HOME ALONE:
THE EXPERIENCES OF HOME SUPPORT WORKERS
IN A CLIMATE OF HEALTH CARE REFORM

by

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B.S.W., The University of British Columbia, 1994

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SOCIAL WORK

in

THE FACULTY OF GRADUATE STUDIES
School of Social Work

We accept this thesis as conforming to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

April 1998

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Date April 22, 1993
ABSTRACT

The transition from institutional to home based health care relies heavily on the caring work of Home Support Workers (HSWs). Despite the importance of their labor, HSWs are under paid, under valued and misunderstood. Policy guiding home based care does little to alleviate this paradox.

Therefore, the purpose of this study is to improve understanding about the ways home care policy impacts the caring experience. The question posed is, What are the experiences of Home Support Workers providing care to cognitively impaired elderly people in the community?

A feminist approach is applied in this qualitative study. Unstructured, interviews conducted with a sample of three HSWs where succeeded by a focus group of leaders in the home support industry. Findings reveal an emotional component to their caring work which is hidden and unrecognized. A model for integrating HSWs into the interdisciplinary care team is proposed.

Limitations of the study and future research are discussed. The timeliness of this topic, and the critical inequities inherent in the home support industry makes this study particularly relevant to social work.
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Acknowledgment

This thesis came to fruition because of the constant mentoring and support of my committee members, Elaine Stolar and Deborah O'Connor. Thank you for the lift.

I am also grateful to my family who nurtured me while I nurtured my thesis. In particular, I thank my mother, Minna, who began the Master's tradition in our family, and who became an honorary committee member due to all the chapters she reviewed.

My husband, Lance, deserves special mention for his substantial “hidden work” in this project. This is for you.
INTRODUCTION

A transformation is occurring in the way health care is provided to elderly people. Institutional care offers staff, expertise, supplies and support in a fixed location for the presumed benefit of care providers and recipients; however, these conditions carry a fiscal cost that society is no longer willing to sustain. Concurrently, the number of elderly health care recipients is rapidly increasing (BC Ministry of Health, 1991). In response, health care services are being redirected to the home where mobile care providers and the domestic setting replace expensive hospital services and infrastructure. In British Columbia, the Royal Commission report, Closer to Home, guides this health care reform, and it does so by relying heavily on the work of home support workers (BC Ministry of Health, 1991).

Although home support workers (HSWs) perform their duties in isolation, their work has larger social implications. They make it possible to implement policy reforms that support elderly people in their homes, enable early hospital discharges, and postpone costly nursing home admissions. Ideally, tax payers enjoy a savings, and seniors can maintain their independence. However, low wages, irregular schedules, work load, limited training, and undervalued, unrecognized work threaten the stability of the home support industry (Burbridge, 1993; Donovan; 1987). For a work force of HSWs to be secured for the future, crucial reforms will be necessary. Understanding the
experiences of the HSW is vital to improving the industry and to meeting the needs of an increasing number of clientele.

The topic of home support workers (HSWs) has both personal and professional relevance, and these experiences were the impetus for this study. I was employed as a HSW for several years as a means of funding my education, and during that time, I encountered both gratifying and challenging aspects of paid caregiving.

Although I recognized the value in my caregiving, and largely enjoyed my work, this was contrasted by the way I was treated by the agency. On many occasions I was spoken to in a tone and manner that made it clear I was not very important and not very bright, yet I was given the responsibility to care for frail older people in isolation from supervision or support. The ten hours of training I received did not prepare me for the extent of need I was confronted with in the community.

In an effort to avoid further negative experiences with the home support agency, I sought work outside the agency setting. I was hired by Mrs. M, a 90 year old woman who had also moved away from the formal agency structure to gain control over her own care. We were two women, one very young, one very old,
brought together by a system of home care that failed to meet the needs of the client and of the caregiver.

A particular experience with Mrs. M illustrates the difficulties experienced by HSWs and their clients. On one occasion, having assisted Mrs. M into the bath and awaiting her request to help her out, I accidentally locked myself out of her house. Deaf and physically impaired, Mrs. M was stranded and so was I - literally and figuratively. This was the result of her wanting to maintain some semblance of control in her life. She had to rely upon a 19 year old student with minimal formal training to help her with the most intimate details of daily living. I was tied to the work due to financial need, and without support or guidance, I learned by trial and error. We were interdependent and alone. After considerable time had lapsed in my frenzied attempt to gain access in the house, I finally shattered a window, finding a very cold, very frightened Mrs. M looking back at me from the bathtub. She could not have felt worse than I. How could a health care system with a mandate to keep people at home simultaneously disempower both workers and clients? This inspired my research.

More recently in my role as a social worker at a long term care facility, I witnessed the residual effects of what HSWs were experiencing in an atmosphere of comprehensive health care reforms. Cutbacks to institutional care
means elderly people are living in their homes longer before moving into nursing homes; therefore, the aging process and/or disease progression is more advanced. The new residents I met had more physical limitations and more cognitive impairment than individuals admitted even a year prior. While formal care facilities have a range of skilled, interdisciplinary staff to draw from, we still struggled to meet these care needs. How, then, were the home support workers coping? A first step towards learning this is to speak to HSWs about their work as professional caregivers.

Chapter one introduces the social theories framing the study and how they are used to understand the research topic. Chapter two builds the conceptual framework. Statistical information is presented about the field of home support work, and the associated terminology is defined. In addition, the literature pertinent to research on HSWs is reviewed, including a discussion of the limitations and strengths of the research. The prevailing feminist thought on women’s role as caregivers is considered; as is the prevalence and consequence of dementia. Chapter three consists of a historical survey of home care policy in Canada as well as a review of the literature on its current state. Chapter four is a detailed discussion of the methodology employed for this study, and Chapter five presents the findings of the two part inquiry. Lastly, the social significance of the results are considered in Chapter 6, and the study’s limitations and
implications for social work are addressed. Future research considerations are also presented.
CHAPTER ONE
THEORETICAL FRAMEWORK

This chapter introduces the two theories guiding the research and relates how they are appropriate standpoints for understanding the experiences of home support workers.

How an issue is understood depends upon the theoretical viewpoint employed. Therefore, it is crucial to present a framework of the theory utilized in this study so that I, the researcher, maintain consistency throughout each phase of the study, and so the reader can follow my logic. I use two primary theoretical perspectives to expand the understanding of HSWs experiences: feminism and poststructuralism. As macro theory, they are comprehensive, and in many instances, abstract, resulting in diverse interpretations of the same concept. For the purposes of clarity and brevity, I discuss only the theoretical elements that relate to this study. As a result, the following descriptions of feminism and poststructuralism cannot be considered comprehensive, but rather they are partial summaries. Each theory is a lens offering an alternative way of looking at the world, and in turn, each helps to highlight issues that may not be immediately visible from conventional standpoints.
A Feminist Paradigm

Feminism is a broad theory encompassing several diverse perspectives that converge in one important way: each school of feminist thought recognizes that women are “oppressed, repressed and suppressed” (Tong, 1989). The views differ in how they see this oppression originating, persisting, and how it can be rectified. For the purpose of this study, I will rely on a more inclusive representation of the major feminist standpoints incorporating the following tenets. Gender, class, economy, and social fixtures such as legal and political institutions are manipulated to shape a hegemony favoring men (Abel and Nelson, 1990). These themes are especially suited to a study concerning the status of home support workers within a changing system of health care.

Another important aspect of feminist theory is the legitimization of personal experiences (Tong, 1989). Unlike scientific thought which shuns subjectivity as a biased flaw, feminism embraces individual standpoints: the purpose is twofold. This is a rejection of the patriarchal, mainstream way of knowing which ultimately excludes women, and it is a deliberate effort to create new discourses that do reflect the female experience.

Because an overwhelming majority of HSWs are women, their exploited labor is considered a feminist issue. Feminism offers an historical context for comprehending the undervalued status of women and caregiving. Neysmith (1995), urges the application of feminist theory in gerontological research
because the people both providing care and requiring care are so often women.

Feminist research methodologies are fundamental to this study and are discussed further in Chapter 4.

The Poststructural Perspective

At its’ foundation, poststructuralism challenges assumptions that knowledge is impartial and essential to all people; rather, knowledge is constructed (Ray, 1996.) Thus, from a poststructural view, there is not one fixed truth: a reality does not constitute the reality; rather, it is one representation of the world (Gavey, 1997).

Poststructuralism is a mechanism for questioning all of our answers. However, it is a complex paradigm which Gavey (1997), asserts, “resists concise definitions.” By denying the existence of a single, stable reality, and endorsing the notion of subjective, constructed meaning, poststructuralism relies upon more abstract, complex descriptions to convey its message. Although this makes learning the paradigm a difficult task, it is a practical side effect for a theory which developed as a rejection to the age of Enlightenment and scientific thought (Kvale, 1996; Ray, 1996). Indeed, at its’ foundation poststructuralism rebuffs the imposition of social theory upon individual experiences because it merely adds to a constructed reality (Kritzman, 1988). Ironically, poststructuralism is itself a social theory, and thus, contains its’ own contradictions. An important note is-
that I do not distinguish between postmodernism and poststructuralism.

Although some of the literature considers slight differences between the two theories (Craib, 1984; Raye, 1996), most often they are regarded as the same (Epstein, 1995; Gavey, 1997; Kvale, 1996; Tong, 1989).

A central tenet of the poststructural paradigm is that dominant social forces achieve their power by defining or "constructing" our social world (Gavey, 1997; Ray, 1996). The individuals/groups with the most power disseminate their ideas to the largest audience, and consequently, their perspective becomes the dominant discourse - the notion accepted by most people as the truth. How this meaning is communicated depends upon who is speaking, what is said and how it is said. As such, poststructuralism is concerned with language and discourse (the system of beliefs, assumptions and values), the context in which people and knowledge develop, the inter-relations of people and ideas, and dichotomous relationships are all important cues for poststructuralism (Craib, 1984; Gavey, 1997; Kvale, 1996). They are capsules of evidence indicating that our social world is fluid and manufactured rather than concrete and constant, and thus, they accentuate the individuality of each person's experience. In this study I will hone in on these theoretical elements. A synopsis of these principles follows.

Firstly, when we speak our language it is generally with a sense that our words are benign tools for expressing ourselves. Poststructuralists see the reverse.
Language is a kind of silent power - a receptacle for subjective ideas about the world. When we speak, the words we use communicate more than the thought that is heard, we communicate a subtext about whether something is good or unacceptable, or if we are confident or uncertain (Kritzman, 1988). Conversely, language is a crucial instrument for peeling away dominant discourses to better understand an individual's circumstance, or societal phenomena (Gavey, 1997). Our language both constructs and deconstructs realities; thus, those who influence language hold a powerful resource (Kvale, 1996).

Secondly, language sets the world into dichotomous relationships, or "binary opposition" (Ray, 1996). The words we use symbiotically take their meaning from what they mean and from what they do not mean. This denies similarities and polarizes the social world into the haves and the have nots. Dichotomous relationships impart power on some while alienating others.

Thirdly, the knowledge we gain from one context is not directly transferable to another (Kvale, 1996). For example, the way a client describes her/his health care needs will be different from a caregiver's perspective. Not only do they view the situation differently, but also the descriptive words and the manner in which the thought is conveyed tell distinct stories. The same occurs when transferring an idea across mediums: we hear something, but we write down something else (Kvale, 1996). This phenomenon is related to context - each
individual is the sum of her experiences, knowledge, and values, and this becomes the lens for seeing the world. Clearly, we all see a different picture, and the process of telling our view changes it once our audience applies their own context.

Lastly, the idea of inter-relatedness is particularly important in research where I am seen to be “co-creating” the participants’ experiences by dialoguing about them (Kvale, 1996). What we speak simultaneously contributes to the story being created, and the knowledge gained from that interaction is not attributed to one person, but to every person involved - researcher and participant (Craib, 1984; Kvale, 1996). However, Kvale writes, “Different interpreters constructing different meanings of a...story is not a weakness, but a strength.” I can be a useful part of the research provided the knowledge output is understood for the reflexive nature in which it was created. The contribution of different voices all telling similar versions of a story upholds some values and creates others.

A poststructural approach to research on HSWs confronts the firmly held social construct that women’s caring is a biological function and an extension of the feminine nurturer role (Baines et al., 1991). Also associated with this discourse is the assumption that caring can be easily understood in concrete, finite terms (Aronson and Neysmith, 1996). Poststructuralism disputes this essentialist construction of home support work by looking to HSWs to uncover their own
meaning of caring work. Feminists would also agree that it is preferable to understand paid caring work from the perspective of the people experiencing it rather than from assumptions generated by outsiders looking in on the job - particularly when the outsiders have something to gain by confining the definition of caregiving. This idea will be explored further in Chapters 2 and 3.

In this study, poststructural theory will help to situate the experiences of HSWs within the broader health care structure and within society. This demonstrates how HSW's circumstances are not merely a result of their own actions, but rather, are symptomatic of external interference. A similar approach was employed by Aronson and Neysmith (1996), Neysmith and Aronson (1996), and Neysmith and Nichols (1994), with the affect of identifying specific areas where policy must reform. The knowledge gained from these studies and the direction it offers proves more practical for effecting change.

Combining poststructural and feminist theory is a delicate balance, and a debate persists as to whether poststructuralism works contradictory to feminist ideals (Ristock and Pennell, 1996). Gavey (1996), admits that by attributing women's experiences to larger social constructs, rather than accepting them at face value, poststructuralism is in conflict with feminist values. Feminists have argued that gender is important only for as much as it constructs our experiences, and as a result, the personal challenges women have confronted lose their surface
meaning (Ristock and Pennell, 1996). However, both ideologies challenge 
prevailing thought and seek to impact new ways of understanding power and
powerlessness. While poststructuralism acknowledges gender as an oppressive
tool, it also recognizes that society is not entirely constructed along lines of
gender. It looks beyond inequities that are immediately evident to unlikely
power sources, and by uncovering them, poststructural theory "equalizes the
playing field" for marginalized people (Ristock and Pennell, 1996). In this way,
poststructuralism is congruent with feminism. Despite variations in ideology,
poststructuralism and feminism are frequently linked in the literature, (Gavey,
1997; Ray, 1996, Ristock and Pennell, 1996; Tong, 1989), proving the theories to
be a compatible and effective pairing.
CHAPTER TWO

CONCEPTUAL FRAMEWORK OF HOME SUPPORT WORK

In the next two chapters, I define the terminology and phenomena implicit in the research topic. In addition, I review the current literature to identify how the issues have been studied to date and what gaps exist in our knowledge. This chapter relates specifically home support workers, women’s caring and dementia.

Home Support Workers

Home support workers play a pivotal role in facilitating health care reforms. They have long been an integral part of community based care, by helping people in their homes with whatever household and personal care tasks are necessary for safety and comfortable. As the supply of health care dollars diminishes, and the demand for home care soars, society has looked to HSWs to balance these obligations. However, this workforce may not be available or prepared to fulfill this need. This study focuses on their role in keeping health care at home.

Home support workers are known by a variety of job titles including homemakers, personal care attendants, home care aides and home care workers. The absence of one consistent job title is indicative of their diverse roles and a lack of industry standards. In addition, HSWs are generally denied
“professional” status and the credibility associated with this label. While the literature predominantly describes them as “non-professionals” or “paraprofessionals” I refer to HSWs as “professionals,” (Aronson and Neysmith, 1996; Donovan, 1987; Donovan et al., 1993). Using the term “professionals” to define the overwhelmingly female home support work force challenges the word’s patriarchal origins reconstructing how caring work is understood (Baines, 1991). However, labels are less of an industry concern than work conditions.

Within this unregulated industry, less than half the workers have formal training, yet they are required to perform their duties in unsupervised, isolated environments (Aronson and Neysmith, 1996; Burbridge, 1993). The typical worker is female, an ethnic minority, approximately 42 years of age, married and contributing half the household income (Burbridge, 1993; Donovan, 1989). Despite their valuable work, HSWs are paid as low as half the wage of their counterparts employed in institutional settings. Schedules are irregular, requiring staff to visit multiple homes in a single day while arranging their own transportation between sites. Not surprisingly, low wages and irregular hours are cited as the cause for an annual turn over rate of 56% of HSW in BC (BCAHSA Report, 1990).
Compounding the substandard work conditions is the chaotic administration of home support services. Although home care is financed by the government, HSWs are not government employees. The actual provision of home support services is managed by an entanglement of individual agencies that range from for-profit American health conglomerates, to non-profit agencies sponsored by community based service clubs. The enormous disparity among the service providers filters down to the home support staff who suffer from the lack of regulation for pay, job training and support. The final casualties are the frail elderly clients who, due to disability, are often already vulnerable individuals, and may deteriorate further without consistent, quality professional support.

With so much depending on the services of HSWs, it is ironic that only a small body of literature relates to this labor force (Aronson & Neysmith, 1996; Burbridge, 1993; Donovan, 1987, 1989, 1993; Eustis & Fischer, 1991, 1993; Hollander Feldman, 1993; Neysmith & Aronson, 1996; Neysmith & Nichols, 1994). However, the relatively new research being done on HSWs suggests this workforce is increasingly recognized as a foundation of health care.

