of interdependence that everyone requires throughout their lives and makes invisible certain forms of labour (Armstrong & Kits, 2004). In particular, the many forms of women's domestic work in the private arena, including caring for dependent (and independent) adults, are made invisible (Armstrong & Armstrong, 2004; Neysmith, 2000). Neoliberalism, then, is characterized by policies which are based on

the ideals of privatization, decentralization, and individualization (Brodie, 2002). The effects of these types of policies are associated with what is commonly referred to as the restructuring of the welfare state. State restructuring has a direct impact on caring labour as it shifts the responsibility of care further onto the shoulders of women and families. Current restructuring signals a shift from shared risks and responsibilities to individual risks and responsibilities (Armstrong & Armstrong, 2004; Neysmith, 2000).

Restructuring the Health Care System in Canada

Neysmith (2000) writes that restructuring the health care system involves "redistributing current and future costs" (p. 7). Restructuring of the health care system redistributes long term care costs from a shared public responsibility to an individual private responsibility. Women and families provide care in their homes and communities, pay more of the financial, emotional, and physical costs themselves, in conditions of declining state support (Armstrong & Armstrong, 2004; Aronson & Neysmith, 1997; Morris, 2004; Neysmith, 2000).

The Canadian health care system is based on an allopathic[9], or curative, medical model which emerged over time as various interests groups – including physicians, pharmacists, midwives, insurance companies, educational institutions, and politicians – jockeyed for power and prominence. Physicians were successful in establishing their position as *the* legitimate experts in medicine by the turn of the 20th Century aided by the institutionalization of medical education in universities, the legitimization of their particular form of medicine, the development of professional bodies, and advancements in germ theory (i.e. hospitals were no longer incubators of death) (Armstrong & Armstrong, 1996). In other words, the health care system in Canada did not evolve "naturally", but is the result of socio-political maneuvering and tensions within a network of power relations and competing interests.

Armstrong & Armstrong (1996) point out five assumptions underlying the Canadian allopathic medical system. First, illness is primarily biological therefore physicians are able to deal with patients quickly rather than considering broader mental, social, and environmental determinants of health and illness. Second, it assumes an

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[9] Allopathic medicine refers to a treatment philosophy focused on penetration of the body either physically through surgery or chemically through medication (Armstrong & Armstrong, 1996).

engineering model of the body which conceptualizes the body as a machine that can be treated according to its component parts. This model of the body promotes the piece-meal approach to medical care and has enabled the fee-for-service payment structure for physicians – they get paid for the part that they fix. Third, the focus of health care is curing illness or disability. This curative focus together with the engineering model of the body has promoted the large scale development of and emphasis on acute care hospitals. As a result, the health care system measures success in relation to "curing" and does not provide the same level of resources to those conditions without a cure or to long term care as to acute care. The fourth assumption is that medicine is based on science and that all treatment has been scientifically tested and agreed upon. The false notion of certainty associated with science also promotes the assumption that most (if not all) people will respond to the same treatment in the same way allowing for the development of narrowly-defined formulas for health care. Lastly, the fifth assumption is that physicians are the experts. In this privileged position physicians remain the gatekeepers to specialists, rehabilitation, and other services and therefore their interpretation and diagnosis of the individual's condition carries significant weight. Based on the curative medical model, the design of the health care system does not favour the long term treatment of permanent conditions such as acquired brain injuries nor does it consider their treatment a priority. In a system based on the curative model, the emphasis is on the initial acute care treatment and the focus quickly dissipates once the individual is stabilized and no longer physically critical. The long term needs and care work that continue over time become invisible when the focus is on acute care and short term, curative methods.

In Canada, the state provides universal health insurance which covers health care provided in hospital and physician services. While health care is administered by the provinces, the federal and provincial governments share the financial responsibility of paying for publicly funded health services. This funding relationship has changed over time as the federal government has downloaded fiscal responsibility and obligation to the provinces (Armstrong & Armstrong, 1996). In 1948, the federal government agreed to cover half the construction costs of all new hospitals in the provinces through a National Health Grants Program. With the Hospital and Diagnostic Services Act in 1957 the federal government paid half the costs of specified services provided in hospitals. These included services such as diagnostic tests, drugs, use of operating

rooms, and physiotherapy provided in the hospital. Through these funding arrangements the federal government encouraged the construction of hospitals as well as services provided in hospitals. In 1957 the federal government made its transfer payments contingent on the services being provided uniformly to everyone; a step towards ensuring equitable services for all Canadians.

In 1966, under growing public pressure, the federal government passed the Medical Care Act which covered the costs of physicians in addition to in-hospital costs. The federal government reinforced national standards by requiring that provinces deliver their health care services according to the five principles of: universality, accessibility, comprehensiveness, portability, and non-profit. Also in 1966 the federal government established the Canada Assistance Plan (CAP), an open ended (i.e. no cap on funding) transfer payment scheme where the federal government agreed to match the province in costs for health and social programs provided that provinces and territories meet federal standards for these programs. As a result, the federal government was able to ensure that provinces meet the standards of the Medical Care Act. By 1977, however, the federal government began to loosen its handle on maintaining national standards of health care for its citizens by replacing CAP with the Established Program Financing scheme. The EPF covered transfer payments for health and post secondary education while CAP covered transfer payments for social assistance. The EPF introduced a cap on federal transfer payments to provinces by basing funding on measures such as previous expenditures, populations, growth of the economy, and transferring some taxation power to the provinces. This signaled a new form of rationality in determining transfer payments; one based on population statistics and economy rather than as a basic right for all citizens. Therefore, in 1984 when the federal government enacted the Canada Health Act (a combination of the Hospital and Diagnostic Services Act and the Medical Care Act) it had less ability to ensure the five principles of this Act would be met by the provinces. In 1996, the federal government further downloaded its responsibility, both in terms of funding and monitoring, to the provinces by replacing the EPF with the Canada Health and Social Transfer. The CHST brought together the EPF and CAP under one funding scheme which combines transfer payments for health together with post-secondary education and social assistance in the form of block funding. Therefore, funding for health is no longer administered through a separate, protected financial

scheme and provinces now juggle the funding needs for these three programs with one general pool of federal dollars.

Federal funding provided through CAP and the Established Programmes Financing Act in the 1960s and 1970s allowed the provinces to reduce their spending on medical institutions and to increase the amount put into community care. However, because neither piece of legislation placed any federal requirements on community care and because community care generally has low priority in a medical model of healthcare this shift in funding did not occur. The situation for community care only worsened with the implementation of CHST given the decrease in federal funding and decreased regulation of national standards for provincial health care systems (Aronson & Neysmith, 1997). Therefore, federal funding restructuring and the downloading of the costs has shifted greater responsibility and burden onto the provinces.

Restructuring and Marketization of the Health Care System in BC

Provinces have adopted a variety of strategies to deal with the increased burden of funding the health care system including downloading the costs onto hospitals, communities, and families (Armstrong & Armstrong, 1996). In BC this downloading and restructuring of federal funding to the provinces coincided with a shift in health care focus from hospital care to community care aimed to reduce user pressure on hospitals and institutions. In 1991, under an NDP government, *BC's Royal Commission on Health Care and Cost* (also known as the Seaton Commission) proposed health care restructuring to shift resources for care in the hospitals into the community thereby providing care *Closer to Home*. While cuts to hospital beds and resources were made, the government did not follow through with a concomitant shift in funding to the community (Cohen, Murphy, Nutland & Ostry, 2005). Therefore, in effect, *Closer to Home* meant the state's withdrawal from sharing long term care responsibilities with families and women. This provincial withdrawal was reinforced with the introduction of CHST and changes to federal funding in 1996.

Restructuring of BC's health care system has continued to focus on downloading and privatizing the costs and responsibilities of care. Since 2001, the unbridled and enthusiastic adoption of neoliberal ideology and market strategies by the newly elected provincial Liberal government has had a particularly devastating impact on health care

services and long term care in BC (Cohen, et al., 2005). In 2001 under the BC Liberals, the Ministry of Health collapsed the existing 52 health regions across the province into 6 health authorities[10]. The Ministry of Health provides block funding to the health authorities who are responsible for managing their own budgets and administering all the health services for their region within this budget.

The effects of collapsing the province into a few health regions has meant that people living in smaller communities have lost services and their needs are often overlooked by those living in larger communities. In addition to collapsing the number of health authorities, the BC Liberals have also relocated services and closed others based on numbers, a market strategy which values cost savings over the needs of people.

In *Health Care Restructuring in BC*, Fuller, Fuller & Cohen (2003) argue that the BC Liberals have enacted two main changes to our health care system since 2001. The first is cutting costs through cutbacks and limiting services and the second is increasing the role of the for-profit private sector in health care as the public sector recedes. Both these measures illustrate the marketization of the healthcare system. The cuts include: no public health insurance (MSP) coverage for treatment considered "para"-medical such as physiotherapy, chiropractor, eye services, and massage therapy (unless provided in the hospital); closures of hospitals and hospital beds; restrictions in seniors' subsidies for medications; and no coverage for housekeeping services to frail elderly and disabled living in the community. In practice, however, housekeeping services have been reduced and not entirely eliminated (Cohen, McLaren, Sharman, Murray, Hughes & Ostry, 2006). Since costs for care in hospitals remain publicly funded these cutbacks target those living and caring in the community.

In regard to long term community care, the Liberals announced the *Continuing Care Renewal* plan in 2003, a 3 year plan which they claimed would address the

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[10] These health authorities are: Northern Health Authority (NHA) which covers the entire northern region of BC; Interior Health Authority (IHA) which covers the Thompson, Okanagon and Kootenay area; Vancouver Island Health Authority (VIHA) which covers Vancouver Island, the islands of the Georgia Strait, and mainland communities north of Power River and south of Rivers Inlet; Vancouver Coast Health Authority (VCHA) which covers Vancouver, North and West Vancouver, Richmond, and the Coast Mountain communities; and Fraser Health Authority (FHA) which covers the large area of the Fraser Valley. The sixth is the Provincial Health Services Authority (PHSA) which is not responsible for a specific geographic region, but is responsible for and coordinates specialized services available to the entire province such as BC Children's Hospital and the BC Cancer Agency. The majority of BC's population lives in the VCHA and FHA and therefore these regions have the largest budgets and the most services (BC Ministry of Health website).

continuing care needs of British Columbians. However, from the period of 2001 to 2004, government cutbacks have led to reduced long term care beds (even with an increase in assisted living beds, which do not meet the same needs as residential care beds, there remains a net drop of 1464 beds) and cuts to home support (housekeeping and non-medical assistance) and home care (nursing services). In addition there have been cuts to acute care beds (1279 bed closures from 2002-2004) (Cohen, et al., 2005). More significant than any one single area of cuts is the combination of cuts to in-hospital beds together with the cuts to home health services and the lack of funding for community services. The BC Liberal's *Continuing Care Renewal* 3 year plan did not guarantee that the money saved from closing residential beds would follow the seniors into the community. Care is only better in the community if the resources are shifted over to the community. In addition to cutting beds, hospital stays are shorter. Shorter stays in acute care beds mean that higher levels of nursing and medical care need to be provided at home at the same time that home health services are being reduced (Cohen, et al., 2006). Using the BC Ministry of Health statistical records, Cohen, et al. (2006) report that for the period between 2000/01 and 2004/05 the number of clients receiving home support dropped by 24% and the number of hours of home support decreased by 12% (Cohen, et al., 2006).

The second change implemented by the BC Liberals is the increasing role of for-profit services as the public sector withdraws (Fuller, et al., 2003). As evidence of this, Fuller, et al. (2003) cite the increase in private-public partnerships (also known as P3 partnerships) to cover the cost of new hospitals and facilities; the contracting out of "non"-medical services from public unionized workers to contract workers hired by private companies; the emergence of for-profit surgical facilities; and the increase in private for-profit residential care facilities. Underlying the encouragement of for-profit services in BC's health care system is the false assumption that for-profit practices are always more efficient and effective than public services. Since 2003 there has been a shift to privatizing health support services in hospitals and other health care facilities (Stinson, Pollack & Cohen, 2006). These services, considered to be non-medical, include cleaning, laundry, and meal preparation. These workers are doing more work for less pay under conditions where there is less time for appropriate training with greater physical, economic, and emotional costs to themselves (Stinson, et al., 2006). Insufficient training and a lack of support have shown to decrease the quality of these

services. While they may not be "medical" services, they are critical to maintaining a clean and healthy environment and therefore declining services have significant consequences for those who are ill and more vulnerable.