With an annual turn over rate of approximately 60% in the home support industry, several studies have theorized about the reasons for difficulties in retaining workers (Burbridge, 1993; Gilbert, 1991; Hollander Feldman, 1993; Kane & Kane, 1987; Neysmith & Nichols, 1994; Schmid & Hasenfeld, 1993;
Weissert, 1985). Quantitative findings have focused on concrete causes such as burnout and low wages (Burbridge, 1993; Hollander Feldman, 1993; Schmid & Hasenfeld, 1993).

However others studies (Donovan et al., 1993; Gilbert, 1991; Neysmith & Nichols, 1994) used qualitative methods to identify the reasons HSWs resign, and the results were quite different. The findings indicate that HSWs have a commitment to their work that goes beyond monetary issues, and instead, they are challenged by factors like emotional strain, lack of personal advancement and inconsistent work schedules (Gilbert, 1991; Neysmith and Nichols, 1994). The discrepancies between these findings accentuate the lack of understanding we have of HSWs, and the need for further exploration into their experiences.

Regardless of the reasons for the labor shortage, the literature consistently affirms that the current home support industry will not meet future care demands (Burbridge, 1993; Gilbert, 1991; Hollander Feldman, 1993; Kane and Kane, 1987; Neysmith and Nichols, 1994; Schmid and Hasenfeld, 1993; Weissert, 1985). Burbridge (1993), considers this predicament from the perspective of economics and the theory of supply and demand. According to this theory, as the population ages, health care needs will increase, thereby, creating a demand for HSWs. Correspondingly, a stable supply of home care providers will develop
in response to the demand. Home support's failure to follow this traditional labor pattern distinguishes it as a unique industry worthy of further study.

Stemming from a need to secure a stable work force of HSWs, another body of literature relating to HSWs is emerging in the less academic journals. Typically focusing on home support administration issues such as time management (Servance and Cervantes, 1996), training (Clinco, 1997; Wilen et al., 1997) and retaining staff (Kennedy-Malone, 1996; Parsons and Taylor, 1996), these topics indicate a growing concern for the employing agencies and less attention towards improving conditions for the workers.

In her longitudinal study of HSWs in New York city, Donovan (1987, 1989) facilitated the unionization of HSWs and introduced unions as a strategic instrument for improving work conditions for home support workers; however, it has one critical shortcoming. Although Donovan's study makes a powerful argument for organized labor, it is limited by its specificity to New York city. Canadian HSWs belong to a different union and the urban context disregards the nuances consistent in rural work experiences. Her study highlights an important gap in the Canadian body of research.

Most of the current literature describes home support work in terms of the physical labor of caring (BCAHSA, 1990; Burbridge, 1993; Donovan et al. 1989;
Woodruff and Applebaum, 1996). These characteristics include helping with activities of daily living (ADLs) such as: meal preparation, cleaning, toileting, bathing, mobility (including lifts and transfers), and some medical treatments. While these tasks are a fundamental part of the HSW role, they represent a superficial view of the caring work performed. Conversely, Neysmith and Aronson (1996), adopted qualitative methods to study what HSWs identify as caring work. This research method enabled HSWs to describe their work more completely, producing findings that were inconsistent with the quantitative studies on the same subject. Work was characterized as: being supportive, alleviating loneliness, listening and helping clients with tasks that exceed what the worker is mandated to do. Qualitative research has revealed how traditional ways of understanding caregiving in terms of physical labor inadequately represent the actual work that goes into caring. This is an important deconstruction of HSWs' caring work, and because related qualitative research is rather recent and scarce, more research is warranted to build and support this alternative discourse.

There is also an interesting trend towards the consideration of quality in home care. This likely stems from the surge of attention focused on concepts like quality assurance and continuous quality improvement - ideals borrowed from the business and management sector. Several studies are concerned with improving the quality of work life for HSW with the intent of securing a labor
force for the future (Applebaum, Atchley, Bare, and McGinnis, 1990; Eustis, Kane, Fischer, 1993; Hollander Feldman, 1993; Neysmith and Nichols, 1994). However, the same notion of quality has been used to assess how HSWs effect the quality of life of elderly care recipients (Lawton, Moss, and Duhamel, 1995; Woodruff and Applebaum, 1996). These findings identify HSWs as significant contributors to the quality of life for older adults. Of these studies, only one (Aronson and Neysmith, 1996) considers the HSW's perspective. This noticeable absence in the literature supports the need for further research from the HSW's position.

The Enigma of Caring

The concept of women's caring receives considerable attention in the literature, and sets a theoretical context for understanding caregiving as a devalued role (Abel & Nelson, 1990; Baines et al. 1991, 1992; Tong, 1989). The general premise of the theory is that caring has been socially constructed to appear not as a skill, but as a natural aspect of women's biological makeup. Consequently, the caregiver role is not valued as real work. Although helping professions such as nursing and social work receive some legitimacy, direct care providers like HSWs occupy the lowest position in the health care hierarchy. This accounts for their poor wages, invisibility and lack of recognition of the complex caring relationships (Diamond, 1992). My proposed research is a medium for reaching
female care providers and questioning the prevailing social perceptions on
caring, by identifying how they define their own work.

Despite women's increasing visibility in the paid labor force our role as unpaid
caregivers has become engendered in our social order. Women constitute the
majority of family caregivers, and as unpaid laborers, we perform
approximately 85% of the home care that would otherwise overwhelm
government health care budgets (Able and Nelson, 1990; BC Ministry of Health,
1991). Perhaps what is so striking about this enormous workload is that most is
done without prompting. Wives, daughters, daughter-in-laws and the like, take
on the responsibility of caring and the economic, social and physical burdens
that frequently accompany caregiving. Undertaking this role is often considered
a moral obligation for women that does not require compensation.

While the social risks of caring have received attention in the feminist literature,
the physiological risks of caring have also been studied. Several studies found
stress and burnout to be hazards of HSWs' labor (Bartoldus et al. 1989; Bradley
& Sutherland, 1995; Feldman, 1993). Moreover, Neysmith & Nichols (1994)
recognized a connection between physical strain/fatigue and home care work.
Within the abundant research on violence in the work place, no studies
specifically relate to HSWs; however, other research has confirmed that the
circumstances surrounding their work places them at risk of being victimized-
(Sussman et al., 1994). These findings highlight the physical and emotional challenges involved in doing caring work. Moreover, they suggest that given the range of problems associated with doing their work, the future of the industry may not be secure.

Caring is highly personalized work, yet the relationships that develop between HSWs and care recipients have received modest attention. Studies from the perspective of the informal caregiver (Kaye, 1985), and more recently, from the standpoint of the care recipient (Barer, 1992; Woodruff & Applebaum, 1996) explore what it is like to interrelate with HSWs in caring relationships. In each study, the association is identified as a necessary and complex entity; however, the researchers' use of quantitative methods do not allow for rich data on such a personal issue.

Recently, qualitative studies have considered the relational aspect of caring, identifying an inseparability of emotional and physical care giving (Aronson & Neysmith, 1996; Donovan, 1989, 1993;). These finding challenge the prevailing view that caregivers can maintain a distance or "objectivity" in their intensely personal work. Other studies have considered the concept of emotional care, but not in relation to HSWs (Aitken, 1995; Baines, Evans and Neysmith, 1992; Eustis and Fischer, 1991; Eustis et al., 1993; Neysmith and Aronson, 1996).
Furthermore, Devault (1990), found that the English language is often inadequate to express the personal and less visible aspects of women’s work. This theory is supported by Aronson’s and Neysmith’s (1996) research which found HSWs struggled to articulate the considerable amount of work they performed that fell outside of the physical job description. Indeed, Brown and Smith, (1993) implore that a language be developed to describe what caregivers actually do, before policy discourse becomes so firmly solidified in its definition that it is resistive to change. Because language is the foundation of qualitative analysis, this research method corresponds well to a study of HSWs where language is so crucial.

Having stressed the demands of caring, I must also acknowledge that caring can be enormously rewarding work. For many women, the human connection shared between care recipients and their care providers constitutes a positive experience. Furthermore, feminists are increasingly reclaiming women’s caregiving to herald this social contribution, and to challenge the prevailing view that caring has little value (Fisher and Tronto, 1990).

The Dementia Phenomenon

Compounding the challenge of caregiving is the occurrence of dementing illness. Dementia is not a part of normal aging, but it primarily strikes people in their later years. Dementia is a chronic loss of cognitive ability severe enough to
profundely interfere with normal living. An estimated 15% of people over 65 are afflicted - a rate which will increase as our population ages (B.C. Ministry of Health, 1991). Varying forms of dementia prompt different kinds of behaviour and require different therapeutic approaches to care; thereby, placing further demands on caregivers to have an expansive knowledge and skill set. For instance, stroke survivors may be quite emotional and have impaired speech, while victims of Alzheimer's disease may exhibit more aggressive outbursts, memory deficits, and a desire to constantly be on the move (Aronson, 1994). It is important to understand the prominent symptoms associated with dementia to comprehend the scope of the work facing caregivers each day.

Perhaps the most recognized feature of dementia is memory impairment. In the Alzheimer type dementia, it initially presents as minor forgetfulness, but evolves into severe short-term memory loss, and eventually, long term memory is absent (Askham and Thompson, 1990). Memory impairment is manifested in innumerable ways including repetitious speech and questioning. This requires caregivers, like HSWs, to repeat instructions, redirect conversation and approach communication in a manner congruent with each individual's abilities. Moreover, due to the progressive nature of many dementias, and the sometimes daily shift in capability, care providers must constantly adjust to meet changing needs. In addition to the time and skill necessary to care for a memory impaired
client, caregivers must also cope with the emotional exhaustion that can accompany this work.

Cognitive decline associated with dementia effects orientation (ability to relate to time, place or person), attention (focus and ability to follow direction), learning (capacity to grasp new information), and judgment (discerning right from wrong) (Fabiano, 1987; Mace, 1986). While the consequences of these limitations are significant, perhaps what is most striking is the combination of results that can occur depending on the person and her/his individual response to the disease process.

Although dementia directly effects mental function, indirectly it has a profound physical impact. Restlessness and wandering are consistent with the middle stages of Alzheimer’s type dementia, and these behaviours require caregivers’ constant supervision and intervention (Demling and Bass, 1986). Absently leaving a door unlocked, or even briefly leaving the person unattended can result in injury or a state of disarray that require further time and energy to rectify. In this way, caring for people with dementia appears similar to caring for an infant, but their age and life experience preclude treating them like children. This presents a challenging dichotomy for caregivers to overcome, but one which Kitwood (1990), stresses is crucial. He argues that society is quick to impose a standard disease pathology upon people with dementia; thereby,
depriving them of their former identity. Caring for the person not the dementia is the objective.

Aggression is a common characteristic exhibited by people with dementia. Deteriorating neurological function can reduce inhibitions and alter a person’s ability to make sense of her surroundings (Askham and Thompson, 1990). For dementia sufferers who are aware of their cognitive deficits this frequently leads to feelings of frustration, and sometimes verbal and/or physical aggression directed at the very people responsible for their well-being - the caregivers. Individuals with more advanced cognitive impairment may misinterpret their environment as hostile and lash out in response (Wilen et al., 1997). As a result, even regular routines can be fertile ground for unpredictable physical confrontations.

While people with early dementia have impaired cognitive function, their physical functioning is frequently unaffected (Lincoln, 1980). Therefore, caregivers are challenged not only by clients’ confused behaviors, but also by their physical stamina. From my own experience as a HSW, I know this to be a tiring, unpredictable combination that demands of the caregiver full attention and creative interventions.
The result is that dementia sufferers' comprehensive care needs place enormous demands on care providers (George and Gwyther, 1986). For HSWs, meeting these ever changing care needs within small allotments of service time presents its own challenge. Balancing the safety and well-being of a cognitively impaired, elderly person with the worker's schedule limitations and agency policy is an awkward task, and one which presumably has emotional if not physical costs for HSWs (George and Gwyther, 1986). Wimo and Kraken 1994, found that because dementia care is so labor intensive, it also bears a high financial cost, particularly in institutional settings. Although home based care can reduce some of this financial burden, this approach necessitates a skilled labor force of HSWs, and adequate resources must be in place to assure the safety of both the individual and community (Wenger, 1994).

Research about HSWs and their work with cognitively impaired clients would expand our understanding of home support work, and how dementia factors into the formal caregiving experience. In addition, such research would speak to the effectiveness of home care policy. For example, if HSWs feel ill-prepared to meet clients' dementia care needs, then policy would appear to be insufficiently guiding practice. At present, a significant body of literature relates to family caregivers of cognitively impaired older adults, identifying unique, far-reaching consequences associated with dementia care (for example: Chenoweth and Spencer, 1986; Fittings et. al, 1986; Gilhooly, 1984, O'Connor, 1995). Perhaps in
response to this data, an organized system of caregiver support groups exists for such informal care providers. However, research is slower to focus on the experiences of paid caregivers for elderly dementia sufferers such as HSWs'. Although HSWs may indeed encounter their own challenges to providing dementia care, without the research to highlight the problem, resources like support and education groups will not be available to their profession. While few studies address the subject of HSWs and dementia care (Motenko, 1989; Wimo and Kraken, 1994), a number of researchers indicate a need for further inquiry into the rather hidden vocation of home support work (Aronson and Neysmith, 1996; Eustis, Kane and Fischer, 1993; Burbridge, 1993; Neysmith and Nichols, 1994). This gap in research is overdue and necessary: as such, HSWs’ dementia care experiences form an important component of this study.

My proposed research about HSWs builds upon the urgency of the problem implicit in the studies to date, particularly with respect to recent the feminist discourse by, Aronson and Neysmith, (1996); Baines et al. (1991), Neysmith and Aronson, (1996), and Neysmith and Nichols, (1994). In particular, this study relates to Aronson’s and Neysmith’s (1996), work which concluded that health care policy ignores the emotional labor of HSWs, and consequently, serves to depersonalize their work. Like their research, I too am concerned with how home care policy exploits HSWs; however, this differs from my proposed study in one important aspect. I am also seeking to understand how HSW are
surmounting these problems and what other ways they envision improving their position. Their study encourages further research into HSWs' caring experiences, and it serves as an important springboard for my inquiry.
CHAPTER THREE

HEALTH POLICY IN PERSPECTIVE

This chapter is the final component of the conceptual framework. It specifically addresses the issues of health care reform and home care policy.

Motivations for Home Care

Home care, also known as home based care or community care, is an old concept gaining new momentum in response to several recent social phenomena. The following is a summary of the circumstances propelling the demand for home care services, revealing the extent of the need and reinforcing just how crucial home health care is now and for the future.

The world’s population is aging, and as the proportion of older people increases, so does the incidence of physical illness (Christiansen and Grzybowski, 1993). Health care resources are straining to meet the current need, and the industry’s ability to address future care demands is in question (Badgley, 1987; B.C. Ministry of Health, 1993; Denton, 1987.) However, physical health is only one aspect of wellness. When dementia care needs (as discussed earlier) are factored in to the health care budget, a critical picture emerges.

Another reason home care is receiving more attention is related to changing domestic patterns. While informal or family caregivers have traditionally been
relied upon to subsidize health care with their free services, they are a
dwindling resource (Able, 1990; Askham and Thompson, 1990; Neysmith and
Nichols, 1994). Women are typically the family caregivers; however, due to
increased career options and marital breakdown their availability as 24 hour a
day, unpaid care providers is no longer secured (Askham and Thompson, 1990).

The most powerful motivation for home care is fiscal restraint (B.C. Ministry of
Health, 1991; Benjamin, 1993). Health care demands are draining government
coffers faster than the tax base can support it, and home care is largely
considered a less expensive approach to addressing public health needs.
However, home based care is not a fool proof endeavor. The infrastructure must
be in place to support a system of health care outside of institutions. Problems
with home care arise when funds are cut from hospital budgets, but fail to be
redirected to home based services- a growing concern (Armstrong and
Armstrong, 1996; Aronson and Neysmith, 1996; Benjamin, 1993). Clearly, there
is a risk that the human side of health care will be ignored in favor of cost
savings.

In addition, governments have been quick to make assumptions about the
desirability of home care for healthcare consumers. For example, provincial
reports claim that the quality of life for BC's seniors will improve by receiving
care within their own homes (Ministry of Health, 1991). The assumption here is
that all elderly people prefer to receive care in their own homes. While many people do prefer the option of home care, this is not a universal truth. Moreover, Woodruff and Applebaum, (1996) raise an important issue: care at home does not guarantee autonomy for the care recipient. Rather, there can be an element of dependency on the care providers. This is true in instances when there are not adequate services available to meet clients' care needs. Distanced from support and supervision, the care arrangement intended to empower clients may actually disable them further. While the motivation is intense for developing a comprehensive home care industry, it is not without risk for the caregivers and health care clients. Home care policy is charged with the responsibility for balancing human costs with financial costs.