Marketization of health care refers not only to cost cutting and the inclusion of for-profit service and companies in the health care system as discussed above, but also to the adoption of market strategies and economic rationality (Armstrong & Armstrong, 1996; Garland, 1997) as the dominant rationality underlying BC's health care system. The introduction of market strategies and economic rationality are in line with the neoliberal emphasis on the "free" market and the autonomous individual exercising "consumer" choice. The Guidelines for Planning Brain Injury Services in BC (BC Ministry of Health Services and Ministry of Health Planning, 2002) refers to brain injury survivors and their families as "consumers". The adoption of market discourses in health care construct the patient as "the consumer" and place emphasis on for-profit companies to provide "options" for health care, and assume that "free" market principles provide the best and most efficient service. In this fictitious scenario, for-profit companies and health providers compete with each other to provide better service in order to woo potential consumers and thus the market and consumer choice guarantees the best and most efficient health services. The power for the consumer lies in her ability to choose amongst various options; in other words, to take her spending power elsewhere. However, this re-construction of the patient in the language of "consumer" and "options" is problematic for a number of reasons. The reality is that in health care, most patients do not have the time or luxury to "shop around" for the best service nor do they feel that they have the expertise to identify the "best service". Instead they rely heavily on physicians whose role as experts is reinforced with increasing technologies used in health care and their specialized training (Armstrong & Armstrong, 2004). Decisions around health care are often made in a context of crisis where emotional and physical resources of patients and their family and friends are often depleted. In the case of long term care, many options, such as private residential facilities, are also too expensive for many people to afford. Therefore, this lack of choice and real options result in women and families providing this care at a high cost to themselves.

Garland (1997) writes that "economic rationality" not only refers to financial considerations in administration, but also to the adoption of a language of risks and rewards, probability, and the targeting of interventions; the emphasis on objectives of

cost-control, efficiency, and effectiveness; and the reliance on economic *technologies* such as audits, devolution of responsibility, and market competition[11]. This economic discourse is exemplified in the *Guidelines for Planning Brain Injury Services and Supports in British Columbia* which states, "The challenges faced in the health care sector are many, including the recent change in governance structure of the health authorities; core services review; expectations for health authorities to operate within limited funding; and the responsibility for ensuring cost-effective and efficacious, evidence-based and outcome-driven services." (Ministry of Health Services and Ministry of Health Planning, 2002, Executive Summary). Armstrong & Armstrong (1996) argue that the implementation of economic rationality in health care results in a redefinition of success based on numeric markers and is consistent with definitions found in the marketplace. The more served (or serviced), in shorter time, at lower cost equals progress and success. This rationality can have devastating effects for people who are chronically ill, such as those with an acquired brain injury, who require health services for conditions which are not easily treated or "fixed" or for whom improvements are not easily quantifiable.

Conclusion

The context of care for unpaid caregivers of a brain injured family member in BC is one in which state support is withdrawing while the role of the private market is increasing. First, cutbacks and privatization of health services ranging from acute care to rehabilitation services to long term care mean that unpaid caregivers are required to provide more care work both in terms of amount and intensity. When their family member is discharged after shorter stays in the hospital unpaid caregivers are responsible for covering the cost of medication and rehabilitation services, such as physiotherapy or massage therapy, themselves. Second, with the adoption of economic rationality and a focus on numbers, speed and efficiency it is likely that rehabilitation programs will emphasize a fast rate of patient turnover in order to secure public funding. Therefore eligibility criteria for these intensive publicly funded services may be interpreted in increasingly narrow and stringent ways in order to admit those most likely to demonstrate observable improvements quickly. The result is that many of those with the most severe or critical brain injuries may be considered ineligible for these

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[11] Garland applied this argument to the penal system and criminological field.

rehabilitation services. Without the support of these specialized services, the challenges for unpaid caregivers increase as they shoulder the care work in the community themselves. Finally, the combination of cutbacks, privatization, and the emphasis on market based efficiency result in less flexibility of formal health services for unpaid caregivers in the community. For those who are eligible to receive publicly funded home health support, home support workers are now limited in their ability to provide housekeeping services which is critical to overall health. Also, home support workers are often immigrant women who are not well supported and have not received adequate training for more difficult cases (Cohen, et al., 2006; Stinson, et al., 2006). Clearly the shift towards marketization of health care results in an increasingly challenging context for unpaid caregivers.

CHAPTER 5: RESEARCH METHODS AND METHODOLOGY

Methodology

This thesis is based on qualitative methods and data was generated using in-depth, semi-structured interviews. Denzin & Lincoln (2003) write:

> "The word *qualitative* implies an emphasis on the qualities of entities and on processes and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry." (p. 13, italics in original)

Qualitative methods, therefore, are consistent with the ontological and epistemological position of contemporary feminist approaches that view reality and knowledge as socially constructed and highly contextual[12]. Rejecting the idea of the "objective" researcher and "truth" claims characteristic of positivist traditions the aim in contemporary feminist methodologies is not to seek a pure objectivity which does not exist, but to recognize, account for, and make as transparent as possible, the subjective position of the researcher in constructing knowledge (Denzin & Lincoln, 2003).

In-depth interviews allow for the examination of the rich details and interconnections between people's accounts of their daily practices and larger social structures. The use of in-depth semi-structured interviews also provides the space for participants to express themselves using the language, words, and discourses that they choose to draw upon and that are available to them. It provides greater flexibility in the

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[12] Denzin & Lincoln do not argue that qualitative methods are the exclusive research method of feminist methodologies. Qualitative methods are not exclusively aligned with any single theoretical paradigm and in fact can also be used in positivistic based research (Denzin & Lincoln, 2003). However, feminist methodologies tend to choose qualitative methods over quantitative methods since the former is more consistent theoretically with feminist approaches than the latter and is better suited to answer the types of research questions asked in feminist research (McCall, 2005).

interview structure and format and allows for the researcher and participant to explore different areas and topics that may arise during the interview itself. I take the position of Holstein & Gubrium (1995) that the interview process is an active and dynamic encounter between the researcher and the participant whereby both are involved in the data generation process. In other words, knowledge, or data, is not being "extracted" from the participant by the "objective" researcher, but participant and researcher – who both occupy specific subject positions – generate data together through the medium of the interview process. The researcher plays an important role in this encounter by providing the framework for the participant through the questions she asks and how she introduces and explains the research project itself (Holstein & Gubrium, 1995).

Reliability and validity are measured differently for qualitative methods than for quantitative methods and within qualitative methods there is ongoing debate over the satisfaction of these measures (Denzin & Lincoln, 2003). For the purposes of this thesis I take the position of Mason (2002) who argues that reliability in qualitative methods involves demonstrating to the reader that the data generation process and analysis of the data are appropriate, thorough, accurate, and honest. This is achieved by the researcher maintaining a high level of transparency and detail when outlining her sample selection process, data generation process, and analysis (Mason, 2002). Regarding validity, Mason (2002) distinguishes between validity during the data generation phase and validity during analysis. Validity during data generation deals with the questions: What can my data sources and generation methods tell me? and How well can they do this? (Mason, 2002, p. 189). These questions require that the researcher explain how she came to the conclusion that her research methods are valid and appropriate not only by considering theoretically the strategies used, but also by providing consideration and detail regarding the specific participants, specific interviews, and specific questions asked (Mason, 2002). Validity in data analysis or interpretation deals with the question: How valid is my analysis and the interpretation on which it is based (Mason, 2002, p. 191). Mason (2002) argues that this question is assessed by how thorough an explanation the researcher provides regarding how the "end-product" or final interpretation was reached. Lastly, I agree with Mason (2002), contrary to some feminist standpoint theorists, that my own position and experience as an unpaid caregiver does not privilege my own interpretations nor does it provide de facto validity to my interpretations. I do contend, however, that my experiences as an unpaid caregiver *did*

significantly influence this thesis through the questions that I asked, my interactions with participants, and my interpretations of the data. I discuss my own subject position and its influences on the research process in the remainder of this chapter and in the following analysis chapter.

Participant Recruitment

I used purposive sampling methods to obtain my sample of 6 participants[13]. This is an appropriate sampling strategy since the aim of this thesis is to provide an in-depth examination of a small number of specific participants and not to formulate results generalizable to the larger population (Palys, 2003). Criteria for inclusion in this study were broad given its exploratory aim. The criteria were that the participant identifies as a primary caregiver for a family member with an acquired brain injury and that s/he is 19 years or older[14]. My goal was to maximize the diversity in the sample in order to include the experiences and practices of diverse caregivers who have not received much attention in caregiving research. This inclusion addresses a gap in the caregiving literature discussed earlier which focuses primarily on the experiences of White, heterosexual, middle-class, and middle-aged to elderly women. Therefore, I did not place any restrictions on gender, ethnicity, age, socioeconomic status, cause of injury, time since injury, co-residence, and family relationship between caregiver and care receiver. I chose to include all forms of acquired brain injuries since brain injury services across all health regions in BC do not differentiate between traumatic and non-traumatic brain injuries in terms of service provision. This also expanded the potential pool of caregivers who could participate.

I recruited participants from June to November 2006. I initially focused on recruiting participants through caregiver support groups operating through non-profit community brain injury associations funded by the health authorities. I was familiar with these associations because of my short-term employment as a community support worker in one of these agencies several years ago. These agencies provide support to

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[13] My initial aim was to have a sample size of 4-5 participants. However, after five female participants were recruited I was contacted by the sixth participant whom I included since he is the only male caregiver in my sample.

[14] Initially my criteria for inclusion also included: that the brain injury be moderate to severe, that the brain injury occurred post-1996, and that the caregiver co-reside with the brain injured family member. However, I dropped these criteria given the low response rate of interested participants.

those living with an acquired brain injury in the community and their family members by providing a drop-in centre, day activities, and information and referrals to other services. I contacted the executive directors[15] of these agencies via email and phone, discussed my thesis with them, and sent them a one-page summary of my research goals and a handout for potential participants via email. Following these discussions, the executive directors gave me the names of the facilitators for both caregiver and survivor support groups to contact directly regarding participant recruitment. I included survivor support groups at the suggestion of the executive directors since there is a very small number of caregiver support groups and facilitators of survivor groups often have contact with caregivers. I discussed my research with the facilitators directly via phone and email and sent them handouts to present and pass out to interested caregivers[16].

This initial recruitment effort did not meet the number of participants I was aiming for and therefore I expanded my strategy to include caregiver groups not specific to brain injuries. I emailed caregiver support group facilitators listed on the *Caregivers Association of British Columbia*'s (CABC) website in the Vancouver area and sent them the same information as the first group of facilitators above. The CABC is a provincial non-profit organization that aims to "support, educate and advocate for unpaid family caregivers in British Columbia" (CABC Website). I also contacted the Acting Executive Director of the CABC and advertised my study on the online caregiver's support group to reach those caregivers who may not have the time or resources to participate in a support group in the community. Lastly, I posted advertisements[17] of my study at Vancouver General Hospital and Royal Columbian Hospital (two hospitals in the Lower Mainland that have neuro-trauma units and deal extensively with acquired brain injuries at the acute level), GF Strong (the primary rehabilitation centre for acquired brain injuries in the Lower Mainland), two Vancouver neighbourhood community centres, and ran a 3 week advertisement in *The Peak*, SFU's student newspaper. I included community centres and the ad in the newspaper in order to cast a wide net and reach those caregivers who may not be involved in any formal caregiver or brain injury services.

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[15] As a community support worker, I knew the executive director of one of these agencies. Although the executive directors did not have any direct involvement with participant recruitment I recognize that my previous working relationship may have helped to gain approval in contacting support group facilitators.

[16] I also offered to attend the support groups and make a brief presentation about my research project; however, I left it up to the facilitators to recommend what they felt would be most appropriate for their groups and in the end I did not attend any groups myself.

[17] See Appendix A for a copy of the advertisement.

In deciding to recruit primarily through support groups with the assistance of facilitators I recognize that there is selection bias and less diversity since caregivers who participate in support groups are likely to be more similar to one another than those who do not. In addition those who attend support groups also have the resources (time, energy, transportation, geographic proximity, etc.) to attend and cultural recognition of their usefulness for them. Facilitators also served as important gatekeepers in my recruitment strategy and they are more likely to approach those caregivers with whom they are most familiar and therefore those who are most involved which also results in selection bias. Although I assured interested participants who contacted me that they were not obligated to participate, those who agreed to participate were likely "pre-selected" by the facilitators. However, in spite of these limitations, using support groups is a common method of participant recruitment in caregiving research as they provide access to this specific population. Also since I am not concerned with generalizable results this form of purposive sampling is acceptable. My main concern, therefore, is not about how random my sample is, but to what degree it provides a diverse sample of caregivers. In this regard, I was able to obtain a relatively diverse group of participants which I will present in greater detail later in this chapter.

Data Generation

Data was generated using in-depth semi-structured interviews and took place from October 2006 to January 2007. I had contact with each participant (either by phone or email) prior to the data generation phase and discussed this study with them. I advised each of them that participation in the study would involve at least one interview with the possibility of a second interview if they agreed to it. At the start of the first interview I went over an informed consent form with each participant and began the interview after they agreed to it and signed the form. I interviewed all 6 participants twice and all interviews took place in the participant's home, were conducted in English, digitally recorded (with the participant's agreement), and transcribed by myself. Following transcription I deleted the audio file from the recorder and computer hard drive and stored a copy on a secure password protected web server to which I have sole access. These stored interview files will be deleted at the completion of this thesis. All identifying names of individuals were deleted or replaced with pseudonyms in the transcripts. In several interviews, the care receivers were also present in the home;

however, they were either in a different room or occupied with head phones[18] to provide privacy for the caregiver and myself during the interviews. All of the care receivers were told by their caregiver that s/he was participating in this study.

I interviewed each participant twice (approximately one month apart) in order to explore and generate a large amount of detailed data regarding their caregiving work. I developed a general framework of questions prior to conducting the interviews which I used as a guide to ensure that I discussed similar topic areas with each of the participants. The questions I asked dealt with: how the brain injury occurred and what the circumstances of the injury were; what services their brain injured spouse received from the time of injury to present; what their involvement and care work is/was from the time of injury to present; what their current daily caregiving involves and how it is organized; what their experiences with health care services, providers, and other professionals are/were like; what services they may require or policy recommendations they may have; and demographic information[19]. In exploring each of these various areas my aim was to allow the participant's own experiences to direct the specific questions and discussion. Therefore, the interviews differed in their points of emphasis according to the different experiences of the participants. Each interview was approximately 1.5 to 3 hours in length. I transcribed and reviewed the first interview for each participant prior to conducting the second interview with the same participant.

I began the second interview by reviewing the main points from the first interview and asking any questions that arose for me as I read through the first interview transcript. This process allowed me to check some of my initial interpretations with the participants and to allow them to make any corrections or additions to the first interview. Checking with participants increases the validity of my interpretations and also provides them the opportunity to be more actively involved in data generation. The format for the remainder of the second interview varied depending on the participant. For some the second interview covered topics in the general interview framework that we had missed during the first interview while for others the second interview focused primarily on exploring in further depth areas that had already been discussed in the first interview. I

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[18] In one interview the care receiver was in an adjacent room and was watching TV without head phones; however, there was enough space and volume (from the TV) between the care receiver and where we were having the interview to provide privacy.

[19] See Appendix B for a copy of the interview questions.

was also able to discuss themes that were emerging from the first set of interviews with participants in the second set of interviews[20]. I made field notes directly following the interviews and kept a reflexive journal in which I recorded my thoughts, comments, impressions, or reactions while conducting this research. I did not keep a reflexive journal in a systematic way, but wrote whenever I felt something was noteworthy with the intention that I would use these entries as a way to keep track of and to refer back to my own personal responses and to provide some contextual reference.

My own role as an unpaid caregiver was significant throughout the participant recruitment and data generation phases. In my introductions to facilitators and to potential participants I explained that my interest in unpaid caregiving to brain injured family members stemmed from my own experiences as an unpaid caregiver to my father. I decided to make my own position clear to participants as a way to build rapport and a relationship with the caregivers who were involved in this study. During the interviews I also shared my own experiences if participants asked me specific questions or to provide context for a question or topic area that I was interested in exploring with the participants. By answering questions that participants had for me about my own personal experiences, I feel that this helped to decrease (although did not eliminate) the power dynamic between myself and the participants as we both shared our personal stories with one another. In some of the interviews I also directed data generation by asking participants specifically about certain forms of caregiving practices which emerged in the transcripts of other participants. Although I used my notes from my reflexive journal and review of the first round of interview transcripts to bring to my attention areas that I may be overemphasizing or neglecting in the interviews, it is possible that I focused more heavily on those areas or issues that I had personally experienced myself.

Qualitative Data Analysis Methods

This thesis is based on the inductive analytical approach. In the inductive approach "the researcher will develop theoretical propositions or explanations out of the data, in a process which is commonly seen as moving from the particular to the general"

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[20] Since I had a staggered start with the interviews, some of the second interviews for the earlier participants coincided with the first interviews of the later participants. As such, I was able to draw on and incorporate emerging themes to a greater extent with the later participants than with the earlier ones.

(Mason, 2002, p. 180)[21]. This approach is consistent with exploratory qualitative research and in practice it involves moving back and forth iteratively from the data generated to existing literature in order to formulate arguments and propositions. I take the position of Mauthner & Doucet (2003) that data analysis methods are not neutral, but are specifically chosen and reflect the ontological and epistemological assumptions of the researcher as well as her role in data generation. I began data analysis following the completion of the first interview and therefore subsequent interviews were influenced by this early stage analysis. The implication of the researcher in the construction of knowledge and in interpretive qualitative analysis requires that the researcher be reflexive throughout the analysis stage (Mauthner & Doucet, 2003). Lincoln & Guba (2003) define reflexivity as "the process of reflecting critically on the self as researcher" (p. 283). This process of critical self-reflection extends from the beginning of the research process when the topic of study is being determined through to the writing stage (Lincoln & Guba, 2003). In writing this thesis I took into account my audience, including the participants who agreed to share their stories for this research, and how the final written product might be received and interpreted by them.

I developed a draft coding framework following the completion of the first round of interviews by reading through these transcripts. At this stage the codes were not applied to the data, but were used to organize the emerging themes and ideas. Given that my focus is on daily caregiving practices and health care services I identified the various forms of caregiving practices that participants spoke about as well as any discussions of health care services, health care workers, and other larger social structures. I applied the draft coding framework to all the transcripts following the completion of the second round of interviews. In this first reading of the complete set of transcripts, I read both rounds of transcripts for each participant to gain a holistic view of each participant's narrative and applied the draft codes to these transcripts. I also made notes and identified other themes or points which I thought were not covered in the draft codes[22]. Following this first reading I revised the coding framework and arrived at the

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[21] The abductive approach to data analysis – where data generation, data analysis, and theory building occur simultaneously – also overlaps with the inductive approach; therefore I understand that these are not clear cut categories and that the research process is dynamic and crosses these boundaries (Mason, 2002, p. 180).

[22] The initial draft codes did not differentiate between the various forms of caregiving practices and included various forms of capital (i.e. economic, social, cultural, and symbolic). I found that the capital codes were less helpful than I had originally anticipated and therefore did not include them in the final coding framework.

final set of codes which are: Care Supervision, Direct Care Work, Advocacy Care Work, Emotion Care Work, Health Services, Insurance, Legal System, Welfare System, Employment, and Policy.

During the second complete reading of the entire data set, I applied the final coding framework to the data and I also applied what Mauthner & Doucet (2003) refer to as a reflexive reading of the transcripts. Citing Brown (1994), they describe this reading as involving "a 'reader-response' element in which the researcher *reads for herself* in the text. She places herself, her background, history and experiences in relation to the respondent. She reads the narrative *on her own terms,* listening for how she is responding emotionally and intellectually to this person" (Mauthner & Doucet, 2003, p. 419, italics in original). Mauthner & Doucet (2003) discuss this reflexive reading as a reading done on its own; however, due to time constraints I combined this reflexive reading together with coding the data. Mauthner & Doucet (2003) recognize that time constraints are often a limiting factor in the data analysis process and while they propose a model for data analysis they also support the adaptation of their model.

Demographic Profile of Participants

All the participants in this study are married spouses to their family member with an acquired brain injury – 5 wives and 1 husband. Their current age ranges from 40 to 66 with their age at the time of their spouses' brain injury ranging from 30 to 63. This range in age covers the young adult to middle adult periods and reflects diversity in their period of life. The youngest caregiver and her husband had not had any children yet (a goal that they had previously planned for before his brain injury) while the oldest caregiver and her husband were retired at the time of injury and were ready to enjoy their free time with their grandchildren. All except two participants have children; however, only one of the five participants had children living with them at the time of the injury. Four participants immigrated to Canada (2 from Western Europe and 2 from South America; 3 as adults and 1 as a teenager) while two participants were born in Canada. At the time of injury two participants were in long-term full-time employment, two participants were employed in contract work, one was unemployed, and one had taken early retirement without a pension. No participants were in full-time employment at the time of the interviews.

The date when the injury occurred ranges from 1997 to 2005, with a period of time as a caregiver ranging from 2 to 10 years. In all cases, the brain injured spouse was the only person injured at the time. Three of the brain injured family members have a traumatic brain injury resulting from an external blow to the head while the remaining three have an acquired brain injury from a stroke. Two of the brain injured family members have been diagnosed as having a mild brain injury with the remaining four positioned differently along the continuum of having a moderate to severe brain injury. All of the latter four were hospitalized in acute care for a period ranging from 3 weeks to 3 months with 3 admitted into a rehabilitation facility following acute care. Two of the four continue to require 24 hour care, one solely as a result of his brain injury and the other due to the effects of his brain injury together with his pre-existing condition as a quadriplegic. By the end of the second interview, all 6 participants were caring for their brain injured family members at home.

CHAPTER 6: DATA ANALYSIS

Caregiving Practices and Health Care Structures

In the following analysis I focus on unpaid family caregiving practices and their intersection with health care structures which allows me to identify the specific conditions or context in which particular forms of caregiving practices emerge. I begin with a chronological[23] presentation and analysis of caregiving practices and health structures at three main sites following a brain injury: first, in the public space of the acute care hospital during the early stages of the brain injury; second, in negotiating rehabilitation services following acute care; and third, in the community when the brain injured family member returns home. In the final section I discuss the diversity amongst caregivers focusing on financial resources and gender. All the names that I use in this analysis are pseudonyms and, in order to protect their confidentiality, I have changed some details of the participants' narratives that do not affect the overall analysis.

Private Care in the Public Arena

Caregiving for a family member with an acquired brain injury differs from caring for an elderly family member in that the injury occurs at a distinct point in time and, depending on the level of severity, may initially involve an extended stay in a hospital[24]. For each of the caregivers in this study, their spouse was taken to the hospital directly following their brain injury. In all four cases where the brain injured family member was admitted to the hospital, caregiving by the family member began in the public arena of the hospital. In contrast to most gerontological caregiving research which focuses on

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[23] Not all cases are entirely chronological since there was some back and forth in the sequence of treatment following the brain injury for some; however, since this does not affect the overall analysis I have chosen to present it this way for reasons of clarity.

[24] I am not arguing that the frail elderly do not ever require hospital care, but am emphasizing the contrast between elderly care which generally progresses over time and caring for a brain injured family member which occurs following an injury at a distinct point in time and is often marked by immediate hospitalization.

unpaid caregiving in the home, four participants in this study spoke extensively about the unpaid care work they provided in the public site of the hospital.

In the hospital setting the care work of participants emerged at points in which the nursing staff was unable to provide sufficient formal care. In BC's health care context where hospitals are dealing with cutbacks and nursing shortages, the direct care work that participants provided ranged from feeding and bathing to nursing care to companionship. The January 2003 monthly report card by *Friends of Women and Children in BC* (UBC Centre for Women and Gender Studies Website) reports that the BC Liberal government's cuts to hospital staff has meant that family members must now provide basic care needs for their loved ones in the hospital. The adoption of market rationality together with a medical model of care organizes time in the hospital around efficiency and provision of care for a "typical" patient and does not give nurses the flexibility to provide adequate care for patients who have more complex care needs (Armstrong & Armstrong, 1996). Emily (Non-Immigrant, mid 50s) is caring for her husband who has a traumatic brain injury from a fall. As a result of his brain injury, Emily's husband has significant difficulties with speaking and in being understood. Emily's husband's limited communication increases the complexity of his care since it requires a great deal of time and creativity to understand him. From the time of his brain injury Emily's husband required a large amount of direct care and Emily provided much of this care herself because of her fear that the hospital nursing care was inadequate. She describes her care work in the hospital:

> *E: I lived at the hospital. I just lived – I took leave from my work and I was there from the time they gave him breakfast to the time he went to sleep and one of the [kids] would come so that I could go and get lunch. Yeah, because he couldn't talk. Well at first I was there because I wanted to make, you know, I was terrified he was going to die. Um and then as he was, you know, getting a bit better the fact that he couldn't communicate with anybody, he was frustrated, he was mean and cranky to them and, um, the nurses didn't know what to do and the nurses had no time to try to figure out what was wrong with him and he was really having a lot of problems with a lot of different things and a lot of pain so. You know he couldn't swallow. They were worried about his swallowing and there just wasn't anybody to – I didn't feel safe leaving him there. It was just too busy and I saw some pretty scary things happen to other people and I felt that if you didn't have a family member there your chances of having a bad fall or choking or something you know was a good possibility.*
>
> *I: So what was a typical day for you like when you were there?*

E: Um I did everything for him. I fed him his meals, I dressed him, changed him, washed him, you know, I just took care of him. I tried to make it a little bit – you know, the nurses had so many people and I was there anyways so I did whatever I could to, you know, and he would rather of me done some of the things. You know he was more calm because I can't imagine waking up and realizing, once he started realizing, that nobody understands what he's saying. Like it's a foreign language and nobody getting it.

This excerpt also illustrates the tension between the nature of clock time which organizes the public space of the hospital and the nature of process time which is more appropriate for care. Twigg's (2000) study of long term home care for the elderly considers the temporal and spatial ordering of care in the community in the UK. She demonstrates how the structure of time in the home is reordered when paid care is provided in the private space. Process time, according to Twigg (2000), is ordered around the process of completing a task rather than on clock time in which tasks are ordered by the clock. She argues that process time is specifically related to care work and is therefore gendered given that care work is gendered. For example, in process time the ordering of time is based on the process of feeding, regardless of how long it takes, and not on the clock which regulates how long patients are given to eat (and how long nurses are given to feed them). Hospitals, however, schedule meal delivery from the kitchen at a specific time and tray pickups after a certain regulated period of time according to the clock. When family members, such as Emily, enter the hospital site as caregivers they reorder the structure of clock time in providing their spouses' care. Emily takes the time to complete the slow task of feeding her husband who has swallowing problems regardless of the quick ordering of meals according to the clock.