**Historical Context of Provincial Home Care Policy**

The original impetus for the British Columbia's community care policy came from the 1991 *Closer to Home* report sponsored by the Ministry of Health. In general, the report recognized inequities in health care delivery, advising that control of health care services be given to local communities, and that care be provided in-home as much as possible: this system promised lower health care costs and quality improvements (B.C. Ministry of Health, 1991). The policy that followed in 1993, *New Direction*, outlined the strategy for implementing these reforms. Health care services would be decentralized to 102 regional based boards serving as resource brokers for particular regions of the province.
However, *New Directions* was viewed as too cumbersome and bureaucratic, and it was replaced on November 29, 1996 with *Better Teamwork, Better Care*, a model that shrinks the number of managing bodies to 45 (B.C. Ministry of Health, 1996). Throughout the evolution of provincial health care policy, one philosophy has remained constant: the people living in a community know best what health services they need and how to provide them.

The conviction with which the health care reforms have been presented suggests strong, explicit supporting health policy. However, clearly articulated, definitive policy directives are difficult to find. The document most closely resembling a home care policy statement is found in the *New Directions* plan, and is titled, *New Direction #3: Bringing Health Closer to Home* (ND#3). This home care policy advocates for the provision of health care services in people's own homes, and for the decentralization of the health care structure, but its effectiveness is questionable. Now nearly five years after the document was published, the rhetoric is old and out dated. Indeed, the regionalization model has been developed, launched, demolished and revised in that time; however, ND#3 continues to be the primary home care plan.

The policy document ND#3 is comprised of five "Priority Actions" which outline the procedures by which health care services will be brought closer to home. An examination of the rhetoric reveals timid if not weak statements about
how and when home based care will be expanded in the province. Under bold captions proclaiming, PRIORITY ACTIONS, the section pertaining to home supports states:

The Government will continue to promote and develop a continuum of services, ranging from community-based services to centralized acute and medical care, by continuing to give priority to expanding home support and other community-based services.

It hardly meets the expectations of the title. Wording like, “continue to promote,” and “continuing to give priority,” suggests the government is uncertain how it will approach the weighty issue of increasing home support services while decreasing acute care. Not only is the rhetoric flimsy, but even in its entirety, the policy statement means nothing substantial: this is not a policy that will usher in reforms. Moreover, the action date for this policy to be initiated is listed as “Ongoing” (BC Ministry of Health, 1993) - an obvious statement of non-committal.

Whereas other reforms presented in ND#3 are assigned completion dates and specific actions, policy relating to home care is vague and superficial. Taken out of context, it would appear government has little interest in home based care, but ironically the second of two major reforms addressed in ND#3 declares, “...we must provide more services in people’s homes.” (BC Ministry of Health, 1993). Indeed, home care is a major foundation of health care change reiterated throughout the supporting documents, but the policy support is weak (BC Ministry of Health, 1991, 1993). Without clear policy directives, the entire home
care industry, including home support workers, is left to falter. Furthermore, government can manipulate language loopholes to justify less funding or changes in health care philosophy.

Manson Singer (1994), attributes the absence of explicit provincial home care policy to a piece of federal legislation. In 1991, the Canadian government made a monumental reform to the nation's health care system, when it passed the Government Expenditures Restraint Act (GERA) (Manson Singer, 1994). Historically, under the Canada Assistance Plan (CAP), the federal government provided dollar for dollar transfer payments to each province for the financing of health care services. This funding not only afforded the country's costly universal medical programs, but it also provided the federal government with leverage to ensure provinces followed the five principles of medicare. However, the cost-sharing initiative was disbanded with the introduction of the GERA which would dramatically decrease federal transfer payments and force provinces to self-support their own health care systems.

In response, the BC government was forced to develop less costly alternatives to traditional health care delivery—enter New Directions (BC Ministry of Health, 1993). Before the GERA was passed into legislation, BC's Closer to Home report proposed that home base care was in the best interest of the care recipient. However, after the transfer cuts, bureaucrats recognized that the cost savings
involved with home base care was also in the best interest of government. This would become the underpinning and the motivation behind the *New Directions* document and supporting policies.

Interestingly, the ambiguity of the *New Directions* document is matched in the supporting legislation. All home based care in BC is governed by the *Continuing Care Act* (CCA) which gives the Minister of Health the authority, "...to designate continuing care services, to protect clients by establishing certain operating and program standards, and to intervene in crisis situations." (Vancouver Health Board, 1996). This description of the CCA leads the reader to expect an in-depth home based care directive to support the policy; however, this is not the case. The CCA is a three page document comprised of six sections laden with cumbersome legal language. Indeed it authorizes the health minister to govern home care services, but the act avoids specific details such as rate reviews, baselines for service hours or standards for direct care providers. Such details form the heart of the policy as they have a powerful influence on the quality of care the client receives, and the quality of work life for the HSW.

Furthermore, the CCA has not been revised to reflect provincial home based care reforms. Since it was first assented to in June, 1989, not only was the act not expanded to include aspects of ND#3, but it was actually *consolidated* in December, 1994 (Province of British Columbia, 1989). Although it remains a legal-
statute, the CCA is rather a weak document which fails to contribute validity to provincial home care policy.

Given the importance of home care as a government cost savings measure, one expects to see policy that protects this valuable industry to ensure its future existence. Aronson and Neysmith (1996) found that although health policy depends upon home care to support a dramatic shift away from acute care, it simultaneously sabotages its' chance for success. This is illustrated by the lack of definitive policy to guide practice and the oppressive nature of those policies that do exist.

Home Care Policy Research

Given the dearth of home care policy, it is not surprising that related policy research is also limited. The issue of a national home care policy for Canada was studied by Neysmith, (1995). Her findings highlighted the low political priority of a viable home care system as evidenced by a lack of federal standards. While acute care services are regulated across all provinces by the Canada Health Act, home care is not. Consequently, provincial governments are not obliged to fulfill any quality standards for home care services. Armstrong and Armstrong (1996), also offer a critical review of Canada’s trend towards community care. They propose inadequate government funding transfers as the weakness in home care reforms.
From a provincial perspective, little scholarly writing has been published about British Columbia's home care policy despite lively public dialogue challenging its' feasibility. This reveals a serious gap in the literature, and warrants a critical analysis of the evolving home care policy.

The HSWs’ role is essential to support the philosophical shift to home care. Pressure on the health care system is building as a result of fiscal restraint, reduced institutional care resources and an increasing number of elderly health care recipients. A strong home based care system is necessary to fill the service void, but to date, increased government financial backing for home care has not been forthcoming. In addition, the work force may not be available or prepared to meet the demand for home support services. Low wages, irregular schedules, work load, limited training, and undervalued work threatens the stability of the home support industry. A review of work conditions for these care providers must be a priority to protect future access to health care. An important first effort is to examine the experiences of home support workers.

The purpose of this study is to understand the caring work HSWs do in an environment of political change. I consider work to be any effort, physical or emotional, extended to accomplish an outcome. Furthermore, I include dementia in my inquiry because of the increasing incidence and the multitude of care needs associated with dementia sufferers. The resulting question guiding
this research is: *What are the experiences of Home Support Workers providing care to elderly, cognitively impaired people living in the community?*
CHAPTER FOUR

METHODOLOGY

In this chapter, I discuss the concept of feminist research methodologies, as this was the context in which I conducted the study. In addition, I present the research methods employed to generate the data, and the rationale behind their use.

Feminist Research Methodologies

The ultimate goal of feminist research is to add to our understanding of how women experience and view the world (Devault, 1990). Feminists contend that this task cannot be accomplished using prevailing social theory as it was developed by men for men, and thus, disregards women's ways of knowing. Neysmith (1993), makes an important distinction between feminist research methods (specific research techniques) and feminist research methodologies (the principles and practice guiding research). Therefore, using feminist methodology does not confine me to only certain types of sampling or analysis; rather, all research methods are available to me: it simply depends upon why and how I apply them.

The principles of feminist methodology most relevant to my study are Neysmith's (1995), three principles which she applied to her own research on
home support workers. Firstly, gender determines how language and words are used to communicate meaning. Secondly, power is generated along lines of gender, class, race and sexuality. Moreover, power is inherent in all social relations, and is responsible for constructing dominant discourses while silencing others. Lastly, the social world is frequently discussed in terms of dichotomies; thereby, creating assumptions about the preference of one over the other. These three tenets of feminist methodology then guide research practices in four major ways.

Research conducted using feminist methodologies acknowledges an inseparability between the researcher and the research. The notion of objectivity is rejected in exchange for clear admissions of where the researcher feels her biases exist (Devault, 1990; Neysmith, 1991). I also represent my connection to the research by writing in the first person: whereas in scientific inquiry, such personal involvement is forsaken as prejudicial.

A second practice issue, is viewing participants' individual experiences within their social context. Smith (1987), asserts that although women are experts about their personal experiences, our way of knowing is largely constructed by the male dominated discourses. Therefore, women do not have a clear view of all the external forces impacting their lives, and it is the researcher's responsibility to consider experiences in the context of patriarchal oppression.
A third practice is recognizing that because women and men experience the world differently, gender is a factor that would alter findings. Therefore, simply comparing the sexes does not account for how we understand and experience life differently. Women need to be understood separately from men, and thus, they can be studied separately from men (Smith, 1987; Neysmith, 1995).

Finally, congruent with feminist research practices is the selection of a research topic which is relevant to the advancement of women's equality. Adding to the body of knowledge on women's issues elevates our visibility and challenges prevailing discourse which construct how women are understood.

Throughout my discussion of the research procedures, I relate my actions and intent to the feminist methodologies described above. To begin, I hold some assumptions about the overall research topic that I need to acknowledge. My candor about these biases is intended to inform both myself and the reader of my views to reduce reactivity—my distortion of the data (Maxwell, 1996). A primary assumption I hold stems from my feminist standpoint, and an inherent belief that women are exploited as free or inexpensive care providers based on our gender. In addition, I assume that health care policy purposefully, though not maliciously, marginalizes HSWs. Although I believe that governments want to improve the working
conditions for HSWs, the pressure of fiscal restraint overrides this good intention.

This research is non-positivist, interpretive and feminist in its approach. Unlike objective, logic driven scientific methods, this qualitative framework provides a flexible scheme for understanding participants' experiences; moreover, it recognizes value in the personal and subjective. Because of an assumed power dynamic inherent in the HSW's labor, a predominantly female HSW industry, and my own philosophy, a feminist approach is most appropriate for this design.

Before discussing the research design in depth, it is important to clarify how the study was organized and how I present it here. The research evolved into two distinct phases. The first phase occurred during the eight month period between September 1996 to April 1997, and focused upon the personal experiences of HSWs and their caring work. The results generated during this stage lead me to think of the broader social and political systems contributing to the HSWs' experiences. Therefore, I expanded the sample to include another group of HSWs in order to understand the role external forces might have on their work. This idea formed the basis for the second phase of research which occurred during the seven months between September 1997 and February 1998. Each phase involved its own ethics approval, sample recruitment, data collection and
analysis. Under each heading in this chapter I first present the methods employed in phase one, directly followed by a discussion of the methods for phase two. Where methodologies are similar between the two phases, I rationalize its use only once.

Sample

Phase 1.
The participants for the first phase of research conformed to a limited set of criteria requiring that they be female or male HSWs employed in the industry for at least one year and working with elderly, cognitively impaired clients. No criteria excluded individuals due to age, gender and race; however, participants were required to speak English. This delimitation is due to my unfamiliarity with other languages, and my need to be able to clearly understand the data. Criterion sampling made it possible to select all willing participants who were within the study parameters.

Participants were deliberately selected for the knowledge they own as experts in the home support industry. This method, purposeful sampling, was selected because, it corresponds with qualitative methods, maintains credibility, offers a set structure for selecting participants, and conversely, provides the flexibility to use alternative sampling methods should the need arise.
Prior to initiating the recruitment process, I approached a non-profit home support agency to advertise for participants from their pool of staff. After receiving a letter of consent from the agency, I applied to the University of British Columbia Ethics Committee, and received approval to conduct the study.

An agency wide voice mail message, posters and word-of-mouth were used to advertise the sample search. However, despite the cooperation of the home support agency, this recruitment method proved ineffective and yielded only one participant. Unexpectedly, there were several HSWs not associated with the agency who expressed an interest in participating. As a result, I relied heavily upon a third snowball sampling strategy whereby friends and colleagues identified potential participants who then contacted me directly. This method elicited four potential participants. It appears that one-to-one contact with HSWs rendered more positive responses than less personal recruitment methods.

Due to the timing of the study, two individuals were unable to participate, leaving a total sample of three for the first phase of research. It should be noted that all participants were socialized in Western society; therefore, the sample did not reflect the preponderance of HSWs who originate from foreign countries. This sample size was intended to adequately reflect both the typicality and range of the population, while being realistic in the scheme of a small study.
Several efforts were made to avoid possible ethical pitfalls in the sample recruitment. To assure participation was voluntary I clearly described the study purpose and design with each participant. Confidentiality and anonymity was guaranteed for both the participants and the home support agency, and they were informed of their rights to withdraw from the study at any time without consequence. Participants signed a form indicating their informed consent.

Phase 2.

Prior to initiating the second sample recruitment, I received approval to proceed from the University of British Columbia Ethics Committee. Purposeful, criterion sampling is a method used to recruit any participants who meet a set of specific parameters. I employed this approach for the second phase of research, as I was seeking atypical HSWs. Participants were required to have a thorough knowledge of the Long Term Care (LTC) system, and/or membership on the union executive: characteristics which are the exception among HSWs. The purpose of these limitations was to hear from HSWs who could link their personal work experiences to the larger system of home based care. In this way, I hoped to understand what HSWs regarded as the external influences on their caring work, and how these pressures could be reduced.

Three HSWs were recruited via a third party contact at the British Columbia Government Employees' Union (BCGEU) headquarters- the union representing
home support workers in BC. Another participant, a former HSW now working as a LTC assessor, was identified via snowball sampling for a total of four people participating in the second phase of the study. Their years of experience were generally far greater than the average HSW, and three are recognized leaders in their industry. It is noteworthy that although the sample size was smaller than typically recommended for focus groups, it was justified by the exceptional qualifications I required of participants (Carey, 1994).

While two participants knew each other well, a third HSW had limited contact with these participants, and the forth was unfamiliar to the group. Each woman was assured as much anonymity and confidentiality as possible, but I explained that their involvement and comments would be known by the focus group participants.

Data Collection Design

Phase 1.

The challenge to selecting data collection methods is keeping the structure loose enough to allow for fluid transmission of information, and formal enough to answer the research questions (Maxwell, 1996). The interview method was an appropriate choice for this study, as it is typically known to generate a large quantity of data quickly (Marshal and Rossman, 1995). In addition, the personal interface facilitates a relationship between myself and the HSWs. This is
important, as comfort and trust between the two parties promotes more open communication, and consequently, more informative data. As a feminist methodology, interviews are important tools for eliciting participants’ subjective experiences (Marshal and Rossman, 1995). Therefore, the meaning assigned to these experiences is defined by the HSWs and valued as such. Lastly, interviews provide non-verbal data: an important secondary source of information (Marshal and Rossman, 1995).

Despite these attributes, interviewing also poses some potential problems as the primary data collection method in this study. The process of transcribing and listening to hours of taped interviews is very time consuming; nevertheless, the contact with the participants’ dialogue provides an opportunity to review participants’ responses, and thus, aides in the analysis (Marshal and Rossman, 1995). The extremely personal nature of the interviews also requires careful data storage to protect HSWs confidentiality. While there is always a risk that the interviews may not yield in-depth information, my interviewing experience is an asset for preventing this problem (Marshal and Rossman, 1995). I am also aware that the subjective nature of this data lends itself to being shadowed by my own interpretations. Ideally, this is avoided with an appropriate sample size, thoughtful interviews, and careful documentation. Regardless, the data is open to my personal bias: this cannot be avoided, but my biases are stated candidly in the research (Marshal and Rossman, 1995). Finally, participant cooperation is
essential to elicit meaningful data. I could not anticipate how each HSW would react in an interview, so relied on my sampling techniques and interpersonal skills to create a comfortable, safe interview environment (Marshal and Rossman, 1995).

With this in mind, each of three HSWs participated in an individual, unstructured, in-depth interview that was audio recorded, and personally transcribed. The duration of each interview ranged from approximately 1 hour to 2 1/2 hours, and participants selected the venue for our meeting. The interview guide (Appendix A) consisted of only one primary question which I posed at the start of the discourse. I asked each woman to talk about what she does in a typical client visit from the time she arrives until she leaves. This open-ended question was intended to be broad enough that it could include whatever the HSWs recognized as work. A sub-question relating specifically to dementia care was introduced if the participant did not address it first. Moreover, I asked for further details when participants raised particularly intriguing points, but their detailed discourses were such that I rarely needed to intrude. With their permission, I wrote brief notes throughout the interviews to document my ideas and thoughts prompted by the dialogue.