A health care context of diminishing services provides a growing space in the hospital site and places increased pressure on family members to provide additional care for those with more complex care needs. Brotman's (2002) study of ethnic elderly women and community care in Ontario demonstrates how health professionals expect family members to assist with language translation in a context of diminishing state funding for community care. While family caregivers often fill in these growing spaces in the public arena they are expected to provide this care work voluntarily, without pay, and are in the lowest position of authority vis-à-vis health professionals (McKeever & Miller, 2004). The participants in this study were aware of their subordinate position; however, their narratives also challenged the dominant image of the "subordinate" caregiver in order to ensure the well-being of their family member. Similarly, McKeever & Miller

(2004) describe how mothers of children with disabilities "... in order to obtain desired services and/or appropriate care, mothers described as having engaged, or being perceived as having engaged, in provocative and, at times, quite conflictual relations with professionals and others. These activities were often at odds with their subordinate position as mothers vis-à-vis health professionals" (p. 1182).

Sofia (Immigrant, late 30s) also provided a great deal of care work in the hospital because of inadequate formal care; however, in her caregiving practices she describes engaging in activities that challenged her subordinate position as a family caregiver in the hospital arena. Sofia's husband spent several months in the hospital following his brain injury which was complicated by a pre-existing long term disability. Care for Sofia's husband was complex because his pre-existing disability masked many brain injury effects. Because of Sofia's extensive experience in caring for her husband prior to his brain injury she was an expert regarding his care and knew to look for subtle changes with which the medical staff was not familiar. At times this led to conflict between Sofia and the medical staff; however, this did not dissuade her from providing direct care herself when she felt that the care in the hospital was inadequate:

> S: ... He was in the ICU and the nurses said to me, ok I don't have to spend a night there because he's in the ICU he gets the care he needs so there's no use for me to stay. And I said, well of course I trust in ICU and I trust people in Canada um so I left. But I said, oh tomorrow I'm gonna go to church at nine before I go I'll just call and ask how he was doing, which I did. And the Sunday I phoned like around quarter after 8 or so and a nurse said to me, 'he's fine'. And I always ask very specific, because I know specific symptoms or signs in a [person with his pre-existing disability] to know if the person is well or not so I asked, is he sweating, if he has shivers, or wet face or things like that. She would answer to everything, 'no, he's fine he's talking he's alright, he's alright'. And she just told me, 'the bed is wet again. We are changing the bedding and that's all right'. But when you heard about that it's not right because a person is having an indwelling catheter it's not fine to wet the bed. It means the catheter collapsed and you have to change it and a person that is disabled like he is, a [person with his pre-existing disability], can get a stroke if you don't if you don't solve the problem. So actually I asked her, 'can you please change his catheter?' She said she cannot because there's no doctor there. So I thought, ok, so I just hang up the phone called a taxi and went there. When I got there and I asked her for help and she said, 'give me 10 minutes I cannot help you right now' so I had to change his catheter.
>
> I: Did they know that you were doing that?

S: Of course they knew. And um he was not fine at all. He was already in shock, already in shock. But again he couldn't speak for himself. He could not. So I had to do that and from that day I haven't left his side at all.

Sofia describes in detail knowledge of her husband's medical condition and the subtle symptoms and physical indicators of distress in her husband. She is highly assertive in her role as caregiver in the public arena of the hospital and constructs herself as an expert through the discourse of her caregiving practices. Sofia describes getting a private hospital room for her husband, with the help of a social worker, so that she was able to stay overnight in the hospital and care for her husband. She also describes challenging her husband's physician regarding her husband's care and following through with what she considered to be appropriate care for her husband in defiance of the physician's orders. In the public hospital space Sofia's caregiving practices emerged at gaps in health care and they contested and transformed her position of subordination. Because of her experience in caring for her husband before his brain injury, Sofia was able to construct herself as an expert and to better position herself vis-à-vis hospital personnel. Hospital staff identified her husband's quadriplegia and difficulties in his communication as requiring complex care and this contributed to Sofia's identity as an expert in his care which she uses as a platform in her interactions with health professionals.

In interviewing Emily and Sofia and in reading their transcripts I found myself responding with a sense of familiarity to their narratives. Like them, I also spent long hours everyday providing direct care to my father whose ability to communicate was highly limited. Like them, I also responded to what I experienced as insufficient nursing care in the hospital. Memories of my own feelings of surprise and frustration at the nurses' limited time for patients with complex care needs were evoked in reading through Emily's and Sofia's transcripts. While I trusted that the hospital staff would keep my dad alive, I did not trust that they would be able to provide the care that he needed to improve. My familiarity with these experiences likely brought these examples to my attention during my analysis. Although there were similarities to my own experiences, there were also notable differences which challenged my interpretation of the interaction between caregiver and health professionals. For example, I was surprised by Sofia's assertiveness in caring for her husband in one of the most highly specialized spaces of

the hospital (the ICU) and in defiance of the most powerful professional in the hospital (the physician). As a female immigrant and visible minority with English as a foreign language and no medical background, Sofia's assertiveness challenged my assumption that a caregiver in her social location would likely be silenced and subordinate vis-à-vis health professionals. Sofia's assertiveness therefore challenged me to expand the contextual considerations involved in the interaction between an unpaid caregiver and health professionals; namely their past experience and expertise in providing care to their family member.

Accessing Rehabilitation Services

Following acute care, rehabilitation services are an integral part of recovery for people who have an acquired brain injury (Foster & Tilse, 2003). Negotiating access to rehabilitation services is another key site of interaction between family caregivers and health structures in this study. For many survivors of a brain injury, appropriate and timely rehabilitation services can mean the difference between relative independence and complete dependence, living with family or living in an institution. Provincial services specifically for those living with an acquired brain injury are scarce. According to Guidelines for Planning Brain Injury Services and Supports in British Columbia (BC Ministry of Health Services and Health Planning, 2002) the health authorities are responsible for the planning and delivery of brain injury services in their region as well as coordinating inter-regional services for patients and their families. Several specialized institutions and programs are available to everyone across the province. These are: the BC Neuropsychiatry Program (UBC and Riverview); GF Strong; the Gorge Road Hospital; and the Provincial Brain Injury Program (PBIP). All of these services are concentrated in the Lower Mainland and Vancouver Island[25].

These specialized services together with local community health units provide a continuum of rehabilitation services that range from in-patient, intensive therapy to out-patient therapy to unspecialized day programs in the community. The greater the intensity and specialization of treatment (i.e. greater cost and fewer beds/spots) the more restrictive is the referral process and eligibility for these services. In Canada, the

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[25] The BC Neuropsychiatry Program also had a facility, Skeleem Recovery Centre, for brain injury rehabilitation in the Cowichan Valley; however, this facility was closed in March 2003 because of funding cuts.

health care system is structured such that physicians are "gatekeepers" to these restricted rehabilitation services (Armstrong & Armstrong, 1996; Foster & Tilse, 2003). Foster & Tilse (2003) write that while the common conception is that physicians refer patients to services based on "objective" factors, they argue that physicians are involved in a high degree of interpretation when making referrals. Physicians interpret the patient's needs and whether or not the patient will benefit from services. Physicians also make these decisions within a policy and institutional context which shapes their interpretation of a patient's suitability for rehabilitation services (Foster & Tilse, 2003). "Referral decisions are, therefore, inherently complex and need to be understood as a dynamic phenomenon shaped, not only by characteristics of the individual, but also the interactions and interpretations of health professionals who operate within unique organizational and broader health care contexts." (Foster & Tilse, 2003, p. 2202).

The adoption of market principles and economic rationality within BC's health care context emphasizes "objective" outcomes and efficiency in quantitative terms (Armstrong & Armstrong, 1996; Garland, 1997). These numbers are then used to determine funding levels and measure success. Given this context, it is understandable that physicians in BC will decide whether or not a brain injured patient is eligible for rehabilitation services, in part, on their interpretation of whether or not the patient's brain injury (or rather the effects of the brain injury)[26] are amenable to quick improvement with intense therapy. In addition to these economic or pragmatic considerations, physicians' interpretations can also be influenced by moral and social discourse that construct the patient as "deserving" or "undeserving" (Hughes & Griffiths, 1997). Hughes & Griffiths (1997), in their analysis of the discourses of health professionals who were responsible for referring and accepting brain injured patients into a rehabilitation facility in the UK, found that often a moral or social discourse was used to categorize potential patients as "deserving" or "undeserving". A patient's "deservingness" of services was based on her/his past progress, potential for recovery, the social support available on discharge, family circumstances, and her/his potential to return to work. In other words, assessments and interpretations of a patient's suitability for brain injury rehabilitation went beyond clinical and "objective" standards.

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[26] Foster & Tilse (2003) point out that "brain injury" refers to the cause of a disease rather than a disease itself; however, brain injury is often treated as a disability category within rehabilitation.

At this key site of intersection between caregiving practices and health care professionals and services, advocacy care work emerged as a dominant form of care work. Caregivers actively engaged in constructing their spouse as "deserving" of rehabilitation both through their direct mediation with health professionals and through their practices of seeking rehabilitation services. For some caregivers, such as Emily and Sofia, their advocacy work centred on challenging the powerful discourse that their husbands were "undeserving" of and ineligible for services because they were "too injured". Because both Emily's and Sofia's husbands require such a high level of care (24 hour care) at different points both women were encouraged by social workers and nursing staff to place their husbands in a long-term residential facility. Emily describes how a hospital social worker told her that her husband should be placed in residential care because his care needs were very high and she was "much too young to just give up [her] life". Sofia also describes how she felt that hospital staff had "given up" on her husband and she was unable to access in-patient rehabilitation for him.

Emily, on the other hand, was successful in transforming her husband's categorization from "too injured" to "well enough" and therefore "deserving" of rehabilitation through her care work. Emily spent her time at the hospital providing direct care work in the form of therapy and exercise in order for her husband to reach the physical eligibility criteria:

> *I: And he was in the hospital for 3 months, at [name of acute care hospital] and then what happened after the 3 months?*
>
> *E: Well they weren't sure that he would be a candidate for rehab since that – you have to show that you have to sit up for a certain amount of time and that you're going to, you know, there's so many people that want to get in rehab that you have to be able to benefit from it. I guess that was it and they weren't sure he would. Um so the physiatrist [physician who specializes in rehabilitation medicine] kept coming around and taking a look at him and I kept making him sit up taking him out for walks – he didn't want to go but he was going. He was gonna sit up for 3 hours if it killed him (laughing). You know it was that or I didn't know how to take care of him or I was afraid that he would not be able to come home. And so one day the physiatrist came and he [Emily's husband] was having a really good day and he looked at him and said, 'yeah I think we'll give him a trial at the rehab'. Then he went to [brain injury rehabilitation facility as an in-patient].*

...

E: Yeah because without that, that hope of rehab, then you're - there's not much, I didn't know how else that he would improve you know. Because like with physio and the occupational therapy and the speech that they got while he's in acute care wasn't bad for acute care but it was hit and miss depending on who needed them more that day right. It was never a definite thing that would happen, but I realized that without those people helping him I didn't know how to help him. He wasn't even able to sit up or stand at all. I'm like, how will I take care of him if he doesn't learn to stand a bit so I thought rehab could mean all the difference in his life and it did.

Emily also engaged in advocacy care work to access in-patient rehabilitation for her husband:

E: I talked to the social worker, I talked to everybody I – yes, oh yes – I was very adamant. I was really pushy probably. You know he needed that chance and I think I let them know that it was very important.

...

E: ... if you... don't have an advocate you're just gonna be shipped off to a dementia ward because they – if you can't communicate they don't think you have the intelligence and that's a sad thing.

...

E: Right and then there's other people who fall through the cracks. And that he stayed as long as he did was only because I kept insisting. I kept pushing and asking and I think if he didn't have me advocating for him he would have probably, they would have shipped him off to extended care 'cause he couldn't say anything to them.

...

E: And I know they can't, they can't take everybody and I understand that, but when, you know, you don't really care about that when it's your loved one

I: No you don't

E: No. That's the rest, you can't worry about the rest of the world. You just have to fight for your person.

Through her continuous care work Emily transforms her husband from "undeserving" to "deserving" of rehabilitation in direct and indirect ways. Directly, Emily describes advocating for her husband with health professionals. Indirectly, through her ongoing care work Emily practices the social and moral discourse of a committed wife

which arguably influences the physician's interpretation of her husband's "deservingness". The last part of the quote above also illustrates how Emily was aware of the scarcity of rehabilitation services and the need to "fight", or advocate, for a spot in this context of marketization of health care.

While Emily and Sofia are caring for husbands who were viewed as outside the range of eligibility and "undeserving" because they were "too disabled", Chloe (Non-Immigrant, early 40s) and Hannah (Immigrant, mid 50s) are caring for husbands who are outside the range of eligibility because they are considered "not disabled enough". Both Chloe's and Hannah's husbands are diagnosed with a mild brain injury; an injury that is not easily recognized by the community because they are able to function independently in their daily lives and are able to maintain paid employment. Because ICBC insurance was involved for both men, both were required to undergo a number of tests and assessments in order to determine the severity of their injury and their level of insurance benefits. Hannah and Chloe discuss at length the deficiencies of these medical and cognitive tests in determining disability. The issue from their perspective is that while these tests are designed around a "cut-off" point (i.e. if you fall above the "cut-off" you are not disabled whereas if you fall below the "cut-off" you are disabled), these measures are insufficient and do not measure change in the person pre- and post- brain injury nor do they acknowledge the real life effects of the brain injury. Chloe describes how the clinical measures for assessing and measuring disability are inadequate:

> C: ... But no there's just, I don't know if it's because he was presenting so well or because he was already, see that's the thing if you're already at this level (she points up high extending her arm above her head) before the accident and the accident – well let me rephrase that (she stands up to demonstrate). This is, I'll call it a vegetative state (she brings her hand close to the floor) and that's your total highest, highest achiever (she stretches as tall as she can and extends her arm as high as it'll go) and this is average (she points about waist level) let's say. Well if you're up here (pointing above her head) and you come down to here (she drops her hand a bit) after your accident, sure you're above average but you were up there to begin with. Whereas if you're here (pointing at around chest height) and you go from here to here (dropping her hand below waist) it looks like a bigger step, like 'oh my gosh, something's terribly wrong'. And I'm not making fun of the person that's average, but it seems like a bigger drop so people go, 'oh she's like mentally handicapped' and they're like, 'what's this guy up here complaining about he's here' (pointing above waist height), so they just, I don't think anybody took it as seriously as it should have been from the start.

For both women there is a stark contradiction between the test scores which indicate "no disability" and their daily lives with their husbands. Hannah discusses the effects of having to raise their children on her own because her husband could not deal with any extra stress and having to return to work to support the family while her husband took time off from his employment. Chloe, whose husband had his brain injury when they were both in their early 30s, asserts her husband's disability because she lives and experiences it in various ways everyday including: the inability to make medium or long term plans as a couple; the supervision she provides when they go out to make sure that he is not too tired; the extra attention and time she puts into planning their daily menus and routines in order to have a "smooth" home life; and the loss of shared dreams and goals.

Chloe contests and challenges this image of her husband as "not disabled enough" for services by advocating for rehabilitation and therapeutic services. Chloe's care work for her husband involves transforming her husband as "in need" of services. She does this through her advocacy care work in seeking out services to address the cognitive deficits caused by his brain injury. Her advocacy work emerged at the site of negotiating rehabilitation services because of a gap in services available to her husband. Because of the non-visible nature of his brain injury, much of Chloe's advocacy work centres on contesting the clinical measures which construct and define her husband as "not disabled" and therefore does not meet the criteria of those "deserving" of any rehabilitation services. This was particularly challenging given that her husband's disability was contested in several sites. Because he was injured in a motor vehicle accident ICBC was involved and in the legal arena his disability was constructed and contested by experts and assessments for litigious purposes. In the medical arena his disability was contested given his high scores on clinical cognitive tests and lack of visible injury on biomedical scans. Finally, in the therapeutic arena his disability was contested or defined according to his ability to "function" in the work place. In spite of these challenges, Chloe continues to construct her husband as disabled and "deserving" of services through her advocacy care work:

> C: Well I think trying to get funding for things and, but what I've learned is that if you want someone to get better you have to go and you have to – and when I say fight, I mean positively – go out and you know in a positive way you ask it and you don't give two hoots about where the money's coming from. You're gonna find the money to get that person better. And, um, that's – when I think

about it – that's probably one of our saving graces because so many people say, 'well I can't do that because ICBC isn't going to pay', well ICBC doesn't care about you so, um, sorry (laughing).

Chloe actively seeks resources in the community through both formal channels (support groups, online, community resources) and informal channels (people she meets in social settings) and organizes these services herself through their family physician. Through her ongoing caregiving practices to find and access rehabilitation services for her husband in the community (both traditional and non-traditional therapies) she continues to construct her husband as "deserving" of rehabilitation services.

The ambiguity of the categorization of Hannah's and Chloe's husbands as "disabled" or "not disabled enough" also extend to their own ambiguous identities as caregivers. Whether or not a family member is categorized as a "caregiver" in the health field depends largely on the categorization of their brain injured family member as "disabled" according to biomedical discourses. This demonstrates the complex co-constitutive relationship between the identity or category of the brain injured family member as "disabled" and the identity or category of the "caregiver" by health professionals. Both Hannah and Chloe speak at length about being excluded from much of the planning regarding their husbands' care. They were often not included in discussions of their husbands' therapeutic process or invited to meetings involving health professionals. Chloe describes how she was denied information by a physiotherapist who was treating her husband because of reasons of confidentiality. Hannah responded to this ambiguity by giving herself a new category or title, that of "care supervisor"; someone that she describes as being the hub of the wheel and organizing things from a distance.

H: (Pause). No, I don't think so. I think it would, it would, I think I'm more like a care supervisor like from a more detached position, sort of ah, observing what's going on and then trying, I try to be ready if I'm needed, that sort of thing more. Um, because he does quite well on his own and, um, yes, yes.

On the other hand, while Chloe reflects on the ambiguity of her role as caregiver she accepts this label:

C: ... I guess maybe I don't see myself as a caregiver because people think that caregivers are people that look after invalids or that can't do anything for themselves or that kind of thing but as one report said, 'Chloe is like an invisible

caregiver' and so I can see that it just, I mean, I'm just doing what he, I guess I don't think about it in some ways because I'm just doing what needs to get done.

Chloe continues to construct herself as a caregiver through her ongoing practices of advocacy both for her husband and for herself. As her husband's caregiver Chloe continues to seek out therapeutic services for her husband and in asserting her own role as caregiver, Chloe advocates through making educational presentations in the community regarding what it is like to be the wife of someone with a mild brain injury.

My initial reaction to the interviews with Hannah and Chloe was also to question their role as caregivers. Given my own experiences in providing care, my image of the caregiver at the start of this study was someone who was involved in extensive direct care work of individuals with high care needs; an individual caring for someone "that can't do anything for themselves" as Chloe mentions in the quote above. Incorporating the narratives and experiences of Hannah and Chloe into my analysis involved setting aside my own assumptions of caregiving practices and interpreting their experiences from their own perspectives. Hannah describes how her husband's mild brain injury essentially meant the "death" of who her husband was before. She describes the difficulties in mourning for someone who is technically still alive. Hannah's emotion care work and the resulting changes to their lives following her husband's brain injury are no less significant to her than to the caregiver who is caring for a spouse who has more visible disabilities and requires a higher level of direct care. Chloe also discusses at length the changes to her life following her husband's brain injury and the lack of recognition that she receives from other caregivers of those more severely injured. By considering the care work that emerges when a disability is not recognized or visible I was able to challenge my own narrow definition of caregiving and how I conceptualized care work as well as how caregiving has been understood in research.

Returning Home – Caring in the Community

Returning home from the hospital was a challenging transition for all the participants. For Kathy (Immigrant, late 60s) and John (Immigrant, late 50s) the initial return home from the hospital was premature and was precipitated by gaps in health care services. In spite of Kathy's advocating for treatment for her husband's brain injury, her husband's initial discharge from the acute care hospital was carried through without

any brain injury rehabilitation or planning involving Kathy. Kathy's husband had multiple injuries from a fall while he was working outdoors and because other injuries were considered more medically urgent than his brain injury they received primary medical attention. In contrast to the medical staff's attention to his other injuries, Kathy's care work was focused on dealing with the effects of her husband's brain injury. Part of this care work involved advocating for attention to be paid to his head; however she describes how her efforts were largely disregarded by hospital staff:

> K: ... [H]e was in there [acute care hospital] about 2 weeks until they stabilized him... and the medication and the antibiotics and everything was working and they started him on, ah when he was able to, on OT, occupational therapy, and speech therapy um until he got, just barely moving.

> ...

> I: Ok, you mean getting up out of bed?

> K: Getting up and starting to walk a little bit. And in my opinion I don't think it was enough, but somehow I don't know if they needed the bed there or what. And in the meantime I met the, ah, social workers in there. They were very sympathetic and together with the OT person that was working with my husband there and I kept telling them that's not only that, like he's – his brain wasn't functioning, his brain wasn't functioning, you know. Like he, he wanted to lay down all the time even when the OT person worked with him. He didn't want to sit in a chair, he couldn't sit in a chair. They had to tie him down all the time right. And all he wanted to do was laying down, all he wanted to do was laying down. And ah like feeding, you had to feed him.

> ...

> K: They [hospital staff] knew because I've talked to them you know I've talked to them and I communicated as best I could with them, 'watch out for this, watch out for that' because they didn't know my husband. I knew how he was and the things that he did, that was something very, very severely wrong right.

Kathy describes how she was in disbelief when the hospital staff told her that her husband was being discharged to their home. There was no discharge planning meeting involved nor were there any community services organized to assist with the transition. Kathy was assumed to be the "able and willing" caregiver. While she was willing, her physical, emotional, and social resources were extremely stretched and limited which compromised her ability to care for her husband at home. In addition to dealing with her husband's aggressive behaviour resulting from his brain injury, she was

also responsible for taking him to ongoing medical appointments and out-patient services every other day. Because Kathy does not drive and her husband's behaviour was extremely difficult to manage, she did not feel comfortable taking him on public transportation and had to scramble to piece together help from friends and her daughter. This lack of coordinated discharge planning and Kathy's exclusion from the discharge process reflects on one level the assumption that she is an "able" caregiver; that she will be able to single-handedly manage her husband's care by herself at home and should she need help that she has the resources to seek out this help herself. This assumption, that the family is able and willing to care, underlies much long term care policy (Hooyman & Gonyea, 1995). For example, the shortened hospital stays and severe cutbacks to home support in BC discussed earlier in the context chapter (e.g. Cohen, et al., 2006; Fuller, et al., 2003) are based on this assumption and the effect is to download care to the family and women. Kathy's experiences are an example of what happens when policy assumptions do not match the reality of individual lives. While Kathy was "willing", she was not "able". As the oldest caregiver in the sample, Kathy describes how her own physical health was quickly deteriorating during this period because of the stress of her husband's unexpected injury. Kathy's ability to care for her husband at home was further compromised by the lack of community services available for her. She did not receive any home support or ongoing assistance with her husband's challenging behaviour. As a result of Kathy's ongoing advocacy, her husband was later admitted for in-patient rehabilitation.

John's wife, on the other hand, was referred to in-patient rehabilitation services following her neuro-surgery and short term stay in acute care. However, because of a waitlist she returned home for a few weeks before starting her rehabilitation and it was during this period that John's advocacy work emerged in the absence of brain injury support services in the community. John and his wife live in a smaller community where there are less brain injury services than in Vancouver. John describes this uneasy transition to home:

> J: Mm hmm. Yeah. And then began the difficult time because when they [acute care hospital] released her I had to bring her home, um you know, she, she visually, you know stimulation, you know the light and all this sort of thing and it was just too much for her, or noise or all that sort of thing. Um I brought her home and ah I, you know, I cared for her, but this is when it was very difficult because there was nothing in the community to assist me at this point in time. It was sort of like released from the hospital and 'ok you're on your own'. And this

is when I started kicking into gear, I said, I know a lot of people in the medical field and in the psychiatric through, through my job. You know we've got a neuropsychologist there and psychiatrists who I know personally by working with them in the facility. So you know they gave me a lot of, I had a lot of connections, and then since I hooked up with GF Strong, 'cause there was a waiting list, [my wife] was put on a waiting list a priority waiting list as far as rehab.

...

J: Well in the early days I did yes, I definitely did, yeah [referring to a question I had asked earlier regarding organizing his wife's health care]. I was phoning and researching and, and bothering people. I thought, I mean, it gave me something to do and I was driven, I was actually driven.

Once home, John describes himself as *"kicking into gear"* and advocating for support services in the community. He goes on to say that in his experience *"you can't just let health care happen"* and stresses the active role that caregivers need to take in ensuring that their family member receives appropriate care. John's statement sums up a theme throughout the interviews of all participants which is that caregivers (and individuals) need to actively advocate and pursue health services in order to access what is available; not unlike a competition for scarce resources.

Even in cases where discharge to the home was not premature nor initiated by inadequacies in health care services, the transition to home from the hospital or rehabilitation facility reflects a distancing between the caregiver and services. When caregivers return home with their brain injured family member the reach of health services is stretched and the caregiver is responsible for the costs of care such as medication and physiotherapy. In the Lower Mainland, support services for brain injury survivors and their families in the community range from out-patient services from brain injury programs, case management through the Brain Injury Unit of their local health authority, community programs by local brain injury organizations, and general programs by local health units.