The type of data obtained from interviewing is largely dependent upon my relationship with the participants. To create an atmosphere where participants
would feel comfortable sharing their stories, I was very honest with participants about my research goals. In the interest of creating equality, I clearly acknowledged the participants as the caring experts, emphasizing that my voice was secondary. The HSW's may also have been open to me as a peer, because I worked in the industry for several years, and I shared this information with them. My goal was to conduct the research in a way that was ethical and true to me with the effect of revealing the HSWs' personalized and intellectualized narrative around their work.

Phase 2.

In the second stage of research the four participants were part of a focus group. I selected this method of data collection for two reasons. Firstly, the interviews conducted in phase one were successful in revealing HSWs' personal experiences, and a focus group would enable me to build on particular data. I wanted to hear how the home support profession was weathering changes in the health care system. Furthermore, the information I was seeking was most likely to arise from a group dynamic where ideas could develop and expand through dialogue. Carey (1994), supports the use of focus groups for this purpose.

Secondly, because of the nature of their work, home support workers are isolated from one another with limited opportunities to share ideas and support one another. The focus group functions to bring HSWs together, and ideally
fosters a sense that they are not alone in their work. From a feminist standpoint, this is desirable outcome.

Because the participants belonged to communities throughout BC, logistically it was difficult to bring the women together. Eventually, the single focus group was held at my home, and was timed to coincide with a conference for their union executive. I was prepared with a short interview guide (Appendix B) to foster a semi-structured group discussion; however, participants addressed most of my points without prompting.

My intention was first to establish whether similar experiences were shared between the interview participants and the focus group participants, so I began by asking a similar question about the day to day work they performed. Secondly, the participants were asked to talk about their work within the context of the current health care reforms. In this way, I hoped to move the data beyond the personal realm to reveal a larger picture about HSWs within the health care system. The audio recorded focus group lasted approximately 2½ hours, and with the consent of all the women, I wrote brief notes throughout.
Data Analysis

Phase 1.

Although the data was open to my personal views, I made several efforts to maintain the integrity of each story and to increase credibility. I was forthright about my own relationship to the research, and interviews were unstructured, allowing for participants' stories to unfold as they wish; moreover, every verbal nuance was transcribed, and participants reviewed the text.

Confidentiality and anonymity was maintained for both the home support agency and the participants. I accomplished this by removing all identifying information from the transcripts, and when appropriate, replacing it with pseudonyms; moreover, the identifying data were stored separately from the altered versions. Recordings and transcripts were stored in a locked file cabinet, and computer records were password protected.

Data analysis began in the transcription of the raw data within days of each interview. This process provided the opportunity to familiarize myself with the participants' remarks. Moreover, ideas and insights revealed in transcription were documented in a memo format to be used in future analysis. The participants then received a copy of the transcript to review and approve their dialogue.
The primary method of analysis was a contextualizing technique called narrative analysis. Through this approach the data were analyzed for the whole story they revealed. Rather than breaking down each person's dialogue, each transcript/narrative was considered an individual entity that would stand on their own distinguishable from the others. The interpretation was a three way process of checking comments against the text as a whole, connecting it with what the literature stated, and considering my own evaluation of the situation. Consequently, themes were unearthed in each story. This is consistent with the hermeneutical approach to data analysis (Kvale, 1996). My purpose for employing this method was to represent the data fairly while also moving the person's story beyond the immediate words. My intention was to understand the HSWs' experiences more intensely, and to uncover the meaning of their work in relation to health care reform.

Phase 2.

I personally transcribed the audio recordings verbatim, and each comment was attributed to the participant expressing them for ease with data analysis. Transcription also provided an opportunity to familiarize myself with the focus group discussion and to take notice of emerging trends in their stories. Journal memos were kept throughout this initial stage of the analysis. Participants received copies of their own comments to review and or edit.
The primary method of analysis was constant comparative which seeks to identify both consistent themes and contradictions in the discourse (Ristock and Pennell, 1996). A first step was to locate statements that had similarity, and then to categorize these segments of the data (Strauss and Corbin, 1990).

To facilitate the coding process, I created different versions of the transcript. The first was the sequential, original transcript. A second grouped the comments according to the participant who spoke them resulting in four separate transcripts. Proceeding from these documents, I did a line by line analysis. I used a highlighter to identify particularly poignant statements, metaphors, interesting use of language, and recurring issues. Furthermore, I wrote analytic interpretations on the left hand margin of the transcripts, to capture my thoughts about the data as I read.

Each participant's comments were compared against her entire story to reveal either consistency or contradiction. The same effort was extended to compare their stories against the other three participants. An important tool for this aspect of the analysis was the "word find" function in my computer program. This allowed me to quickly search or confirm if other participants had used the same word(s) to describe their experiences. Furthermore, it enabled me to locate a quotation within the transcript with only one key word- a crucial time saving
device. Eventually, clear patterns emerged linking the participants’ experiences and at times distinguishing them from the others’.

After numerous readings of the transcripts, and concurrent memo writing, I identified recurring themes in the data. As a result, I used the word processing function on my computer to copy the coded quotations to a new file, and subsequently, I categorized them. What appeared were three main topics crudely labeled as: personal work experiences, work relationships and systemic experiences, and several sub-topics. These themes comprised the framework for writing the results chapter; however, the analysis continued throughout the writing process. Data that did not fit within the established codes were studied for what they did reveal, or for what they contradicted. Referring to the quotations, my previous examination of the discourse, journal notes and the related literature, the analysis evolved as I wrote.

By continually referring back to the data, rereading and refining the codes, I was able to theorize about what the HSWs were experiencing. Because this theory was generated from the participants’ own words, as opposed to being conceptualized and then tested against the data, it is labeled “grounded theory” (Maxwell, 1996). Grounded theory also recognizes the researcher’s own beliefs are part of the interpretation, and as such is consistent with feminist methodology (Ristock and Pennell, 1996).
In summary, this study involved two stages, and two methods of data analysis. In the first phase, the narrative analysis considered statements in the context in which they were said, and thus maintained the integrity of the data. Conversely, in the second phase, the constant comparative method fractured the data into smaller categories to reveal relationships and themes. The combination of the two methods values the knowledge inherent in the individual experience, and allows for the generation of theory about these experiences (Maxwell, 1996). My decision to use these complimentary analysis methods rendered a comprehensive research design.
CHAPTER FIVE

FINDINGS: PHASE ONE

In this chapter, I present the findings of the individual interview analysis. This is my attempt to draw out the most pertinent work experiences of the participants - three home support workers. Despite the differences between participants, the analysis also reveals startling similarities. To better portray the parallels in their experiences, I have organized the findings according to the major themes consistent across each story. These are identified as: hidden work, the home support system, residual impacts of being a home support worker and dementia care. These four headings are also intended to make an easy path for navigating the results and absorbing the impact of the HSWs’ experiences. The participants’ generosity in talking to me about their work was motivation to keep my impressions grounded in their words and actions. As a contextual feature, I begin by introducing the three women.

Sylvia: The Temp

Sylvia is an attractive 27 year old, single woman of Caribbean decent. She exudes a positive outlook, and appears enthusiastic and friendly. Sylvia was raised in Canada and England in a middle class family, and thus, although she is a visible minority, she does not reflect the predominantly new immigrant women from lower socio-economic groups that comprise the home support work force. Sylvia lived the majority of her life in urban Ontario, at the time of the
interview, she resided in the Vancouver area while completing graduate work in the social sciences. Her educational background is extensive and includes two undergraduate degrees and a certificate of specialization.

Sylvia volunteered to participate in my study after hearing that it related to home support workers. Although she last worked as a HSW six years ago, her experiences had been so powerful that she still had strong feelings about her time in that role, and she was very agreeable to sharing her impressions. Her work experience extended over a two year period and totaled approximately 10 months. Sylvia initially expressed concern that she could not offer significant data due to the short duration of her employment; however, she also acknowledged that within the brief time she was a HSW, she learned a great deal.

Sylvia was employed as a HSW during her summer breaks from university. She was honest about feeling dependent upon the job to afford the tuition and expenses of living away at school, and she admitted that it was not her preferred employment. In addition to feeling like she had few employment options aside from home support work, her "starving student" status presented barriers to accomplishing her work. Unable to afford a car, she relied on public transit to travel to multiple client homes each day. Although she was compensated for bus fare, she was frustrated by her time and effort spent simply to get from one site
to another in the hot Ontario summer climate. Furthermore, although she felt mature enough to do the work, Sylvia saw her young age as a obstacle to gaining the trust and respect of her clients. One issue that stood out for me was her disclosure that, as a visible minority, she encountered both overt and covert racism on the job- sometimes from the very people she provided care for.

The idea to work as a HSW was inspired by her mother who was also working in health care as a nurse. Moreover, her older sister was also a HSW at the same agency, and Sylvia explained that they were a constant source of support for each other. On most days, the two debriefed after their last appointment to share their feelings and stories about their work- an opportunity Sylvia recognizes is seldom available to HSWs.

Sylvia’s was the shortest interview of the three participants. Our one 45 minute interview took place on the university campus we both attend. I distinguished a slight British accent as a result of her years lived over seas. She seemed confident and at ease, joking and sharing some initial small talk before commencing the interview. I was impressed by how articulately she spoke, and she had a style of concluding her comments by reiterating the initial question and briefly summarizing her point. This made for a transcript that was easy to follow, and it demonstrated her tendency to address one topic completely before discussing a new issue.
Anne: The Lifer

Anne is a 45 year old Caucasian woman employed full-time as a HSW for nearly 12 years—significantly more than the national average. As a single mother, she relies solely on her income to support her and her teenage daughter. In an effort to increase her wage, Anne completed the Home Care Aid certificate program, and is proud of being at the top of her union pay scale—$13.00 an hour. She expressed an interest in participating because not only did she work as a HSW, but also she was an unpaid caregiver to a friend in the community.

Anne's hectic work schedule made arranging an interview a challenge. We eventually met at a local coffee shop during a break between her client appointments. Her appearance was clean and casual, and her manner was friendly but serious. It was evident that Anne had a great deal to say about her role, and despite the busy, sometimes loud coffee shop atmosphere, she appeared focused and undisturbed throughout the 1 ½ hours.

Anne gave the impression of taking her job very seriously. In addition to furthering her education in home support care, she attended nearly every in-service her agency sponsored. However, despite her many years as a HSW and her commitment to her work, Anne spoke mainly of her unpaid caregiving experience. This topic was close to her heart; ironically, the woman who Anne was caring for was the wife of a former client. The two women developed a close
bond over the years that Anne visited the home, and their relationship endured after his death and into the elderly woman’s own battle with Alzheimer’s disease. Her role as a friend gradually expanded to include caregiving work as the woman’s dementia progressed, but Anne received no payment for her work. The intensity of her unpaid caregiving role was illustrated by her commitment to, “pop by after work every night and, like, bring her whatever she needs.” Over time, doing “whatever she needs” had evolved into an overwhelming amount of work ranging from doing her tax return, transporting her to medical appointments, cleaning, cooking, shopping, and responding to her multiple daily phone calls. Considering that her paid work required Anne to be available for 10 hour shifts on week days, her life was dominated by caregiving work.

**Heather: The Renegade**

Heather is a 30 year old Caucasian woman who, at the time of our interview, had recently graduated from university with a degree in nursing. She works the night shift on an orthopedic ward at a large Vancouver hospital, and rents a house with several friends. While in school, for 2½ years she was employed as a HSW at a local home support agency, working almost full-time hours to afford her education. Her clientele included older adults with dementia, but she also cared for a number of younger quadriplegics. She left her agency job to work privately for a number of clients who managed their own home support services. This arrangement provided flexible hours and less bureaucratic interference than
agency based work. On occasion, Heather still accepts private home support jobs, including one over Christmas when she accompanied a client to Hawaii for his vacation.

Heather was referred to me as a participant by a mutual friend, and she responded immediately and with enthusiasm about the prospect of talking about being a HSW. The 1 ½ hour interview took place at her home after she finished her last of five straight night shifts. If I was surprised to find her vacuuming and moving furniture when I arrived, by the end, I understood Heather as an outgoing, out-spoken individual with an admirable energy level. Her strong physical appearance and confident voice gave me the impression that she could tackle any challenge she encountered in her caring work, or in her daily life. Indeed, this was later supported by her story. As the only participant who did not wish to use a pseudonym, Heather seemed fearless about owning and expressing her opinions and comments.

**THEME I. HIDDEN WORK**

Consistent within each participant’s experience was a theme that I refer to as hidden work. This is labor the participants talked about, but did not name. Sometimes this was tangible, physical work, but more often, it seemed to reflect an emotional or relational component of their caring work.
Almost immediately, Sylvia exposed a contradiction between what the home support agency mandated her to do, and what work she actually did. Sent to a client’s home to do, “light housekeeping or making meals,” evolved into much more, and Sylvia indicated, “It was any number of things- it wasn’t just light housekeeping or making a meal, it was, it was a whole range of other activities.”

When asked to elaborate on what these “other activities” might be, Sylvia proceeded to loosely describe some typical household chores- tasks that did indeed seem like “light housekeeping.” Her apparent difficulty articulating these “other activities” was initially surprising to me particularly because she spoke with such clarity for the majority of her interview. However, later in our discussion, when she was no longer on the spot for examples, Sylvia revealed several aspects of her work that clearly went beyond cooking and cleaning.

Unsolicited, Sylvia described the challenge of simply gaining entry into some clients’ homes:

I’d spend a lot of time banging on the door because, um, either they had some hearing loss, or they were, you know, not too eager to answer the door. Eventually they’d come to the door, and you’d have to explain in quite detail, and very clearly, who you were, and what you were there for.

On another occasion, managing the physical labor posed a particular challenge:

I’d have to basically, on my own, figure out how to turn this guy, get him out of bed into his wheelchair and do all these other things on my own.

In addition, Sylvia recognized relationship building as an important aspect of her work with clients:
They came to like you, and trust you. Sitting down and having tea and chatting...you didn’t feel so much like you were there just to do all this housework. You were there- it’s for the companionship too.

Concrete examples of home support work were easily accessible for Sylvia, but she did not seem to have the language to neatly describe less obvious work like creative problem solving, physical strain and emotional labor. The work remains hidden not only to the general public, but also to the care provider.

Anne’s experience was similar to Sylvia’s in the that she too revealed multiple aspects of her caring work that was hidden from the agency or outsiders. However, Anne’s experience also differs from Sylvia’s in that she recognized and valued her less obvious work. This may be a reflection of Anne’s years of experience as a HSW, and it may also relate to the differences in their age.

As she described her work, it unfolded as well organized phases. My impression of this action was that it seemed like an effort to find order in the sometimes chaotic array of care needs. Anne explained, “it’s an adventure, and it’s just one minute to the next the complete opposite.”

The moment she arrived at a client’s home, Anne started the assessment phase:

Well, when I arrive, I would, um, basically take a look at them to see whether I could detect, you know, moodiness, or whether they’re kind of down or whether they’re up. So you sort of know, just by looking at them, what kind of mood they’re going to be in.
Brief discussions could also elicit information about a client:

   Like today, as soon as I buzzed her and she said, ‘Hi,’ I knew she wasn’t well. I picked that up from just listening to her voice on the intercom.

The process of making sense of her clients’ changing care needs was a complex set of tasks. Her success in this regard relied upon her relationship building skills to connect with care recipients, as well as her assessment skills to identify daily shifts in her clients strengths and weaknesses. Moreover, upon determining a care plan, Anne had to have the expertise to accomplish the work. Still, other times she relied on more intuitive means such as client “vibes” to direct her care for that day. Assessment was part of her routine with every client, and Anne relied heavily on this phase to guide her caregiving. Clearly, it was an important aspect of her work; however, it was not part of her formal job description. Though this work was perhaps implicit in her work, she was the only one identifying it explicitly. When asked if her supervisors were aware of this part of the work, Anne smiled and simply answered, “no.” Assessment work was hidden work.

Building on her initial client evaluation, and depending on the client’s mood, Anne then initiated a process of negotiation, adjusting her routine accordingly.

   If she, you know, balks at you wanting to help, I just sort of let her be for a while, and then reintroduce it later.
Instances when clients are “agitated” or “lashing” require her to “walk on eggshells.” Balancing her own schedule/routine with the clients’ shifting needs was an effort to personalize her care; however this also demanded considerable expertise. By recognizing that assessing and negotiating are indeed “work,” Anne distinguished herself from the other two participants who, at first glance, described their work by its’ physical, concrete characteristics. Experience may account for Anne’s expanded definition of caring work, but what she did not talk about was what this extra work means for her.

Another common feature of her caring routine was tea time. However, like the other participants, she used this activity for more than just refreshment:

Usually if they offer tea it’s because they need to talk, and I find it just as important to take the five minutes out of our time and sit with them then to go in there and just clean, clean, clean. If sitting down and having tea is going to make him happy and get whatever he has on his chest off of it, then I can leave there knowing he feels a little bit better.

Her comment illustrates a contradiction between what she regards as important work, and what her supervisors are telling her is important work. Though she reconciles the differences by taking time out for tea, she also restricts herself to only a few minutes.