The caregivers in this study who are caring for husbands with the most intense care needs, Kathy, Emily and Sofia, were involved with a case manager and received paid home support. These services; however, are organized differently for the three caregivers. Kathy and Emily both receive home support directly through their individual case managers who contract out these services to private home support companies (an

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example of the privatization of health care). While a regular weekly home support schedule works for Kathy, this home support structure does not work for Emily. Emily chooses to organize her home support around her own schedule rather than incorporating a fixed weekly schedule into how she organizes her care work. One reason for this is the extra effort and disruption of bringing in and training a new home support worker. Emily recounts how the home support worker was late in arriving twice: once when she had a scheduled surgical procedure for herself and a second time when she had made arrangements to go out with a friend. Emily discusses how this lack of reliability causes her a great deal of stress, often more stress than it is worth, and therefore she does not use the maximum monthly hours of home support for which she is eligible. As Cohen, et al. (2006) suggest, severe cutbacks in home support provision in BC have reduced the ability of workers to provide consistent services to clients and their caregivers. Emily understands the inconsistency in home support workers as partly "her fault" because she does not maintain a consistent weekly schedule; a moral judgment about her choice stemming from a powerful discourse that states the caregiver should be subordinate to health structures. However, by choosing to organize home support around her schedule rather than the other way around, Emily is able to maintain her own schedule which is more consistent with their lives prior to her husband's brain injury and preserve her "social identity". Dyck, et al. (2005) argue that when public care enters the private home, the homes and bodies of the disabled become inscribed with disability through the organization of the home and body. The researchers demonstrate how women receiving care in the home contest this inscription of disability by maintaining a "social identity" through their personal grooming or by keeping certain spaces in their home private. For Emily, the choice to maintain her own weekly schedule according to her own timeline is also her way of contesting the inscription of disability. She comments several times throughout her interviews that she does not want their lives to end; that they are too young to live as if their lives were already over. The difference between Emily's and Kathy's response to an imposed home support schedule may be due in part to their difference in ages. While Kathy is in her 60s and was at a stage in life where she was looking to slow down when her husband had his injury, Emily is in her 50s and was still living a very active lifestyle with her husband when he had his stroke.

Sofia's home support is organized differently as is her home. While Emily is able to maintain a social identity in her home space, Sofia and her husband's apartment is clearly inscribed with signs of disability because of the medical equipment required to meet her husband's complex care needs. For example, Sofia's husband's specialized hospital bed is in the dining room. The transformation of the living room into her husband's bedroom and the permanent medical fixtures inscribes the home space with signs of his disability. Although Sofia also has a case manager, the paid caregivers that Sofia and her husband are eligible for is provided through CSIL (Choices in Supports for Independent Living). This program is funded by the BC Ministry of Health Services as part of its home support program and administered through the local health authority. Under CSIL the paid home support workers are hired, fired and paid directly by the care receiver (or the person managing their funds) rather than through the case manager and contracted services. This care arrangement was already in place prior to Sofia's husband's brain injury to assist him with his care for his previous medical condition; however, since his brain injury Sofia is now responsible for managing her husband's CSIL funds. Although this funding arrangement theoretically provides Sofia with greater control and more flexibility over the management of her husband's care than Emily or Kathy, in reality she finds it difficult to find and retain caregivers given her husband's extensive care needs. CSIL provides monthly block funding for paid home support therefore Sofia is limited in how much she can pay caregivers in order to stretch out the number of hours they work. Sofia describes how there is little incentive for paid caregivers to stay when they can make the same wage, if not more, caring for someone with less intense care needs. Sofia is currently unemployed in order to care for her husband and because they live on a very limited income she is not able to supplement CSIL funds with her own financial resources. Also, because of her husband's brain injury his communication is highly limited and he is no longer able to train the caregivers himself and explain what he needs directly to them. This means that Sofia must stay home and train and monitor her husband and the paid caregiver which she describes as causing more work than if she were to provide care for him directly herself. Sofia has chosen to care for her husband on her own for the time being although her goal is to find paid caregivers for her husband and to work in paid employment in the future.

Both Emily and Sofia are caring for husbands with high care needs which are compounded by their husbands' communication difficulties. Their caregiving

experiences illustrate the challenges for caregivers of family members with the most complex disabilities as they struggle with insufficient supports in the community. The health care supports that do exist, such as home support and CSIL, are limited in the way they are structured and/or in the amount of funding they provide to meet the caregivers' needs. Emily feels limited in her ability to use home support because of the inflexible structure of this service; if she does not have a consistent weekly schedule she cannot have a consistent worker. For Sofia, who is in her late 30s and in an employable stage in her life, caring for her husband limits her ability to work outside the home and contribute to their family income and her future economic security. The structure of CSIL funding assumes that either a family caregiver is available to supplement the care provided through CSIL (because they do not need to work outside the home or there are multiple family caregivers that can share this responsibility) or that the person receiving care does not require such a high level of care.

Caregiver Diversity – Resources and Gender

In this final section I focus my analysis on caregiver diversity and illustrate some of the differences in caregiving experiences and discourses in my sample of caregivers. Contrary to policy assumptions that paint a narrow image of the unpaid caregiver in long term care as a White, middle-aged to elderly, middle class woman my sample of caregivers range in their ethnicity, age, access to resources[27], and gender.

Rather than applying an analytic framework that treats these differences as objective causal factors I examine how differences in resources and gender play out in unpaid caregiving. Specifically, I focus on how resources associated with paid employment influence the caregiving practices of different participants. I follow this with a discussion of John's experiences and discourses as a male caregiver and examine his caregiving discourses within a gendered caregiving context.

Secure attachment to the labour force was an important resource for Emily and John. They were both in full-time professional employment at the time of injury and the

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[27] I chose to use the term "resources" instead of "socio-economic status" or "class" in this discussion because "status" and "class" require placing individuals into different categories of SES or class normally based on some combination of their income, education level, and type of employment. However, these categories are not useful in my analysis since I am interested in how different levels of resources (economic, social, etc.) influence caregiving practices and not in identifying specific categories of caregivers.

security of their paid employment provided them with the economic resources, flexibility and time to provide the intense and long hours of care in the early stages of their spouses' brain injuries. Both Emily and John were provided with paid leave from their employment to provide care in the hospital and Emily was able to negotiate a flexible work schedule from home in order to care for her husband when he initially returned home. This flexibility allowed her to work the minimum number of years required to avoid a large penalty to her pension. Since the injury, both Emily and John have taken early retirement; however, they continue to receive extended medical insurance through their former employers as they provide care in the community. In the current context of marketization and cut backs, this is a critical resource for both in subsidizing health costs such as physiotherapy and medication for their spouses living at home.

In addition to the direct economic benefits of paid leave and extended health insurance, the security of paid employment also freed up time for them to advocate for services for their spouses. For John, his employment also provided him with important social resources and connections to assist in his advocacy work. The physicians and health professionals who were his co-workers provided invaluable feedback for John when he discussed the diagnostic and rehabilitative services his wife was receiving. John describes how he felt like *"a kid in a candy store"* to have access to these professional opinions and to advocate for services accordingly.

In contrast, Sofia does not have any security provided through employment as she was not employed at the time of her husband's injury nor is she currently employed. Sofia and her husband continue to live on a very limited income provided by the state. Because of a lack of economic resources Sofia's caregiving practices include the additional challenge of securing money in order to access health services. For example, although Sofia's husband was considered "too disabled" to benefit from in-patient rehabilitation, he was eligible to receive therapy as an out-patient several times a week. In order to pay for the high cost of fuel Sofia had to piece together sporadic paid work. This extra unstable work combined with her care work for her husband left her extremely tired. The rehabilitation facility offered to go out to their home; however, this would be only two or three visits in total by the therapist so Sofia declined this option. She felt that her husband needed, and deserved, more therapy than what the home visits could offer. In part, Sofia was able to provide this intense level of caregiving because of her relatively young age and good health which provides her with the physical resources

needed to balance caring for her husband's complex needs with securing financial resources. However, the lack of economic resources also placed additional burden on her already high levels of care work.

As the sole male in my sample of participants John provides a unique perspective on caregiving. Because feminist caregiving research has largely neglected the caregiving experiences of men, his narrative is important in my analysis of caregivers. However, since John is the only male caregiver in this study, my interpretation of gendered differences is necessarily preliminary. According to the feminist literature reviewed I understood that as a male, John is a minority in his role as an unpaid caregiver (e.g. Stobert & Cranswick, 2006) and that the type of caregiving work that men do is generally different from women (e.g. Morris, 2004). Therefore, I approached his interview with an expectation of noting differences between John's caregiving practices and the care work of the other female participants. I found that analyzing his transcripts were challenging because I did not find the differences between his and the female caregivers' caregiving practices that I had expected from the literature. I had also assumed that John would be less likely to speak about emotion care work as a male; however, he spoke more extensively about providing his wife with emotional support following her brain injury than the female caregivers did for their spouses. At the same time, John's transcripts were very different from the others in that he provided less detail of his direct care work that emerged so readily in my interviews with the female caregivers and demonstrated some reticence in speaking about his direct care such as meal preparation. John only spoke about his direct care when I prompted him with very specific questions and described him and his wife as normally following traditional gender roles in the home. Contrary to much of the literature, there was a lack of difference between John and the other female caregivers in *what* they did. However, I noted a difference in *how* they spoke about their caregiving practices or the discourses they drew on to describe their care work.

John's goal to have his wife return home and to be her caregiver was clear from the outset. He identifies very readily with his role as caregiver and he describes how this role was immediately recognized by the hospital staff. John describes feeling like part of the health care team from the beginning:

> *J:... You know you have to be proactive and get out there and phone people and get the resources and all that and I did a lot of that. You know I even, when she*

was in [name of rehabilitation facility] I went to the meetings you know and what was happening to her I mean, they, which is what I enjoyed, I enjoyed being included as a care- 'cause they looked at the caregiver as a major part of recovery. They look at that now, it's a major factor. And that's why they got me involved at [name of acute care hospital] right in the beginning because they know how important it is for people with a brain injury, I mean, you're gonna be there for the rest of your life. It's never gonna go away so get 'em in 'cause they understand the patient you know.

Like the other female caregivers in this study, John describes providing a range of caregiving practices for his wife including direct care work, emotion care work, and a substantial amount of advocacy. What is noteworthy, however, is the difference in how John describes his care work as compared to the other caregivers. John draws on masculine discourses to describe his care work such as *"kicking into gear"*, being *"driven"* in his care work, and attacking his advocacy work as *"a project"*. The gendered articulation of his care work is also captured in his statement that *"you can't just let health care happen"*. While I pointed out above that this captures the active role taken by all caregivers in accessing health services, it is also consistent with a masculine discourse which assumes agentic ability to direct health care services to meet the individual's needs. Also in contrast to the other female caregivers in this study, John discusses "moving on" and not having his wife's brain injury be the central focus in their lives. This readiness to "move on" cannot be explained by John's wife's present condition (although she is quite independent and not visibly disabled she is not the "least disabled" of the brain injured spouses) or the length of time since the injury (other brain injured spouses who are "less disabled" had their injury earlier than John's wife).

I suggest that interpreting this difference between John and the other caregivers in their articulation of their care work requires consideration of the gendered context of caregiving. In his qualitative study of elderly male caregivers, Russell's (2007) analysis revealed that the gendered nature of caring and traditional gender norms made the transition to caregiving difficult for men. However, in contrast to earlier studies of male caregivers, once they adapted, the male caregivers in his study were heavily involved in their wives' direct care. John also was fully involved in every phase and form of his wife's care and did not receive any home support or care support from family members. In her study of fathers who are primary caregivers to their children, Doucet (2006) notes that several fathers describe caring in "estrogen-filled worlds". She illustrates the challenges of fathers, who do not fit the dominant image of the female caregiver, as they

navigate through female caregiving spaces such as playgrounds and parent-child community groups. Similarly, I suggest that there is tension in John's role as caregiver to his wife given the prevailing gendered association of caregiving with female or feminine qualities. John's use of masculine discourses to describe his caregiving practices provides an acceptable and accessible way for him to discuss traditionally female work. Secondly, his readiness to "move on" suggests that he does not consider his role as caregiver as something permanent; perhaps because of this inconsistency between the dominant image of the female caregiver and his identity as a male. In other words, he is able to conceptualize an "end" to his care work and an end to his identity as caregiver. This is consistent with Henderson & Forbat (2002) who, in their analysis of caregiver-care receiver dyads, write that when wives care for husbands it is seen as a "normal" extension of their marital relationship, whereas when husbands care for their wives it is considered as something "extra" to their relationship because it does not have the same level of normativity. Based on one male and 5 female caregivers, this study is limited in what it can suggest regarding gender differences in caregiving. However, John's transcript is suggestive and it illustrates that caregiving continues to be constructed as female and feminine work. While John used masculine discourses to articulate this work and his orientation to caregiving was different (i.e. caregiving was temporary not permanent) his caregiving practices included all forms and was not limited to traditionally male work.

CHAPTER 7: CONCLUSION

Conclusion

This examination of caregiving for a specific injury illustrates how unpaid caregivers provide care for a specific injury in a context of health care restructuring and marketization. Brain injury survivors often require a spectrum of health care services ranging from acute care to rehabilitation to long term community support. Through these various stages and sites of care, the caregivers in this study adapted their care work to respond to gaps or inadequacies in health services. These gaps included: stretched and insufficient nursing care in hospitals, scarce rehabilitation services resulting in competition for beds and waitlists, and inflexible and inadequate community supports. With cutbacks to nursing care in the hospital and greater reliance on family members to provide basic care in the public space of the hospital there is greater fluidity between "private" and "public" spaces and practices. Advocacy care work emerged as a dominant form of care when caregivers were negotiating rehabilitation services. Caregivers actively constructed and transformed their brain injured family member in order to fit stringent eligibility criteria of "in need" and "deserving" of services. The transition to care in the community was challenging for all caregivers as they assumed greater economic costs for care (such as for para-medical services) and were responsible for seeking out and advocating for support services. Those caring for spouses with the highest needs had the greatest difficulties in finding adequate support services.

In a context of marketization and diminishing services, unpaid caregiving requires the ability to adapt and respond to gaps in publicly funded health services. Caregivers in this study drew on their personal, economic, and social resources in order to respond to these gaps and advocate for services. This health care context places a great deal of responsibility on unpaid caregivers to ensure that their family member receives adequate care and results in greater disparity in health care between those with greater and lesser resources. Finally, a preliminary gender analysis of the caregivers in this sample is

consistent with recent work emerging in the literature examining male caregivers (e.g. Russell, 2007), gender did not appear to influence the caregiving practices but did affect the discourses used to describe care work. John's use of masculine discourses to articulate his care work reflects a gendered context of care.

What does it mean that such a high degree of advocacy was required by family caregivers to provide care and services to their family member? The need for persistent and committed advocacy care work by unpaid caregivers to secure services reflects a health care system where the goal of "universality" seems more a myth than a reality. Downloading the costs and the adoption of market principles in health care has meant cuts to services, narrower eligibility criteria for existing services, and greater disparity in health care for British Columbians. The narratives of the caregivers in this thesis illustrate the diverse challenges of providing care in this context of marketization of health care. However, a common feature shared by all the participants in this thesis is that they have the resources to ensure a certain level of care and quality of life for their brain injury family member. Perhaps the greatest failure of the current health care system then is felt by those caregivers and care receivers who do not have these resources. Sofia expresses this concern poignantly:

> S: And the thing is what about if I am the disabled person and I don't have anybody that represents me? Then you are lost. Because if you already have an injury you know you are already dealing with that now you have to fight for your rights and fight for what you can get, you don't have the energy to do all of this. Um now when you cannot speak and you have a brain injury you cannot remember anything you cannot even talk properly so then you're gone. You're stuck in places that nobody sees.

Policy Implications and Areas for Future Research

Although, as discussed earlier in this thesis, scholarly debate continues over the role of the state in individual lives, my exploratory research suggests that the state should share the responsibilities of long-term care. While the development and administration of these policies are very complex given the high degree of diversity between and amongst caregivers and women, this does not preclude the need for these policies. Several policy implications emerge from the interviews with the participants which deal with economic security in employment, funding for health services, and payment for care. The policy implications tied to employment deal with policies at the

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federal level and are attached to labour force participation while policy implications for funding services and payment for care are at the provincial level.

I briefly consider two policies related to paid employment. First, my research suggests a recommendation that employers provide caregiver leave benefits, which would place a shared responsibility for care onto the state and employers. Because BC does not require employers to provide caregiver leave for those caring for a dependent adult, providing this leave is largely at the discretion of the individual employer (Armstrong & Kits, 2004). Second, when individuals make the decision to take early retirement in order to provide care for an adult family member, there should be a policy option for individuals to continue contributing to their pensions. For example, Emily made the difficult decision of choosing early retirement because of her caregiving responsibilities. However, by taking early retirement Emily is not able to contribute to her pension which means she will be supporting her husband and herself on a smaller income when she turns 65. This restriction in effect penalizes the caregiver for providing care at home rather than supporting her in her long term caring work. Policy recommendations attached to paid employment are complex and have gendered implications given differences in labour force participation between women and men. Women are more likely to be precariously attached to the paid labour force and are more likely to be in part-time, temporary, or lower paid employment than men; therefore, supports attached to paid employment may have the effect of favouring men over women. Although these recommendations would support Emily in her care work, it is imperative to recognize that for many women, who make up the majority of caregivers, these policies may not be sufficient.

The second policy implication is to reinstate public funding for para-medical services and therapies, which the BC Liberal government cut in 2002, in order to support the caregiver and the disabled family member in the community. When care is provided in the community, the individual is responsible for the direct economic costs of care. These include the costs of maintenance for medical supplies such as wheelchairs, mobility aids, costs of medication, and ongoing therapy in the community. For several care receivers in this study, additional forms of therapy were critical to maintaining their mobility and therefore critical to their independence at home. For several participants, the private cost of therapies in the community were either beyond what participants were able to afford or were limited to what was covered through private medical insurance

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provided by their (or their spouse's) current or past employer. I suggest that cutbacks in public funding for para-medical services in the community, such as physiotherapy, signals a shift towards increased dependence on private forms of insurance (often attached to labour force participation) for caregivers and their disabled family members. This shift increases the disparity of access to health services for individuals based on their labour force participation and their level of economic resources.

The third policy implication deals with paying family members to care. This emerged as a policy issue for Emily and Sofia who are caring for husbands with the highest and most complex care needs. As illustrated in the preceding analysis, the complexity of their husbands' care needs creates the greatest difficulties in finding appropriate home support and respite. Caught in a catch 22, the caregivers who arguably require the most support due to their intense care work feel that they are least able to find appropriate support because of the complexity of their care work. Emily discusses how she would like to have the option of paying family members rather than home support workers to care for her husband while Sofia, who is struggling to balance paid employment with her caregiving, discusses how the state should allow for spouses to be paid for their care work. According to the *Public Funds, Family Commitment* (2002), payment of public funds for caregiving cannot be given to parents, children, or spouses regardless of their residence, or relatives living in the same residence as the person with a disability. Although some exceptions can be made based on language, cultural or geographic barriers, these decisions are made on an individual basis and are meant to be temporary. As such, this policy prohibits the support arrangements that may be most suitable for those caregivers with the greatest need.

Lastly, there are several areas for future research which build on this study and address the limitations outlined in the first chapter. First, for this thesis I focused solely on the perspectives of unpaid caregivers in understanding the interactions between caregiving practices and health care structures. An extension of this would be to include an examination of these interactions from the perspective of health structures and professionals and possibly the care receiver (depending on the severity of their injury). In particular further research which considers the complex process of referral to critical rehabilitation services from the perspectives of these various players would be useful in understanding how these services are distributed in a context of diminishing state support. Second, as an exploratory examination I did not focus on a particular health

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care policy or service. Therefore, an area of further research might involve considering a specific policy or policy guideline (such as payment to families or *Guidelines for Planning Brain Injury Services and Supports In British Columbia*) or service (such as home support or CSIL) in order to examine these in greater detail. Finally, although my aim was to obtain a diverse sample of caregivers there were limitations to their diversity and my analysis remains preliminary. It would be useful to examine in greater detail how specific intersections of gender, ethnicity, level of resources, age, and sexual orientation unfold for unpaid caregivers in their care work.

REFERENCE LIST

Acorn, S. (1995). Assisting families of head-injured survivors through a family support programme. *Journal of Advanced Nursing,* 21, 872-877.

Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health and Illness,* 27(2), 161-187.

Armstrong, P. & Armstrong, H. (1996). *Wasting Away: The Undermining of Canadian Health Care.* Toronto: Oxford University Press.

Armstrong, P., & Armstrong, H. (2004). Thinking It Through: Women, Work and Caring in the New Millenium. In K. R. Grand, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson, & K. Willson (Eds.), *Caring For/Caring About: Women, Home Care and Unpaid Caregiving* (pp. 5-44). Aurora: Garamond Press.

Armstrong, P., & Kits, O. (2004). One Hundred Years of Caregiving. In K. R. Grand, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson, & K. Willson (Eds.), *Caring For/Caring About: Women, Home Care and Unpaid Caregiving* (pp. 45-73). Aurora: Garamond Press.

Aronson, J. & Neysmith, S.M. (1997). The Retreat of the State and Long-term Care Provision: Implications for Frail Elderly People, Unpaid Family Carers and Paid Home Care Workers. *Studies in Political Economy,* 53 (Summer): 37-66.

BC Ministry of Health Website. Retrieved April 11, 2007 from http://www.healthservices.gov.bc.ca/socsec/index.html.

Brodie, J. (2002). The Great Undoing: State Formation, Gender Politics, and Social Policy in Canada. In C. Kingfisher (Ed.), *Western Welfare in Decline, Globalization and Women's Poverty.* Philadelphia: University of Pennsylvania Press (pp. 90-110).

Brotman, S. (2002). The Primacy of Family in Elder Care Discourse: Home Care Services to Older Ethnic Women in Canada. *Journal of Gerontological Social Work,* 38(3): 19-52.

Bryson, V. (2003). *Feminist Political Theory: an introduction.* Hampshire: Macmillan.

Canadian Policy Research Networks, Inc., (2005). *A Health Balance: Caregiving Policy in Canada – Backgrounder* (2005). Retrieved Dec., 28, 2005 from http://www.cprn.com/documents/40910_en.pdf.

Caregivers Association of British Columbia Website. Retrieved April 30, 2006 from http://www.caregiverbc.ca/website/.

Clarke, J. N. (2005). Fathers' Home Health Care Work When a Child Has Cancer: I'm her dad; I have to do it. *Men and Masculinities,* 7(4), 385-404.

Cohen, M., McLaren, A., Sharman, Z., Murray, S., Hughes, M. & Ostry, A. (2006). From Support to Isolation: The high cost of BC's declining home support services. *Canadian Centre for Policy Alternatives,* June 2006. Retrieved Feb., 16, 2007 from http://policyalternatives.ca/documents/BC_Office_Pubs/bc_2006/support_to_isolation.pdf.

Cohen, M., Murphy, J., Nutland, K. & Ostry, A. (2005). Continuing Care: Renewal or Retreat? BC Residential and Home Health Care Restructuring 2001-2004. *Canadian Centre for Policy Alternatives,* April 2005. Retrieved May 2, 2006 from http://policyalternatives.ca/documents/BC_Office_Pubs/bc_2005/continuing_care.pdf.

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color. *Stanford Law Review,* 43(6), 1241-1299.

Davies, C. (1995). Competence versus Care? Gender and Caring Work Revisited. *Acta Sociologica,* 38:17-31.

Dean, H., & Thompson, D. (1996). Fetishizing the Family: The Construction of the Informal Carer. In Jones, H. & Millar, J. I. (Eds.), *The Politics of the Family,* (pp. 145-165). Aldershot: Averbury.

Degeneffe, C. E. (2001). Family Caregiving and Traumatic Brain Injury. *Health and Social Work,* 26(4), 257-268.

Denzin, N. K. & Lincoln, Y. S. (2003). Introduction: The Discipline and Practice of Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Landscape of Qualitative Research: Theories and Issues (2nd Ed.)* (pp. 1-46). Thousand Oaks: Sage Publications.

Doucet, A. (2006). 'Estrogen-filled worlds': father as primary caregivers and embodiment. *The Sociological Review,* 54(4), 696-716.

Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). the home as a site for long-term care: meanings and management of bodies and spaces. *Health and Place,* 11(2005), 173-185.

Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of Caregiver and Family Functioning Following Traumatic Brain Injury: Social Support Moderates Caregiver Distress. *Journal of Head Trauma Rehabilitation, 17*(2), 155-174.

Fincher, R. (1993). Women, the State and the Lifecourse in Urban Australia. In C. Katz & J. Monk (Eds.), *Full Circles: Geographies of Women Over the Lifecourse,* (pp. 243-263). London: Routledge.

Florian, V. & Katz, S. (1991). The Other Victims of Traumatic Brain Injury: Consequences for Family Members. *Neuropsychology, 5*(4), 267-279.

Foster, M., & Tilse, C. (2003). Referral to rehabilitation following traumatic brain injury: a model of understanding inequities in access. *Social Science & Medicine, 56*(2003), 2201-2210.

Fraser, N. (1989). *Unruly Practices: Power Discourse and Gender in Contemporary Social Theory.* Minneapolis: University of Minnesota Press.

Friends of Women and Children in BC, 2003. *Report Card, January 15, 2003, BC Health Care Cuts and Caregivers: Diminishing Support, Shifting Responsibility.* Retrieved Nov. 16, 2005 from http://www.wmst.ubc.ca/pdf_files/fwcbcRep/FWCBCJan03.pdf.

Frosch, S., Gruber, A., Jones, C., Myers, S., Noel, E., Westerlund, A. & Zavisin, T. (1997). The long term effects of traumatic brain injury on the roles of caregivers. *Brain Injury, 11*(12), 891-906.

Fuller, S., Fuller, C. & Cohen, M. (2003). Health Care Restructuring in BC: A CCPA policy brief. *Canadian Centre for Policy Alternatives.* Jan., 2003. Retrieved May, 2, 2006 from http://policyalternatives.ca/documents/BC_Office_Pubs/health_restructuring.pdf.