The social opportunity of sharing a cup of tea with her clients helped them to feel better, “because mental health is just as important as physical,” but it also satisfied Anne’s concerns for their well-being. Tea time also facilitated the
personal relationship shared between care provider and care recipient. Caring for her clients emotional needs did not necessarily demand physical effort; nevertheless, it was work.

As Heather embarked on a description of her direct care work, I was surprised to discover that she struggled to see the value in her work. Earlier she had criticized the home care system for not acknowledging HSWs’ accomplishments, but she failed to make the connection to her own experience.

“I do actually need to be there, but sometimes I felt like I wasn’t doing anything.”

Like Sylvia, Heather seemed bound by popular discourses on what constitutes work. Those explicit definitions overshadowed the implicit caregiving work and restricted how they could talk about their experiences. As a result, productive work was tangible work. Heather initially described her work in terms of concrete actions like, “getting her up, and getting her dressed and feeding her,” and “I’d make her lunch. If she hadn’t bathed I’d give her a bath.” The effort and knowledge necessary to accomplish her work was not immediately obvious to Heather- it was hidden.

However, later in the interview she seemed to unearth some of the hidden work she performed, acknowledging a multi-dimensional texture to her work:

I’m not saying it wasn’t hard work because it really was, um, a lot of times it’s emotional. I mean it’s a hard job.
Once in the frame of mind where she could describe intrinsic aspects of her caring work, the examples seemed to come with ease. To begin, she spoke about how deceptively basic work can seem on the surface to outsiders.

You know it sounds really easy, ya you feed her, but it took forever- like two hours!

As Heather goes on to explain, the work of feeding was much more involved than merely putting a spoon to a client’s mouth.

Not everything works for every client. We gave her liquid food, but she didn’t know how to suck it up from the straw. You know, even just cooking a certain kind of food, or mushing it up, or putting it in the blender and giving it to them as a milkshake with lots of fruit and stuff would work for some person, but it wouldn’t work for others. So, you just kind of have to just figure it out. And maybe try a few things before you figure that out.

In addition, examples of maneuvering equipment like “Hoyer lifts” and special wheel chair adaptations, also added to the complexity of her workload.

Another level of her caregiving was managing relationship boundaries.

I had this one client who was younger who use to hit on me all the time.

While individual client relationships created challenges for Heather, interacting with client families in the context of the private home environment posed its own unique dilemmas.

Because they had a live in person that was a private person, she had been with the family for four or five years, and she was really nice, and a major part of the family. And so I was sort of the temporary her while she was gone, so they expected me to eat dinner with them, and you know. They were always chatting and asking me about my life, not a lot, but you know. But, I’d usually
try to uh, I don’t know, like I did get to know the family fairly well, but um, you still have to draw boundaries. Because you’re still there to work, and um, so I found that kind of hard there because I didn’t want to get too involved. Because it was a stressful situation, but um, I found out the hard way that, you know, if you’re in somebody’s home every week, every day, like, you’re not doing anything else, you get too involved with too much. And then you go home you need, you need, you need to, um, draw the line. But, um, on the other hand, you know, you’re not a robot, so, you can’t…I don’t know, so I didn’t really mind just kind of eating with them. Because that’s their normal life, and they don’t want the hospital atmosphere, so you have to respect what they need.

The contradiction between the client’s need to personalize the caregiving relationship and Heather’s professional need to distance herself from her client’s circumstances resulted in an awkward balancing act she had to negotiate alone. The time and energy expended on the relational aspect of her work was considerable, but it was out of her supervisors’ view.

What Heather eluded to but failed to articulate was, although her work may involve bathing and feeding, the personalized approach necessary to do those tasks was also work. Because her clients varied from elderly people with “dementia,” to young, “quadriplegic” adults to middle age men “dying from stomach cancer,” bathing, for example, would require a different skill set for each person. The language to describe the personalized nature of her caregiving work was not easily accessible to Heather, and it took her some effort to recognize the work at all.
THEME II. THE SYSTEM

Each woman spoke at length about her impressions and interactions with the employing home support agency, and their stories converged in one particular way. Agency management and supervisors were largely ineffective in preparing and supporting home support workers on the job. Moreover, in some ways, the agency complicated their work.

For Sylvia, not only was the extent of her work hidden from her own view, but also, it was hidden from the agency that employed her; consequently, the agency failed to equip her with the knowledge and skills to handle the caregiving demands.

My training was really minimal... and, um, we didn't get much instruction about what kinds of people or what kinds of illnesses we'd be dealing with, or anything along those lines- um, any real idea of what it is like to be working with elderly seniors.

Similarly, each time she was assigned to care for a new client, the background information inadequately prepared her for the extensive care needs she encountered.

It would begin with me getting the information from the office which was very sketchy at best.

In response, part of her caregiving routine included a period of discovery or assessment, just as Anne experienced.

They never really gave too much information, uh, a lot of it you found out once you got to the door.
By neglecting to adequately prepare her with client information, the agency created more hidden work for Sylvia. The job of assessing and planning care needs was unofficially transferred to the HSW without commensurate time allotment, training or financial compensation.

Although Sylvia and Anne both described assessment as a fundamental part of their caregiving routine, they used this tool for different reasons. While Sylvia needed to do her own investigating to compensate for the agency’s limited client information, Anne used assessment to remain current with her clients’ immediate care needs. Though I cannot ascertain a clear explanation for the difference, my suspicion is Anne’s years of HSW experience have resulted in her having lower expectations of the agency: she does not anticipate the agency providing detailed care plans. Consequently, the meaning of assessment has changed over time for Anne. In this way, a HSW’s years of employment would influence how they understand their work.

Speculating about why the agency was lax in providing client information to its workers, Sylvia noted that her supervisors had a physical and emotional distance from the clients.

I guess because they haven’t met with the client maybe. They haven’t met with the other family members, and they don’t know what’s really going on sometimes in these places. I’ve had a few surprises.
Frustrated at the agency's lack of support, Sylvia confessed that she felt, "they were taking advantage of us."

A clear picture emerged from Sylvia's experience: her work consisted of having to meet a diverse range of care needs, for a broad client base, but without the training or support with which to respond. Where then did she learn to do her job? Sylvia supposes that, "Basically, I had to pick up a lot of it as I went along." Her self-reliance required that she use a balance of both "common sense" and "using your past experience to work in the new experience." Indeed, accomplishing her work took work.

Anne also shared her feelings regarding the home support system. In particular, she was concerned about her isolation from other HSWs, lamenting that there were no opportunities to "learn from these other girls." She believed a "support group" for HSWs could remedy the problem of isolation. Clearly, Anne had given this topic some thought, and it suggested she was committed not just to her clients, but also to her profession. However, Anne's observations also underscored a significant problem with the structure of the home support system. As she explained, by performing their work isolated from one another, HSWs are denied peer support, and as Sylvia discussed, there is also an absence of agency support. When considered in combination, the extent of HSWs' segregated work environment is striking. They are completely alone providing
care for their clients. With so much distance between the workers and the agency, it would seem their work was doomed to be unrecognized, and accordingly, uncompensated. Furthermore, if people working within the health care system were unaware of the breadth of HSWs’ caregiving labor, then the general public surely would not have this insight either. HSWs would appear to be missing in action.

Nevertheless, being removed from the agency’s sphere of influence also enable Anne to work around restrictive formal rules. In particular, she was frustrated by limitations placed on what she could and could not do for clients; therefore, she occasionally worked covertly outside the agency’s regulations.

If they [the client] ask me to do something, as long as it’s not life threatening or against Worker’s Compensation, I’ll do it. What [the agency] don’t know ain’t gonna hurt them.

Contradictions between what the agency and Anne identified as important work did not prevent her from doing the task; rather, the moral pressure to help her clients appeared to prevail over the agency’s influence. Therefore, by instituting inflexible, narrow job descriptions, the agency contributed to her accumulation of hidden work. Challenging the authority of her agency left her feeling uneasy, however, and despite my assurances of her confidentiality, Anne remarked, “I’ll probably get shit for talking like this.” Despite the physical distance, the agency still had the power to control aspects of Anne’s caregiving work.
Anne appeared to enjoy her job as a HSW. Caregiving permeated both her private and work life, yet she managed to balance the two. Indeed, her hard work was a source of pride, as were her skills and knowledge. She viewed her job as her “career” and she made no indication of leaving that line of work.

Most striking about Heather’s experience was that her attention focused less on her direct care experiences than on her encounters and her opinions about the home support industry. This discussion appeared to provide a context in which she could then reveal her caring work: it was her way of setting the scene.

Heather’s impression about her employing agency was powerful and direct.

I have to say they’re just terrible. They’re awful, and they treat their employees like crap, and they treat their clients like crap.

Her candid opinions about the agency she previously work for suggested a power struggle between what she thought was right, and what the agency actually did. Her words implied she would not be intimidated, and as she spoke, it seemed indeed, she did rebel against their control.

Heather went on to explain some of the deficits in the agency’s practices. With regard to scheduling, she spoke of how little consideration was given to the workers’ needs.

Like you could be all over the place. If you have a regular life and you’ve got kids, and you’re working like two hours in the morning, two hours in the afternoon, and then maybe at night, you’ve got to get to the other side of Vancouver.
In addition, like Sylvia, she found her training was substandard.

I think I worked for two or three months before they gave me my orientation. I mean, it was pretty brutal.

Based on her experiences, Heather doubted the agency was concerned about the well-being of its’ workers, illustrating her point with the recollection of one particular incident when she called in sick.

So I phoned them and I said, “Look I just had this burn, and I’m in a lot of pain, and I just don’t think I should go to work tonight.” And the person on call was like, “Oh, did you just get a bad sun burn?” And I’m like, “No, I burned my back. Like I was on fire.” And she’s like, “Oh, well do you think you can still go?” And I’m just like, “F*ck you.” You know what I mean? The one time I called. And ya, they’re just like that, because then they have to find somebody to go in at the last minute, and it’s really hard. But it’s not my problem, and you know, that’s my right that if you get sick, you should be off. So I never let them walk over me that way. They didn’t push me because of that.

Indeed, Heather saw the affects of systemic power dynamic impacting her clients, and she spoke of some of these inequities.

Actually all my clients had huge arguments [with the agency] over things like timing- even people they send in, or people aren’t tall enough for the transfers, or people don’t speak English, um, just a lot of different things.

I mean, you’re doing personal care for someone- if your not comfortable being around them there’s no way you should be forced to have that worker.

She supported her criticisms with her own hypothesis about the systemic source of the agency’s problems:

The thing is, the government gives [the agency] the money, and then they go out and hire somebody. So the person who’s the client doesn’t really have a lot of a say, and they really don’t have control
of the money. See, [the agency] doesn’t get the money from the client, so it doesn’t really matter if they piss them off. They’re going to get their money anyway.

Her insight into the policy and procedures guiding the home support system distinguished her from the other participants, and she used it as evidence to support her distrust of the agency. Moreover, it indicated that problems did not necessarily originate at the agency level: government policy was at the root of some corruption in the home support system.

Displeased with the unfair treatment her colleagues received, Heather seemed to take on an advocacy role.

They hire these people who first come to Canada who are just so happy to have a job, and you know, they think they’re making all this money. And I trained so many of the girls, and I would, you know, say to them, ‘Don’t let [the agency] push you around because you don’t have to do that.’

Accordingly, Heather was astute to and critical of systemic control seeping into her own work.

If somebody needs help, like, really late in the day, they [the agency] won’t send someone after a certain time. But if I’m OK with going a little later, and the client wants it, what does it matter?

Agency politics had no place in the private sphere of Heather’s caregiving work.

In response to her frustration with the agency’s intrusive rules, she brashly disregarded protocol:
I use to go in whenever the client wanted. I just didn't care about the politics and all that stuff, so I just kind of went, did my job, and did what I thought the client wanted and needed, and I didn't really care about the rules.

The isolation of providing care in someone's home afforded Heather a comfortable distance from her agency's rule book and enabled her to self-manage her work.

Although Heather had little respect for the agency, she did continue to work there. Philosophically, she seemed able to justify her continued employment by aligning her loyalty to the client, not the agency.

Once I had my hours set up and stuff, I really felt like I was working for the client. And that's how I approached it, and I think that's why I got along with my clients so well.

When the experiences of each participant are seen collectively, the same power issues are obvious in all three stories, thereby, bringing to light the extent of the problem. However, while Anne and Sylvia experienced similar agency interference in their work, they were less vocal than Heather about their disdain, choosing instead to quietly rebel in their day to day work. For Heather, the lack of power that she and her clients had over the caregiving arrangement prompted her to leave her agency and to seek private care work. The implication is that the immensity of the home care system's control cannot be defeated by individual HSWs challenging oppressive agency practices: the problems are simply too great.
However, private home care presented a different set of problems. Heather enjoyed the “flexibility” private care arrangements offered, but she spent more time, “making sure I was paid fairly:” private home support work posed a surprising dichotomy. Without the watchful eye of agency administration, Heather was at risk of being taken advantage of, but in this instance, the client was both the care recipient and the oppressor. This prompted me to wonder, what circumstances have to be in place for HSWs to gain power in their work? Clearly, the problems with the home support system were far-reaching enough to transcend both public and private work arrangements.

**THEME III. RESIDUAL EFFECTS OF BEING A HOME SUPPORT WORKER**

A common theme among the participant’s stories was the long lasting impact of being a home support worker. In different ways, the women felt their experiences as HSWs filtered into their private lives. I considered these findings significant as they illustrated how their caring work was more than mere physical labor. Providing care to aging clients embodied an emotional element so powerful that lingered after the fact.

When I remarked to Sylvia that she seemed to expend tremendous effort in her role as a HSW, she admitted that although being a HSW “was a good experience,” she had “felt burned out.” Regardless of the attention she paid to
her clients’ care needs, their circumstances did not appear to improve. This lead Sylvia to comment:

The more I saw these clients, the more I saw that I wasn’t going to change this mess.

It appeared that Sylvia at one time had an expectation of improving her clients’ lives, but the more she understood about the system of home support services, the more she regarded her efforts as fruitless. This raised questions for me about the intention of the home support system: was it indeed organized to create dependence rather than independence? Oppressed people are less able to protest against their poor treatment. Fewer demands on home care services would equate to fewer dollars spent, and for political leaders, budgetary control is received well by the voting public.

Sylvia’s frustration with both the agency and her feelings of being ineffective at improving her clients’ well-being contributed to her quitting. Although, she was also candid about her intention to use the employment “only as a summer job.” Although six years had lapsed since she last worked as a HSW, Sylvia maintained a closeness to her experience that was revealed as clear recollections and strong opinions. Returning to that kind of employment is not an option for Sylvia, plainly stated, “It’s hard work, it’s dirty work, it’s... it’s unrecognized work.
In contrast to Sylvia's experience, Anne seemed to speak more positively about her caring work. Despite similarities between her friend's care needs and her clients needs, Anne approached her unpaid caring quite differently. For example, on an intellectual level, Anne discussed the "stages of dementia" and associated behaviours. She explained that, "With dementia, it's a fascination with money and mattresses. Two or three of my clients that I've had, that's what they've done with their money." However, when her friend, "lost her wallet in the house and I had to spend hours searching high and low for it," Anne claimed that the friend "knew all along where it was, and she was just playing games."

Reconciling that her friend had the same disability (and prognosis) as her clients presented a conflict for Anne. Her personal connection to her friend called for her to play a different role- not that of a HSW. Interestingly, this shift in persona seemed to prohibit Anne from drawing on her knowledge as a HSW when "off duty."

A dichotomy of paid versus unpaid caregiver was evident. I understood Anne's response as an example of her need to emotionally distance herself from her clients so as not to be overwhelmed by their adversity. From a distance, she could understand client needs clinically. However, in her unpaid caregiving role, Anne was free to feel the full depth of her emotional commitment, but the closer she was to her client, the less she could intellectualize their problems. Anne did not appear to seek a compromise between the two extremes: they were
different experiences entirely. Being a HSW was a professional job, not a social responsibility. This is an important finding for challenging the notion that women’s caregiving work is a natural biological function.

Although no longer working as a HSW, Heather’s experience continues to impact her caring work. In her current employment role as a Registered Nurse, Heather admitted she draws on her HSW experience when assisting with patient discharge plans:

I think that being a home support worker has given me a better understanding that you just don’t push people out the door. If they can’t do something in the hospital, they sure can’t do it at home.

Her transference of knowledge confirmed that her experience as a HSW did imprint a specific knowledge and skill base. Moreover it is evidence that HSWs own important wisdom about caregiving that is not accessible to all health care providers. Using her insider knowledge distinguished her from her nursing colleagues and provided a more complete picture of the patient than what was immediately visible in a hospital room.

THEME IV. DEMENTIA CARE?

An interesting finding which related to all three participants was although they had clients with dementia, the women did not explicitly discuss their dementia care work. Though it was not made explicit, dementia care was implicit in their work. A broader reading of their work descriptions reveals how every aspect of
caregiving was effected when clients were cognitively impaired. Returning to the preceding findings and how they discussed as their work, dementia behaviours impacted their gaining entry to a client’s home, how they organized their workload for a client, meal preparation and feeding. This gives even more meaning to Anne’s earlier comment, “It’s an adventure, and it’s just one minute to the next the complete opposite.” Summing up dementia care in simple sound bites was an unrealistic expectation on my behalf because the work was not simple or easily defined: it altered how the HSWs approached their clients from the time they arrived until they left. Therefore, understanding how they accomplish their work is crucial to understanding the complexity of their work.

With scant opportunity for outsiders to look into how HSWs complete their work, HSWs’ dementia care seems destined to be hidden from popular view. Moreover, the participants’ dementia care work may be hidden from their own view because it seemed a normalized component of their day to day routine. Again, returning to their prior dialogue, the participants appeared to speak matter-of-factly about their interaction with cognitively impaired clients, and from my impression, these encounters were hard work, but producing. For example, Heather laughed as she explained the added effort of feeding someone with advanced dementia.

You know it sounds really easy, ya you feed her, but it took forever- like two hours!
Also implicit in her experience is that the added work of caring for cognitively impaired clients was simply understood as part of her professional role, and as such, was rarely articulated.

Regardless of its personal impact on the participants, positioned as hidden labor, dementia care is less likely to be an acknowledged and rewarded part of home support work. Although the participants may have regarded dementia care as routine, it clearly demanded their time and skills, and accordingly, this role must be attributed to their profession.

The primary reason for the lack of dementia care dialogue seems to stem from a more practical issue: although dementia care complicated their work the profundity of other problems took precedence. For example, as revealed in earlier findings, the participants encountered a tremendous range of client needs encompassing both the young and aged, the mentally ill, mentally handicapped, cognitively impaired, physically handicapped and palliative. Each need demands a different skill set, and it appears that in the scheme of the overall needs of their clients, dementia is merely one of many factors complicating their work. It is interesting to note that the diverse care needs HSWs encounter are less evident in hospitals where services are organized in wards/units according to care need. Despite readily available care staff and resources, hospitals do not have the expectation that their workers should know how to care equally well
for all patients' illnesses. This underscores just how extraordinary the work burden is for HSWs working alone in the community.

In the scope of the other challenges they encountered, dementia did not seem to be the issue that overwhelmed the participants' workloads. Indeed, their work descriptions suggested they had the skills to manage their clients' dementia care needs. As discussed, what they lacked were the allotted hours to complete the breadth of work, the consultation to share information, and the peer support to debrief particular experiences. Systemic problems in health care appear to be complicating the work of these three HSWs more than their clients' complex care needs. This finding is very important. It accentuates HSWs' professional identity as skilled, capable care providers, and by naming the problem as systemic, it shifts the responsibility for improving home care away from the direct care workers to the actual source. Given what these participants accomplished in their work without adequate supports, it seems that improvements to the system of home based care would enable HSW to make significant improvements in the welfare of their clients.

In conclusion, the factor of dementia care was not identified by the participants as an uncommon workload burden, raising questions about why it was not a heated issue. Further analysis revealed a subtler discourse on dementia care, and confirmed that it did add to their caregiving workload. However, compared to
other problems, caring for the unique needs of clients suffering from dementia was not a primary concern. In this way, the absence of discussion on this topic emphasized just how profound an impact other factors - systemic ones - had on their work. With this in mind, I sought to further research the role the health care system had on the work of home support workers. This question formed the basis for a second phase of research.
CHAPTER SIX

FINDINGS: PHASE TWO

A focus group comprised the second phase of research, and in this chapter I discuss the findings of the focus group analysis. Participants were HSWs specifically selected for their unique expertise with their union, or for their considerable knowledge of the LTC system. The discussion unfolded over 2½ hours, and despite the uniqueness of each woman’s experience, three principal topics received considerable attention. Giving consideration to how the participants named their experiences, I labeled the first theme as “caring” work. This reflects what the four women regarded as their HSW duties. The second theme, relating and relations refers to the interpersonal relationships that impact their work- for better and for worse. Lastly, I discuss the theme of health care policy reforms entitled re-forming. Past, present and potential changes to the long term care system have consequences for their work.

In an effort to add depth to their words, I begin this chapter by introducing each focus group participant. However, because the women are elite leaders in their field, they may be easily identifiable with even general details about their background. To protect their anonymity as much as possible, my descriptions of each participant must be limited. Details they willingly divulged in the course of the focus group is the exception.
Participant Introductions

Beth has worked as a HSW for 9 years and is active in her union. She resides in a small BC community and seems deliberate in her efforts to balance family obligations, employment commitments and union work. Her caregiving experience began at a young age when she assisted her mother to care for a close family member. In adulthood, her paid caregiving work was a practical necessity for running a household in contemporary society. However, now a veteran in the field of home support, Beth appears to be committed to her work for more than just a paycheck. She considered herself a client advocate, and spoke of mentoring newer HSWs. In her union role, she seemed particularly concerned with worker rights and improving the profession’s public profile.

Beth responded quickly to my call for participants. During the focus group she gave frank descriptions of her work experiences and her impressions, and her open manner seemed to invite other participants’ comments. In addition to depicting the seriousness of her work, Beth spoke of the humorous side of caregiving. Her participation needed no prompting.

Liz began working as a HSW in her early twenties, and now has 22 years of experience. Liz participates within the union, and she also appeared to collaborate closely with her employing agency to improve conditions for both clients and worker. As a HSW in an urban area, Liz relied upon public transit to
get to her clients homes. However poor scheduling often required her to
crisscross the city several times each day rather than systematically visiting
clients in order of proximity. Understandably, this proved to be a contentious
issue for Liz who also suffered a physical disability that restricted her mobility.
Though soft spoken, throughout the focus group, Liz talked confidently about
her work, and expanded on ideas brought forth by other participants. Her years
of experience also provided a context for seeing how the home support industry
has changed over time.

Rita is a charismatic woman with 18 years of experience as a HSW. Through her
high profile work with the union she has traveled the province to improve
public awareness about the role of HSWs. This work is contrasted by the direct
care home support work she continues do in the rural BC community where she
resides. Moreover, Rita’s stories highlighted some of the challenges particular to
providing home support services in a small, secluded community. Long travel
over land and water was sometimes necessary to access her clients.

Though careful to acknowledge the problems in provincial home care, Rita also
portrayed an optimism about the future of their profession. She clearly enjoyed
what she did, and like her union leadership, she revealed herself to be a leader
in the focus group. Her enthusiasm for this research study was beyond any of
my expectations, and she even expressed her gratitude for the opportunity to speak about her profession.

Kate was noticeably the youngest member of the group, but she distinguished herself from the others in several ways. Kate was employed for 2 years as a HSW, but had been out of the field for approximately 8 years. Unlike the other participants, she knew her time as a HSW was temporary, as it was a means of financing her university education. While Kate’s experiences as a HSW continued to have significant meaning for her, this was contrasted with her current job where she is on the other side of direct caregiving. Now Kate is assessing and allotting hours of home support services for people living in the community. Her insider and outsider views and notably different background provide an interesting contrast to the other participants’, and Kate seemed comfortable sharing her impressions with the group. However, in retrospect, the differences between her and the other participants may have limited how much Kate could join in the discussion.

THEME I. CONSTRUCTING THEIR “CARING” WORK

Formal Job Descriptions vs. Actual Work

Knowing their roles and responsibilities as HSWs was apparently not difficult for the focus group participants. Without prompting, they discussed what they did as part of their caring work, and they revealed a multifaceted vocation.
However, when these responsibilities are compiled, their comprehensiveness seems a enormous endeavor. In addition to performing numerous traditional housekeeping tasks, their work went further than mere physical labor. Beth articulated some of the essential caring work she did.

We are nurturers. We don’t care if you forget. We don’t care if you told us this story 500 times. We’re there to hear it again.

Expanding further she included other weighty roles.

It’s the mental care we provide.

We really do keep people living.

We’re not only the problem solvers, but we’re also the, the advocates for the people that can’t speak for themselves.

Likewise, Rita was committed to more than the physical well-being of her clients.

We’re trying to give the people back- a little bit of dignity.

In this regard, the emotional labor identified by the interview participants was validated again by the second group of HSWs. While this emotional labor featured prominently in their workload, it was not necessarily recognized as a valid part of the HSW job description. Beth explained how the direction she received from her supervisors differed greatly from her own values.

I don’t know about you guys, but we’re told we’re there to provide a service and aren’t responsible for how they are feeling or how they are doing. We’re suppose to report the difference and the changes for that person, but we have no responsibility for that person. It’s that cut and dry.
This discrepancy between what the women defined as caring work and what their supervisors regarded as home support work was quite conspicuous. While the agency managers may have had a concrete, finite understanding of what the HSWs must do for the clients. The workers had privileged access to what actual work needed to be accomplished, and as Rita explains, some have a sense of obligation to their clients which prevents them from cutting back on their caring work.

You know, my husband says to me, how many people are we feeding this week? Because I have to go home- and there’s kids involved- and how do I go to bed at night? How do you look in the mirror?

For Rita, it seemed that turning away from a client’s need was almost not a choice. This sense of personal responsibility for their clients’ well-being was a common theme with each participant, and a primary factor motivating them to continue giving to their clients. Moreover, just like Heather revealed earlier, their commitment seemed exclusive to the clients and was not a sign of loyalty to their agencies. For some of these women, the private context of a client’s home, coupled with one-to-one caregiving seemed to conceal other support systems that may be available to the client: the HSW was all the client had to rely upon. Indeed, Rita commented, “we’re all these people have.” The inter-personal aspect of caring also seems to facilitate an emotional connection between some HSWs and some clients. These conditions seem like a formula for generating strong client loyalties.
In addition to their extra work going unrecognized by the agency, each of the women shared her frustration about the lack of recognition for the work behind their work. Kate voiced her opinion on the subject.

> And obviously we wear so many hats when we work in this area. We counsel, we counsel financially, we do the physical care, the emotional care taking which is perhaps 90% of what we're doing. We do so many things and there's so little of that recognized. The only value is how quickly we can see our clients and given the hours that we have, and that just doesn't cut it. That totally does not dignify what we do. I know it's important, and I know from both ends because I've been outside the system and in the system.

Rita had a similar experience.

> Because I'm in there doing somebody's house work, doing their laundry, doing their shopping, making their meals, um, does not mean, that this is not part of their social well-being.

As Rita explained, mandated house work often required specialized knowledge and considerable effort due to clients' physical and/or cognitive needs. The very work the HSWs described as their most important roles seemed to be hidden work. This finding is similar to the experiences of the participants in the first phase of research. Rita tried to articulate the unseen difficulty behind a presumably simple task like shopping with a client. It was met with understanding laughter from the group.

> She's so lonely, and she wants to go out so much, but it requires me practically carrying her to get her out because she's got something wrong with her legs... I have a couple of them that I would just love to take shopping. But it's not so easy to say "shopping."

Echoing her sentiment, Beth shared how she believed other people would not see the therapeutic benefits of client outings.
...I mean, on the outside it looks like, 'look at those fools, they're making X amount of money to do this.' But it's varying the quality of that person's life, and that's what we're there for.

Not surprisingly, if their work was not being recognized it also was not being rewarded. Liz and Kate saw a broader social connection to their work not being respected.

We spend 12 hour days and we get maybe 8 hours of work in a day. We get no paid lunch time, no paid coffee break, and no time for that. I don't know of any other job like that. I feel like it's slavery in a sense. It's really slavery. Because it's women's work and it's not valued.

And it's harder because you're a woman, and you're seen in this certain role. You know, that was another thing that got me out of it pretty quickly. It's, you know, a stereotyped role and it's demeaning. And it really doesn't make you feel good about what you do and who you are.

Their powerful statements illustrate how external forces impact how the women regard themselves and how they come to understand the social construction of a home support worker. Ironically, as the participants relayed earlier, these outsider perceptions are based on only a partial view of what is actually happening in the caring relationship. If the work was hidden, as so much appears to be, then society is basing its awareness of home support work on incomplete knowledge.

Nevertheless, the discourse suggested that the constant bombardment of negative responses to their work had a personal impact. This resulted despite the participants own confident portrayal of their work as complex and
important. Liz, for example, described home support work as “slavery,” yet she had worked in the industry for over 22 years. For all the problems associated with home support work, the participants devotion to their vocation seemed to surmount those barriers.

As providers of both physical and emotional care, the four women comprised a large and diverse list of job descriptions. However, the immensity of these tasks have an even greater impact when seen in the context of their work climate.

Smoke and Mirrors

Beth introduced the metaphor of HSW as “magician” and used it on two occasions to describe how she and her colleagues managed to accomplish numerous and complex tasks without adequate supports. In some instances, she was even amazed at her ability to actually get the job done. Beth’s experience of trying to create a meaningful Christmas for one of her clients illustrates this challenge.

You’ve got so much more to do, because you’ve got all the extras you’re trying to make them a little bit more happier, and you’ve got the same amount of time to do it in. Like I went out with that 92 year old woman who gave me hell because she couldn’t walk up the stairs, I went out, bought her a Christmas tree because she had this broken down Christmas tree and I didn’t want to put it up. So I went and bought her a real Christmas tree and put it in a plant box, right? It was only small. And I know she likes lots of decorations and everything, so I put it in front of the window and bought lights at the dollar store, and um, balls, and the lights also played music. And I paid for all of this, just so I wouldn’t have to put up this tree so I wouldn’t have to hear her complain that
nobody sees her on Christmas. I wanted to make this moment special for her, and just the added stress of having to put this up. I mean, we’re magicians at times.

Part of the challenge related back to the earlier problem of the job being larger than what the agency acknowledges.

Beth’s use of the magician metaphor presents an interesting contradiction. “Magic” suggests that work was done with seeming ease, and that the struggle of accomplishing these terrific feats was merely an illusion with the HSWs as performers. However, the passion and detail with which these women describe the challenges to their work clearly does not support this interpretation. Beth’s use of the word “magic” seems to indicate how she was surprised at what she was able to do for her clients under time and financial restraint. It was as though she was an observer to her work, realizing as she spoke just what she had achieved. When the “magician” metaphor is compared with another of Beth’s powerful remarks, it suggests that sometimes she has to step away from herself in order to cope with the strain of her work.

I had to literally visualize going to work with all these coats on, and after the first client I take off a coat, and then the next client- I mean I had to visualize this so I could continue on. I would love to call in sick that week because it was hell. I mean, you’ve got six vets, I don’t care what anybody says, Remembrance day is a terrible day, you know, it brings back all these terrible memories. I don’t care if that upsets you know what the reality is.

Caring had a personal cost for Beth, and her remarks implied that she had no alternative professional supports she could call upon to cope with weighty work
issues. She was alone in her predicament. Furthermore, despite her strong aversion to working on Remembrance Day, Beth’s commitment to her clients seemed to override her own needs. This scenario was indicative of the moral obligation that Rita spoke of earlier, but I understand it as an extension of women’s socially prescribed caregiver responsibility.

The notion that Beth’s home support work was done with slight of hand rather than hands on care was far from the truth. Furthermore, the group drew upon another metaphor to reveal just how strenuous their caring work could be.

**Front Line on the Home Front**

Health care reforms require HSWs to adjust from, “the old way of doing home care,” to a home support system with extremely limited resources. The repercussions of such extensive fiscal restraint can be likened to a state of war where products are rationed and people survive rather than thrive. Such was the image put forth by the focus group. In describing their work, the participants' use of metaphors revealed powerful war time images. For instance, referring to the difficulties of meeting her clients needs with inadequate time and support, Rita said, “You’re fighting almost a losing battle everyday.” More than one participant commented, “We are the front line workers.” Proposing solutions to the war like environment, Kate offered, “The first line of defense is, can the family help?” Her second suggestion continued the metaphor:
I think there needs to be more collaboration between our supervisors, their supervisors, you know, all the way down the chain of command.

Given the typical image of "home" as being a comfortable, warm environment, the irony of the militaristic metaphors is even more glaring. Beth explained how home for elderly clients was a danger zone.

You know that person's going to spend the whole weekend at home by themselves, unable to get out of bed by themselves, or care for themselves. We know we have to take them somewhere safe, and that's [the hospital] the only safe place.

If home is not safe for older people, then how can the government promote the shift to home health care as a positive measure. Beth's comments raise questions about deeper policy issues: what is the actual intent of health care reform?

Indeed, home care is proving to be a cheaper alternative to acute care, but is this simply because money transfers to home care are grossly inadequate? The experiences of these HSWs struggling to meet the needs of their clients would appear to support this argument. Furthermore, by denying sufficient funding to home care, the people most affected are the frail elderly and their direct care providers - both of whom are predominantly women. Home care reform was proceeding at the cost of people who are already marginalized. Carrying forward the war theme, I liken this example to America's recruitment of African-American men without formal education to fight the Vietnam war: disempowered people are sacrificed ahead of those with higher status.
Deploying troops comprised of people that society historically discriminates against creates the uneasy feeling that those on the front line are expendable. Beth defined her service as a HSW almost as one who was serving her country, when justifying feeling responsibility for her clients she states, “You’re talking about everyone who doesn’t have a strong voice to fight for themselves.”