Garland, D. (1997). 'Governmentality' and the problem of crime: Foucault, criminology, sociology. *Theoretical Criminology, 1*(2). 173-214.

Gilligan, C. (1997) In a Different Voice. In S. Kemp and J. Squires (Eds.), *Feminisms.* Oxford: Oxford University Press.

Glossary of Brain Injury Terms (n.d.). Retrieved Nov. 23, 2006 from http://www.adlergiersch.com/brain_terms.cfm.

Graham, H. (1983). Caring: A Labour of Love. In J. Finch & D. Groves (Eds.), *A Labour of Love: Women, Work and Caring,* (pp. 13-29). London: Routledge.

Graham, H. (1991). The Concept of Caring in Feminist Research: The Case of Domestic Service. *Sociology, 25*(1), 61-78.

Graham, H. (1993). Feminist Perspectives on Caring. In J. Bornat, J. Johnson, C. Pereira, D. Pilgram and F. Williams (Eds.), *Community Care: A Reader*, (pp. 124-133). London: Macmillan.

Grubbs, L. A. R. (2003). Phenomenological Inquiry of the Primary Caregiving Experience: Challenges, Rewards, and Hopes for the Future. *Dissertation Abstracts International, 64*, 6, Dec, 2272-A. (UMI No. DA3092818).

Guberman, N., Maheu, P., & Maille, C. (1992). Women as Family Caregivers: Why Do They Care?. *The Gerontologist, 32*(5), 607-617.

Guidelines for Planning Brain Injury Services and Supports In British Columbia, BC Ministry of Health Services and Ministry of Health Planning. January, 2002. Retrieved June, 27, 2006 from: https://www.hlth.gov.bc.ca/mhd/pdf/guidelines_brain_injury_2002.pdf.

Heaton, J. (1999). The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness, 21*(6), 759-777.

Henderson, J. & Forbat, L. (2002). Relationship-based social policy: personal and policy constructions of 'care'. *Critical Social Policy, 22*(4), 669-687.

Hill Collins, P. (2000). *Black Feminist Thought: knowledge, consciousness, and the politics of empowerment, (2nd Edition)*. New York: Routledge.

Holstein, J. A. & Gubrium, J. F. (1995). *The Active Interview*. Thousand Oaks: Sage Publications.

Hooyman, N. R., & Gonyea, J. (1995). *Feminist Perspectives on Family Care: Policies for Gender Justice*. Thousand Oaks: SAGE Publications.

Hooyman, N. R., & Gonyea, J. (1999). A Feminist Model of Family Care: Practice and Policy Directions. *Journal of Women and Aging*, 11(2/3), 149-169.

Hughes, D. & Griffiths, L. (1997). "Ruling in" and "Ruling out": Two Approaches to the Micro-Rationing of Health Care. *Social Science and Medicine,* 44(5). 589-599.

Katz, S., Kravetz, S. & Grynbaum, F. (2005). Wives' coping flexibility, time since husbands' injury and the perceived burden of wives of men with traumatic brain injury. *Brain Injury,* 19(1), 81-90.

Kingfisher, C. (2002). Part 1 The Big Picture: Globalization, Neoliberalism, and the Feminization of Poverty. In C. Kingfisher (Ed.), *Western Welfare in Decline, Globalization and Women's Poverty*. Philadelphia: University of Pennsylvania Press (pp. 3-61).

Knight, R. G., Devereux, R., & Godfrey, H. P. D. (1998). Caring for a family member with a traumatic brain injury. *Brain Injury,* 12(6), 467-481.

Kolakowsky-Haynor, S. A., Miner, K. D., & Kreutzer, J. S. (2001). Long-Term Life Quality and Family Needs After Traumatic Brain Injury, *Journal of Head Trauma Rehabilitation,* 16(4), 374-385.

Levine, C., Reinhard, S. C., Feinberg, L. F., Albert, S. & Hart, A. (2003). Family Caregivers on the Job: Moving Beyond ADLs and IADLs, *Generations,* 27(4), 17-23.

Lincoln, Y. S. & Guba, E. G. (2003). Paradigmatic Controversies, Contradictions, and Emerging Confluences. In N. K. Denzin & Y. S. Lincoln (Eds.). *The Landscape of Qualitative Research (2nd Ed).* (pp. 253-291). Thousand Oaks: Sage Publications.

Litt, J. (2004). Women's Carework in Low-Income Households: The Special Case of Children with Attention Deficit Hyperactivity Disorder. *Gender & Society,* 18(5), 625-644.

Machamer, J., Temkin, N. & Dikmen, S. (2002). Significant Other Burden and Factors Related to it in Traumatic Brain Injury. *Journal of Clinical and Experimental Neuropsychology,* 24(4), 420-433.

Mann, S. A. & Huffman, D. J. (2005). The Decentring of Second Wave Feminism and the Rise of the Third Wave. *Science & Society,* 69(1), 56-91.

Marsh, N. V., Kersel, D. A., Havill, J. H. & Sleigh, J. W. (1998a). Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury,* 12(3), 225-238.

Marsh, N. V., Kersel, D. A., Havill, J. H. & Sleigh, J. W. (1998b). Caregiver burden at 1 year following severe traumatic brain injury. *Brain Injury,* 12(12), 1045-1059.

Mason, J. (2002). *Qualitative Researching* (2nd Ed.). London: Sage Publications.

Mauthner, N. S. & Doucet, A. (2003). Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology,* 37(3). 413-431.

McCall, L. (2005). The Complexity of Intersectionality. *Signs: Journal of Women in Culture and Society,* 30(3), 1771-1800.

McKeever, P., & Miller, K. L. (2004). Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices. *Social Science & Medicine,* 59(2004), 1177-1191.

McPherson, K. M., Pentland, B. & McNaughton, H. K. (2000). Brain Injury: the perceived health of carers. *Disability and Rehabilitation,* 22(15), 683-689.

Minnes, P., Graffi, S., Nolte, M. L., Carlson, P., & Harrick, L. (2000). Coping and stress in Canadian family caregivers of persons with traumatic brain injuries. *Brain Injury,* 14(8), 737-748.

Morris, M. (2004). What Research Reveals About Gender, Home Care and Caregiving: Overview and the Case For Gender Analysis. In K. R. Grant, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson, & K. Willson (Eds.), *Caring For/Caring About: Women, Home Care and Unpaid Caregiving.* Ontario: Garamond Press.

Moules, S., & Chandler, B. J. (1999). A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Injury,* 13(12), 983-993.

Murray, H. M., Maslany, G. W. & Jeffrey, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury,* 20(6), 575-585.

Nabors, N., Seacat, J. & Rosenthal, M. (2002). Predictors of caregiver burden following traumatic brain injury. *Brain Injury,* 16(12), 1039-1050.

Neysmith, S. M. (2000). Networking Across Difference: Connecting Restructuring and Caring Labour. In S. M. Neysmith (Ed.), *Restructuring Caring Labour: Discourse, State Practice, and Everyday Life,* (pp. 1-28). Ontario: Oxford University Press.

Orloff, A. S. (1993). Gender and the Social Rights of Citizenship: The Comparative Analysis of Gender Relations and Welfare States. *American Sociological Review,* 58(3), 303-328.

Palys, T. (2003). Research Decisions: Quantitative and Qualitative Perspectives (3rd Ed.). Ontario: Nelson.

Ponsford, J., Oliver, J., Ponsford, M. & Nelms, R. (2003). Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury,* 17(6), 453-468.

Public Funds, Family Commitment: A review of government policy concerning public compensation to family caregivers in British Columbia, (2002). Retrieved Feb., 8, 2006 from http://www.healthservices.gov.bc.ca/hcc/pdf/publicfunds.pdf.

Pyper, W. (2006). Balancing Career and Care. *Perspectives on Labour and Income,* 7(11). Statistics Canada Catalogue no. 75-001-XIE. p. 5-15.

Russell, R. (2007). Men Doing "Women's Work:" Elderly Men Caregivers and the Gendered Construction of Care Work. *The Journal of Men's Studies,* 15(1), 1-18.

Sinnakaruppan, I. & Williams, D. M. (2001). Family carers and the adult head- injured: a critical review of carers' needs. *Brain Injury,* 15(8), 653-672.

Smith, D. (2005). *Institutional Ethnography: A Sociology for People.* Lanham: Altamira Press.

Solari, C. (2006). Professionals and Saints: How Immigrant Careworkers Negotiate Gender Identities at Work. *Gender & Society,* 20(3), 301-331.

Spitzer, D., Neufeld, A., Harrison, M., Hughes, K., & Stewart, M. (2003). Caregiving in transnational context: "My Wings Have Been Cut; Where Can I Fly?". *Gender & Society,* 17(2), 267-286.

Stinson, J., Pollak, N. & Cohen, M. (2005). The Pains of Privatization: How Contracting Out Hurts Health Support Workers, Their Families, and Health Care. *Canadian Centre for Policy Alternatives,* April 2005. Retrieved May 2, 2006, from http://policyalternatives.ca/documents/BC_Office_Pubs/bc_2005/pains_privatizati on.pdf.

Stobert, S. & Cranswick, K. (2006). Looking After Seniors: Who does what for whom? *Canadian Social Trends,* No. 74. Statistics Canada Catalogue no. 11-008-XIE. p. 2-6.

Thomas, C. (1993). De-Constructing Concepts of Care. *Sociology,* 27(4), 649- 669.

Traustadottir, R. (1991). Mothers Who Care: Gender, Disability, and Family Life. *Journal of Family Issues,* 12(2). 211-228.

Twigg, J. (2000). *Bathing – the body in community care.* London: Routledge.

Ungerson, C. (1983). Why Do Women Care?. In J. Finch and D. Groves (Eds.), *A Labour of Love: Women, Work and Caring* (pp. 31-50). London: Routledge.

Wallace, C. A., Bogner, J., Corrigan, J. D., Clinchot, D., Mysiw, W. J. & Fugate, L. P. (1998). Primary caregivers of persons with brain injury: life change 1 year after injury. *Brain Injury,* 12(6), 483-493.

Webb, D. (1998). A 'Revenge' On Modern Times: Notes on Traumatic Brain Injury. *Sociology,* 32(3). 541-555.

Wiles, J. (2002). Daily geographies of caregivers: mobility, routine, scale. *Social Science & Medicine,* 57(2003), p. 1307-1325.

Young, I. (1989). Polity and Group Difference: A Critique of the Ideal of Universal Citizenship. *Ethics,* 99(2), 250-274.

Zygun, D. A., Laupland, K. B., Hader, W. J., Kortbeek, J. B., Findlay, C., Doig, C. J. & Hameed, M. (2005). Severe Traumatic Brain Injury in a Large Canadian Health Region. *Canadian Journal of Neurological Sciences,* 32(2005), 87-92.

APPENDICES

Appendix A

"Caring for a Family Member with a Brain Injury: Unpaid Caregiving Practices, Capital, and Health Care Services"

Jennie Haw
Graduate student
Department of Sociology & Anthropology
Simon Fraser University

I am an MA Student in Sociology at SFU and my study is looking at the relationship between unpaid caregiving practices of people who are caring for a family member who has a brain injury and their experiences with health care services and supports (e.g. hospital care, rehab care, home support, case managers, respite care, community support services, etc.).

> If you are 19 years or older, consider yourself to be a primary caregiver to a family member with a moderate to severe brain injury, and would like to talk about your experiences in caring for your family member then please consider participating in this study.

Participating in this study involves an interview with open-ended questions to allow for discussion (with the possibility of a second interview one month later). Each interview will be approximately 1-2 hours in length and can take place at your home or an alternative location which is convenient for you.

If you are interested in participating, are unsure of whether or not you are eligible to participate, and/or have any questions regarding this study please contact me, **Jennie Haw**, at **[email address]** or **[phone number]**. **Contacting me does not obligate you to participate in this study in any way.**

Appendix B

Interview Framework

Provide preamble of a couple of sentences to remind participants of the purpose of the interview (i.e. what it is about) and to set people at ease

Preliminary question: Can you tell me a bit about yourself: your age, how you are related to your family member with the brain injury, etc. (NB: this may be better situated at the end of the interview depending on the specific interviewee)

Q1. Can you tell me about your family member's brain injury (i.e. when it happened, how it happened, who was involved, etc.)?

Q2. Can you tell me about the treatment or health services that you and your family member received following the brain injury?

Q3. Can you tell me how you became the caregiver to your family member (i.e. how was this decision made)?

Q4. Can you tell me what changed for you when you became a caregiver to your family member?

Q5. Can you tell me what a typical day for you as a caregiver is like?

Q6. Can you tell me about any services related to the brain injury (such as home care, respite care, community agencies, etc.) that you are currently receiving?

Q7. Can you tell me what kinds of services are currently available to you?

Q8. Can you tell me about your experiences in dealing with health care workers and health care services (and possibly insurance providers/adjustors)?

Q9. Can you tell me about how health and social policies have influenced your work as a caregiver (both positive and negative)? Do you have any policy recommendations?

Q10. Are there any other questions that we haven't talked about that you would like us to discuss?