Unlike the nursing profession which has its foundation in the military tradition and often borrows from the language of its roots, the home support industry is a relatively new health care profession formalized within the last 30 years: in peace time. “Charge nurse” and “duty roster” for example, have no historical significance to home support workers; thus, drawing from such a vocabulary hardly seemed an unconscious temptation. Instead, it appeared the participants’ portrayal of their work through militaristic images was not grounded in professional acculturation, but rather was a deliberate effort to accurately describe their work environment. They were part of a war. Caregiving with too many demands, and insufficient tools with which to meet those needs turns the home front into the “front line” of a “losing battle”. Beth’s story about trying to cook for her frail clients without adequate food is reminiscent of wartime rationing.

You open up the cupboard and you got a little bit of cereal, an obscure can of something or other, and then there’s home made preserves that are now not floating but sitting in the bottom of the jar. And you’ve got to provide a nutritious meal for this person, and how the hell do you do that?
Rita referred to this complex task as, "making something out of nothing."

The reforms to health care in this and other provinces are so extensive that it could be referred to as a revolution. It seems all too appropriate then, that HSWs would feel they are in combat as caregivers. This war also comes complete with physical and emotional battle scares as the participants describe some of the repercussions of caring under fire.

The Consequences of Caring

As the participants discussed thus far, on the job they are confronted with: lack of recognition, undervalued work, challenging client needs, inadequate assistance, dramatic health care reform. In response, the women described a personal cost to doing their work under such unfavorable conditions. For Kate and Beth, the cumulative effect of stress ultimately impacted their clients.

If we're hurting right now with our experiences, and from what we see as deficits in what we do, then obviously, that's carrying down to our clients and we know that they're already hurting too.

I'm telling you, that's heavy duty stuff, and at some point, you have to take a step back and say, look, you know, this is hard on me, and if it's hard on me, then it's hard on the client.

Rita also felt the pressure of not being able to do all that her clients needed.

You're having to say, 'Gee, I'm sorry, I know you want to go to the drug store...but you don't have time. And they don't have anybody else sometimes to do that either. But their solution to the problem was- just leave it alone. And, I can't do that. So, you know, it becomes a very stressful job. That's one of the stresses, is dealing with time restraints and trying not to show it to these nice little old ladies.
Emotional stress featured prominently in their stories, but as Kate explains, abuse was also apparent in their work.

I've had clients push me. I've had clients yell, scream, swear, call me names. I've had clients hit on me.

These experiences were generally related to her work with cognitively impaired individuals, thereby, accentuating how dementia care has far reaching consequences for the care provider.

Although the participants expressed a sense of pride in their work, their stories revealed that the strain of being a HSWs affected their professional as well as personal lives. Their experiences also exposed two primary factors which either contributed to or impeded their caring work. These sources were their working relationships and health care reforms.

THEME II. RELATING AND RELATIONS

One to One

As a consequence of assisting clients with intensely personal care, relationships often developed. The participants referred to their clients as “friends,” “special” and other endearing names suggesting that a unique bond could form between HSW and client. This could also be construed as a blurring of personal and professional relationships. As a “friend,” not a paid caregiver, a HSW is perhaps more inclined to perform caring work exceeding the job requirements. However,
home support workers are not informal/family caregivers, and promoting the	ondition that they are "like family" serves to undermine their status as
professionals and further hide their work.

Throughout the discussion of their client relationships, one issue remained
unclear: Does the act of caring result in a relationship, or must the relationship
be present to perform the kind of personal caring work necessary? Liz talked
about reconciling how she could take care of someone she did not care for.

...the other thing that they do that makes me so furious is we've
got two or three Alzheimer's patients- now it's hard enough for
this woman to remember me when I come. They've got 14 HSWs
going in there every single week...so you can't have a relationship
with her even though she would like to and really needs it. She
lives alone. And there are other mentally handicapped people in
the same boat, and that's when people get the best care is when
you can develop a relationship. Not to say that we're not kind to
everybody and do our job and everything like that.

The importance of human connectedness in their work relates to how the group
earlier described their roles as "nurturers," providing "mental care" and
"emotional care." For Liz, firm client relationships were necessary for her to feel
she provided "real care." Recalling one of her major breakthroughs with a client,
Liz attributed this success to her relationship with the woman.

It was really emotional. All this was done because we were able to
build a relationship. All the time there's somebody different. You
know you're not really doing your job when it's somebody
different all the time. This isn't real care.
The client relationship was a popular theme in each of the women’s stories, but several barriers to that relationship were identified. As Liz identified earlier, a critical interference with client relationship development were systemic scheduling problems which often resulted in being assigned different clients each day or week. Similarly, Beth emphasized the importance of “continuity of care” and Rita acknowledged it as an important union issue.

When you get one person in your house on a regular basis, and you build in a routine and you can find this little space where you can provide something that means something—that makes them feel like a human being again, for even like ten minutes

You know, we’ve often discussed this. Every bargaining that I’ve had anything to do with we’ve discussed at the table—even amongst all the HSWs. And it’s been called continuity of care. And that’s one of the things—and actually we’ve built into our agreement that that’s where we’re willing to weigh seniority, uh, how we’re scheduled. Because to us it’s everything.

Family Ties

The client relationship was not the only important connection the participants experienced. Interacting with the client’s family was also part of their caring work. Liz referred to the spin off effect of caring for the older generation of a family.

Oh ya, very often I’ll go to work for mom and dad and the kids will take me down to the basement and say, I’ve got to talk to you about so and so. And the sister will tell me one thing and the brother will take me to a different part and tell me something else.

It would seem that remaining focused on her caregiving work would be complicated when the larger family dynamics interplay.
Although families sometimes interacted with the HSWs, the workers' identity within the family was somewhat more obscure. Rita spoke about the importance of being separate from the family's role.

I always think of us as their [the clients'] own person. You're not family, you're not sitting in judgment— they can tell you whatever they want. And they, a lot of them, know that you're not going to tell anybody else. It makes so much difference.

Liz considered herself as more integrated with her clients' relatives.

I think we're part of the extended family. We're just hired extended family.

However, the incongruity of being both "hired" and "family" was evident to Liz. She discussed how her decision to support a client over the family had negative consequences.

They got me out of there because I was the trouble maker as far as they were concerned. And this woman, I'd gone to her for about 6 years. She was heart broken, but they got me out of there because I was seeing what was going on.

Although family members could extend a sense of familiarity to the HSWs, this relationship was tentative. Still other clients' families were unsupportive from the beginning of the working relationship. Kate spoke about the difference between relating to the client and relating to the family, and the personal impact of alienation.

The client sees you one way, and the family of the client sees you another way. And it's two different things. And usually, some families see you as very valuable to them, to keeping that person in the home and— and other people see you as hired help the house cleaner, the maid that kind of a thing. It's very demeaning.
Beth had an experience where the family's presence actually hindered her ability to care for her fragile client.

We tried to keep a written diary of different things he liked and whether he was toileted or whether he ate, but every time it was put in one place the family took it and hid it. So we'd have to hide it from them and then sort of relay to each other where it was. But the thing was, this man was perfectly capable of making his own decisions. The only thing was blood was thicker than water. He wanted his family around, and he didn't care what kind of filth that he had to live in, just as long as somebody was there.

Despite some of the problems blurring the interface of paid HSWs and family members, many of the participants sympathized with the pressure on families to be caregivers to their relatives. Beth related the difficulty to policy.

The mandate of Closer to Home is for the families to look after ...their loved ones, rather than getting help from outside. I mean now a days, the economics- you can't afford to stay at home and look after your family. I mean, none of us could, most of us are all two income people.

By doubting the practicality of full time family caregivers, Beth appeared to reinforce the need for outside care providers like HSWs.

Relationships within the home were not the only important relationships for the four HSWs. Interrelating with other health professionals also featured prominently in the discourse.

Silent Partners

Although they work within the long term care (LTC) system, the participants emphasized how they are isolated from other professionals working with the
same clients. In particular, the topic of LTC assessors provoked considerable
discussion. While the HSWs were responsible for providing care to LTC clients,
it was the assessors' responsibility to determine the amount of home support
hours or whether service was indicated at all. Despite the connection between
their two roles, the HSWs were not allowed contact with the assessors: their
supervisors functioned as intermediaries. This distance from assessors was a
source of frustration for three of the participants, but rather than rebuking the
system, their anger was directed towards the assessors. Beth articulated her
feelings bluntly.

The LTC assessors don't want to talk to us...I have only once ever
had contact. I mean, we're from a small area so we know who they
are. They don't want to talk to us.

Likewise, Liz and Rita felt a barrier to communicating with the assessors.

We're not allowed to talk to them.

We don't. We talk to our supervisors.

My reading of this practice was that HSWs were considered incapable of
contributing useful information; however, the participants did not understand it
in this regard. It was more a personal affront.

The absence of collaboration between the HSWs and assessors seemed to spark
animosity. When the Ministry of Health cut housekeeping services from the
home support program, LTC assessors instituted the reductions. Though the
HSWs personally witnessed the client impact, they were not involved in the change process. Their omission heightened their dissatisfaction with the LTC assessors. Beth's response was representative of the others'.

...the hole distrustful thing was... continuing care - their long term care assessors didn't even go in and reassess these people, they just cut them off cold.

Despite their limited opportunities to connect with LTC assessors, their roles seemed to interface anyway. Interestingly, developing informal and formal professional relationships with assessors was part of the HSWs' vision for the future.

THEME III. RE-FORMING

Policy in Practice

The third fundamental theme in the discourse related to the larger health care system and recent policy reforms. Participants located their work within the context of the Ministry of Health, and furthermore, they connected what was occurring at the macro, policy level to what HSWs were doing at the direct care level. At first glimpse, their big picture knowledge seemed to clash with earlier accounts of being isolated from all other health care professionals. However, the participants' stories supported the contradiction. Their comments suggested that although the system often overlooked HSWs, HSWs did not disregard the system. Because changes to the health care system impacted the HSWs so
directly, it was in their best interest to keep apprised. Rita talked about the

*Closer to Home* policy reforms and her realization that the plan was flawed.

...we've been trying to get the Ministry of Health, um, anybody who will stand still long enough to listen, to hear us...We also felt that with, with this new *Closer to Home* - I guess when they first came out with *Closer to Home*, we all immediately, because it's our line of work thought this is terrific. I mean, *Closer to Home*, my god, how good can you get. So it was a bit of a shock when at first they didn't want to pay us to look after these people.

This disappointing experience galvanized Rita to become more involved in the policy reform process. In particular, she concentrated on matching proposed changes with the funding necessary to see them actualized.

I sat on a Ministry of Health review for our...standards. I just thought these were great, and I was just very, very impressed with these. But, I sincerely hoped that there would be money attached to these because all of it involved you know- everything we do involves money somehow.

From their direct contact with home care clients, the women experienced first hand the problems created by the *Closer to Home*. Questioning the wisdom behind some of the changes, the participants spoke of how the new criteria for home support service did not reflect who needed care.

Kate laughed at the method for measuring service need.

So it was like, here's a list of seven things and you have to meet four criteria to get services.

Rita added what she remembered.

It had to be life endangering. You had to be over 90.

Beth was also dumfounded by the process.
Ya, maybe you needed seven of the 12 requirements. I can’t remember, it was so ridiculous we couldn’t believe it.

Rita spoke about the psycho-social impact on lonely, aged clients when their home support services were terminated.

To have your service cut... you know, it’s all these people have. We, we’re all these people have. Not all of them, but a lot of these people. You know sometimes we’re the only ones they see. If they’re lucky enough to have meals on wheels people, well jeeze, you know then they get to see another person, but that’s it. And when they have their hours cut... granted, we told whoever would listen that yes, we will see them again- when they fall down those stairs, trying to carry their laundry with a cane.

Beth identified inequities in the LTC system resulting from the reforms.

...if you look at it from a private pay person, there’s a clear two tiered medical system here. Because the family is paying for the service, this person gets the benefits of being able to go out for a drive. Whereas I have another person who’s under continuing care that isn’t allowed that benefit who needs it just as much.

Liz struggled with the incongruity between who the Ministry would support with home care, and who actually needed the service.

Everything has to go with the bath. Now sometimes that’s the only thing these people can do by themselves. One of them said to me that’s a sort of a last vestige of pride, personal pride that I have that I don’t have to get somebody to give me a bath. I can’t do anything else. That’s the only thing I can do. And it really annoys me that that’s the only way their going to get the service or it gets cut. And that’s what happens.

Their stories depicted some of the impediments that policy changes presented to their work. Furthermore, the participants’ observations revealed that they possessed considerable knowledge about both health care reforms and direct
practice. This combined knowledge was power for the HSWs; however, it was not recognized by other health care professionals.

"Give us Credit"

Even with all the barriers the HSWs encountered, they accomplished their work and gained a unique and comprehensive understanding about LTC. However, the women felt this wisdom was undermined by other professionals' failure to recognize the worth of HSWs. Rita articulated the problem.

You know, if just some people would just kind of listen to us and give us credit for having a bit of a brain, and knowing what we do. Because I can tell you who needs the hours and who doesn’t. My supervisor probably can’t. The LTC assessors definitely have no idea. They can go in and in 5 or 10 minutes they decide whether you’re going to get two hours every other week, one hour every other week- I mean I cannot believe some of the stuff. And then... we have clients who have three hours three times a week, and yet you have a client that has two hours once a week and desperately could use another half hour or hour. And we are the people that know.

Likewise, Beth told a similar account.

We are the front line worker. We have all the information. We’re just, I mean just talking tonight, we’re full of information and stories, and anecdotes. We’re the problem solvers for these people. We’re not only the problem solvers, but we’re also the advocates for the people that can’t speak for themselves. We have to be heard.

Their conversation was not limited to merely protesting their second-rate status.

The women also envisioned how their knowledge and contributions could be legitimized.
Coming Out

The HSWs acknowledged their wisdom about the LTC system. They prided themselves on their caregiving expertise. They desired to be heard by their other health care colleagues. These were some of the common elements to each HSW’s story, and two major pathways were proposed for propelling them out of obscurity and into a position of influence. For Rita, the HSW union was the key to elevating their status and improving work conditions - she seemed committed to this pursuit.

Things are changing...I do think that there will be more communication. I do think we will be recognized more. Mainly because a lot of us will never ever give up. We’re always going to talk about it, and making sure people do listen to us...You know, it’s been really hard, and we’re always educating people on what HSWs do. On our last strike, man, it was just like somebody wound me up and pointed me and- go to this meeting talk about home support. People have no idea what we do, and we need to keep out there. We need to keep telling them what we do.

Although Beth did not necessarily share Rita’s optimism, she did appear to share her passion for change.

Number one we’re not on the team. We’re not part of the team talking like we are. It has not come to that, and I don’t think it will ever be a part...In health care, there’s a real cast system. You’ve got the doctors, and nurses, LTC assessors and then you have nurses’ aides, and then you have home care workers. And we are the bottom, and that’s how we get treated. They treat us like we’re a bunch of uneducated people, and we need to be part of the team.

Her appeal for HSWs to be part of the health care “team” emphasized how much they were not currently team members. It also implied that the “team” was the context for receiving “credit” for their expertise, improving the status of HSWs
in the health care hierarchy, and making improvements to the system.

Meanwhile, Beth also identified a hurdle to achieving her collaborative goal.

As long as you have the trust there. But none of us trust anybody.

Though there are many barriers to overcome before HSW are validated as important health professionals, HSWs may not be eager to join the inner circle. Embracing the people who previously minimized the value of their work does not seem like a realistic expectation. How this will transpire is unknown.

Although the mission was clear, details for the journey out of the home and into the LTC spotlight were not.

The home support workers in this study came with different backgrounds and varied views; however, through their work, they shared common experiences. Their dialogue highlighted three main themes that flowed into one train of thought. Setting the foundation, the women shared how far reaching their caring work extends. Next, they spoke of how relationships with clients and clients' families impacted their caregiving. Finally, they connected their work and their work relationships to the policy reforms in health care. The result is a multidimensional view of the home support industry and the larger health care structure.
CHAPTER SEVEN
DISCUSSION

In previous chapters, I presented the findings of two separate data collection endeavors. In this chapter, I integrate all these findings and discuss their social relevance. From the participants' personal stories and comments, a much broader picture emerges about home support workers within the health care system and within society. Literally, there is more to their work than meets the eye.

THE PERSONAL IMPACT OF CARING WORK

The findings reveal that much of HSWs' work is hidden from the casual observer, and sometimes, from the workers themselves. I purposely selected the term "hidden" over the more common usage, "invisible," because although their work is not obvious, it does exist. Hidden work suggests it could be uncovered, and that is the goal of this submission.

As a component of hidden work, emotional labor encapsulates how HSWs do their work in the context of personal relationships with their clients. Participants identified companionship and personal burn-out as some of the effects of giving from the heart. These findings are consistent with the current feminist literature on caring (Aronson & Neysmith, 1996; Donovan, 1989, 1993; Eustis et al., 1993).
Another element of their hidden work is the considerable amount of creative problem solving that they employ to meet individualized need/problems. Lack of adequate training seemed to force the participants to develop these survival techniques of rapid decision making and learning “as they go.” Furthermore, participants relied on their problem solving skills more frequently when their clients suffered from dementia and exhibited unpredictable behaviours.

Neysmith & Aronson (1996) also recognized the complex decision making involved in home support work. Certainly other studies have addressed the issues of isolation and insufficient job training, but they failed to recognize how HSWs compensated (Applebaum, et al., 1990; Burbridge, 1993; Donovan, 1989).

In response to narrow job descriptions, and distance from supervisors, each participant detailed how she went underground with her work and broke with agency policy. This provided some control over their work and enabled them to better care for clients. However, they do this work at their own risk, as they are neither compensated nor protected. In this sense, their out of bounds work was also hidden.

Finding the words to name their work was a struggle for several participants- a result of what Spender (1985), called “man-made” language. The value attached to caring goes only as deep as the visible physical work they do. Ironically, most
activities in personal and work life involve more than what meets the eye; however, in terms of HSWs, they are so distanced from public view that their work is misunderstood. Moreover, as a marginalized group, they lack the power to change the popular perceptions.

Another common feature to the stories was work organization—a finding that corroborated prior studies (Neysmith & Aronson, 1996; Donovan, 1989). As a strategy to manage time constraints and unpredictable changes in client needs, it proved an essential part of their routine, again emphasizing the "lone wolf" characteristics to home support work. But the findings suggest that the isolation HSWs face in their work is not necessarily a consequence of the job. Segregating HSWs fulfills both social and systemic needs.

THE WHY AND HOW OF HOME SUPPORT WORKER OPPRESSION

Why are HSWs Exploited?

According to the expansive literature on the topic, informal caring work is performed primarily by female family members and friends, and their work is under valued, unpaid, and largely unrecognized in Western culture (Able and Nelson, 1990). HSWs step in as care providers when families cannot, but the shift to formal/paid caregiving does not rectify these injustices.
A purpose lingers behind this oppression. Denying HSWs notoriety for their accomplishments serves to perpetuate the social construction that caregiving is not professional work, but rather a biological function. It is merely physical activity with no great significance to society. As a natural human duty, caregiving does not necessitate high wages; consequently, the employment of HSWs is a relatively cheap alternative to free family care providers. Funds are then freed for other services with more social value such as costly doctors fees and the purchasing of high technology equipment. In this way, much of the health care system is supported upon the backs of HSWs.

However, this impropriety is not solely the responsibility of the health care system. Society also plays a role in undermining the importance of caregiving work, and in doing so, certain people benefit. Simultaneously, as HSWs are demeaned, the status of women lowers. A preponderance of HSWs are women, and an association exists between the social insignificance of their work and the social status of the people doing the work. Assuming the role of caregiver means assuming all the associated connotations. Again, a post-structural perspective offers insight. By aligning women to the role of caregiver and offering little reverence for this work, not just HSWs but all women assume a lower social status. The people who gain from this gender construct are those who hold a position of power and whose best interest is served by obstructing women's
equality. Disempowered people are much less of a threat to the socio-political standing of the dominant culture.

Many other arguments can be made for why the health care system and society undervalue HSWs and their work contributions. However, understanding how they are systematically exploited moves us closer to effecting change.

How are HSWs Exploited?
In nearly every aspect of their work, HSWs are treated poorly. According to Donovan et al. (1993), their pay is significantly less than any other health care provider, and non-union workers earn even less. Training is also grossly inadequate to meet the variety of challenges encountered on the job, and education is neither required nor standardized. The argument for national standardized education for HSW has received some recent attention, but the supporting reasons are solely to benefit care recipients. While this is a worthy objective, it ignores that HSWs are also victims of policy shortcomings; indeed, at the crux of the movement to standardize their education is the assumption that HSWs are primarily responsible for inadequacies in the home care system. Rather than receiving acclamation, the workers are subject to condemnation.

Health policy provides a bureaucratic forum for keeping HSWs downtrodden. The current system for managing home support services is splintered and
archaic, functioning as a subsidiary rather than a partner of the Ministry of Health. Both the profit and non-profit agencies who employ HSWs are funded by provincial coffers, yet they do not share the same employee standards. The organization of health care services in the Vancouver/Richmond health region is depicted in Figure 1, and it demonstrates the separateness of home support services from the larger health care structure.

Figure 1. Home support services within the current health care structure of the Vancouver/Richmond health region.

Ultimately, the physical and philosophical distance between home support agencies and the government departments that contract their services impacts client care. The lack of regulation among provincial home support staff means...
some HSWs are denied adequate pay, professional support, benefits and training. Without the tools necessary to do their work, care is compromised and the frail care recipients then suffer. This defeats the very purpose of home care which is to improve or maintain a client’s functional abilities.

Another problem with the service system is the absence of the “customer”. One participant voiced her dismay at what she perceived was a lack of agency accountability to the clients. Because agencies received the bulk of their funding from government sources rather than the care recipients, there is little incentive to grant special requests like specific HSWs and flexible service schedules: the agencies get paid regardless of how unsatisfied the client is. Furthermore, participants identified that consistent client contact and control over their scheduling are two crucial aspects contributing to the quality of their caring work. Stringent agency rules may be construed as another systemic mode of undermining the importance of caregiving and the worker/client relationship.

Clearly, the policy supporting such a chaotic system of home support is flawed, but its damaging effects on the status of HSWs is even more conspicuous when viewed in conjunction with other oppressive health policy reforms. The Closer to Home report envisions a more streamlined, future focused health care system based heavily on the use of home care over institutional care. Although its intentions are admirable, in reality, the program falls short. Armstrong and Armstrong (1996), compare the current trend towards
community based care for the elderly to the de-institutionalization of mentally handicapped people during the 1970’s. They predict that the idea will fail today just as it did in the past because the resources necessary to support the policy are not being made available. The findings of this study support this theory.

The supporting policy inadequately transfers financing to the home care industry despite the increasing reliance on the community based resources; consequently, HSWs are obliged to do more for less. More clients are needing home care services, and reduced access to institutional care means clients are sicker and needier than ever before; however, the hours of home support necessary to care for these people are not being allotted. The result is a defeated, overwhelmed and exhausted work force of HSWs. Furthermore, their already marginal social status denies them a powerful voice to exalt their plight. It is hardly an oversight.

Keeping HSWs in a constant weakened state of subservience and fatigue drains their motivation to fight back. The participants’ use of war imagery to describe their work is perhaps less metaphoric than it initially seems. HSWs are placed in a defensive position always with grossly insufficient resources to do their work as a means of attacking their spirit. Furthermore, HSWs’ isolated work environments are in the government’s favor serving as natural barriers for obstructing efforts to organize a backlash. Aligning HSWs so closely with the
domestic sphere also distances them from the rest of the health care community, and again, this dichotomous relationship is hardly accidental.

The HSWs in this study articulated the difficulties of distinguishing their relationships to their clients and client families. The familial lines are blurred, and understandably so given their peculiar position as personal confidant and hired help. In short, HSWs have been manipulated into the role of surrogate family caregivers, and in doing so, they are subject to the same marginalized status as their counterparts - the family.

Although clients and workers may also benefit from forming relationships, without reality grounding forces such as collegial support and collaboration, the client bond can be confusing. The expectations clients have of family members are projected onto the HSWs, thereby, bridging the dichotomous relationship of family vs. professional. Setting emotional boundaries and time limits are difficult under these circumstances.

As pseudo-family, home support workers are more likely to extend themselves further in the their caring work. Morally compelled to meet their client’s needs, home support workers give more than what is required; thus, compounding their already overburden workloads. This corresponds with the findings of Aronson and Neysmith (1996), who emphasize that HSWs’ overwhelming
commitment to their clients is not volunteered, but rather coerced from them by a sense of social responsibility.

In addition, a strong familial relationship distracts the workers' attention away from the structured health care system and solidifies their position firmly within the confines of the home. Out of sight out of mind. Bureaucrats then have less resistance to inequitable home care policies. While provincial health policy has effectively exiled HSWs to the fringes of our health care structure, it has failed to fully extinguish their potential for action against the hegemony.

HOME SUPPORT WORKERS OF THE WORLD UNITE

Unionization

Despite a multitude of systemic deterrents, HSWs are organizing for change. Without the political education or experience to assist them in their action, a quiet revolution is transpiring. The skills honed from their expansive job requirements are transferable to their own professional development. Advocating for their clients, managing with inadequate resources to do the work, and having a perspective of the whole health care structure from their outside perch: these are some of the skills HSWs are drawing upon reinventing themselves as unlikely rebels.
A crucial catalyst for change is the movement for unionization. This brings with it higher wages, employer standards, employee rights, and a vehicle for being heard. However, not all home support agencies are union shops, and the industry is newly partnered with the British Columbia Government Employees Union (BCGEU). According to the research participants, barriers to organizing such a segregated work force, include fear of employer persecution and lack of information about unions. The potential exists for the union to bring enormous improvements to the home support field, but advances have been slow.

Nevertheless, HSWs are not absolved of their own responsibility to advance their cause. Though policy makers have an enormous role in improving work conditions for HSWs, their best defense is in representing themselves. Their numbers are substantial enough that they can gain strength simply by organizing for the same cause. Latent power exists in their essential services.

In addition to uniting HSWs, the union is a connection to credibility. Other reputable health fields have both professional associations and unions. Representatives of the BCGEU speaking with officials from the BC Nurses Union or the Health Sciences Association may bridge attitudinal barriers between professions.
Another, perhaps unlikely, opportunity for the home support industry exists in the current health care restructuring. Although *Closer to Home* policies are proving detrimental to HSWs, the regionalization process, could serve them well. This procedure directs communities to reorganize and reevaluate the way they render health care services, and consequently, many are consulting with HSWs, other care providers and the public. The Capital Health Region in Victoria included HSWs in their discussion panels, and although it is unclear whether their suggestions will be followed, these forums are opportunities to raise the public profile of HSWs. As both professionals and citizens of their communities, HSWs must seize the chance afforded them by the restructuring process.

**Structural Reorganization**

Improving the status of HSWs must begin with the reorganization of the way home support services are contracted. To begin, home support services would best be managed by local health departments rather than independent, often for-profit agencies. The argument for disbanding the current system of home support agencies is based in the major criticisms expressed by the participants’ and supported in related research (Donovan, 1987; Donovan et al., 1993; Neysmith and Nichols, 1994). Regardless of where they are stationed, HSWs are funded by provincial government coffers, so health departments would not suffer financial losses. In fact, given that many home support agencies generate
profit, the province could earn moneys from reclaiming home support administration. In addition, most of the assessors who allocate home support hours work out of the health department; thus, home support workers seem like a logical addition to the employee roster. HSWs could benefit because affiliation with the health departments would elevate the profile of HSW and create an element of consistency in practice standards. Emerging from the shadow may indeed offer a spotlight of understanding and respect.

Reorganizing the delivery of home support services was identified as priority by the Vancouver/Richmond health region (1997). Unless HSWs are under the same jurisdiction as their home care counterparts, they will be construed as separate and not equals. Furthermore, the physical distance between the home support agencies and the home care offices is a barrier to open communication. Currently HSWs are not privileged to the informal consultation that naturally occurs at work sites, and which is necessary for building cooperative work relationships. As the findings demonstrate, the current system denies HSWs even formal forms of consultation and collaboration. Animosity about their second rate status compounds the poor rapport shared with LTC case managers and other members of the home care team. Therefore, it is imperative that physical, systemic and attitudinal barriers be rectified to incorporate HSWs into the home care structure.
A preexisting template for centralizing home support agencies and moving HSWs into the collaborative process is found in the provincial health care regionalization plan. Policy states that each regional health board or community health council is responsible for consolidating the health care resources in their community by eliminating redundant services, and enhancing others (BC Ministry of Health, 1993). Whenever possible, these updated programs will then be moved together under one roof to make accessing community health services a simpler process for the public. These clustered resources are called Community Health Centres or Integrated Community Health Networks (ICHNs), and there is one associated with each officially defined community (BC Ministry of Health, 1993).

ICHNs were not proposed with the intention of benefiting HSWs, but it could have that residual affect. As an umbrella structure, it eliminates the most obstructive physical barriers between home support agencies and Continuing Care offices. Moreover, as ICHN members, differences among home support agencies can be addressed more systematically. Ideally, the agency structure would be disbanded in favor of government employee status to create sameness with other health care professionals.

This potential model of organizing an inclusive system of health care resources is depicted in Figure 2. Building on the proposed plan for the
Vancouver/Richmond Health Board (V/RHB), Figure 2 shows the flow of decision making power beginning at the Ministry of Health and continuing to the Directors of the Health Board (V/RHB, 1997). The larger geographical area is broken down into seven individual Community Health Committees (CHC) which would be managed by a committee of local residents. The health care resources within each community, (including the Long Term Care division of the Health Department), would be streamlined under the ICHN. My proposed addition to this model is an easy transition of including home support services in the function of the Health Department, so that HSWs would be members of each ICHN. Compared to how health care is currently organized (see Figure 1), the proposed model has equal value for all home health care services - including the contributions of home support workers.

Figure 2. Model for merging home support services into proposed Integrated Community Health Networks (ICHN) for the Vancouver/Richmond Region.
In addition, the proximity to one another provided under the ICHN model fosters the beginning of familiarity between health care employees, and sets the foundation for a higher profile for HSWs. A central location also presents an opportunity to change formal policies that prohibit HSWs and LTC staff from collaborating without the agency supervisor as an intermediary.

It is discriminatory and infantilizing that a HSW cannot directly contact a LTC case manager about a client concern, and it is testimony to their systemic oppression. Participants in this study were emphatic about the need to change this barrier. Direct communication access among all health care providers must incorporate HSWs.

Many questions remain about how the ICHNs will function, what services will be lost in the restructuring, and how they will address a broad range of diversity issues. Notwithstanding these details, utilizing existing policies to advance systemic changes is the avenue of least resistance with the best potential for initiating improvements.

**Interdisciplinary Teams**

So much of HSWs' exploitation seems directly tied to their segregation and sole charge. However, they rarely are the only health care professionals caring for a client. Doctors, home care nurses, social workers and the like, play a vital role in
supporting people in their own homes, and a logical addition to this health care
team is the HSW.

A definition of the interdisciplinary care team format is necessary to ground the
model I propose, and it also clarifies what is often a muddled understanding of
what constitutes multidisciplinary and interdisciplinary practice.
Interdisciplinary teams involve more interaction among health care
professionals. Regular, systematic meetings occur where team members share
information towards collectively planning patient care; moreover, the staff are
informally consulting and collaborating on care issues outside of scheduled
meetings (Satin, 1994). Team members are equal regardless of their role,
including the leader or facilitator (Siegel, 1994; Wieland, Kramer, Waite and
Rubenstein, 1996). The interdependence of this model distinguishes it from
multidisciplinary teams. It is seen as a more difficult level of collaboration to
attain, but it is intended to offer more holistic care by looking beyond mere
medical intervention (Wieland et al., 1996).

Typically, interdisciplinary health care teams include members from: medicine,
social work, nursing, dietetics, physiotherapy, occupational therapy and
pharmacy (Siegel, 1994; Wieland et al., 1994). This grouping reflects diverse and
important skills, yet it clings tightly to a medicalized view of health. Consider
this amalgamated definition of interdisciplinary care teams: the purpose of
interdisciplinary practice is to bring together separate skills and knowledge to accomplish a common purpose for the benefit of the client (Drinka, 1994; Siegel, 1994). If this is the goal, why would we want to limit team membership to its current realm? We may well be denying the client, and ourselves, the opportunity to hear valuable insights from otherwise hidden sources - like HSWs.

Geriatric care is considered fertile ground for interdisciplinary teams because for elderly patients, more types of care needs arise and interplay; therefore, a collaborative combination of health professionals is the optimum approach to care (Siegel, 1994; Wieland et al. 1996). Moreover, collaboration at an interdisciplinary level provides a holistic lens for viewing problems and strengths (Wieland et al., 1996). We hear how other health professionals interpret a situation and how our perceptions fit into a larger view of the individual.

From a poststructuralist perspective, learning how other people frame a problem highlights just how much we construct meaning, and how that limits our understanding of a situation (Satin, 1994). For example, a physician’s and a social worker’s perspective of the same case will vary dramatically based on their professional acculturation (Clarke, 1994). Perhaps one or none of these
views is correct, but each tells a different story about the client which would be obscured if we did not communicate as a team.

In addition, the interdisciplinary team provides some very practical benefits. Team process fulfills our need to consult on difficult cases. Regardless of our education and experience, some “cases” will elude us, but in these instances, we have a professional responsibility to seek practice advice. Interdisciplinary care provides this forum. However, interdisciplinary teams benefit not only the staff, but also the patient/client. Teams have the strength to effect administrative change. Group consensus can have greater influence on policy change than staff working independently of one another; thus, the team approach can be an important vehicle for improving patient care (Satin, 1994).

In ideal environments, interdisciplinary teams offer numerous benefits; however, achieving this level of team effectiveness involves a tremendous amount of work. More frequently, teams fail to reach their full potential or stumble altogether (Clark, 1994). I will now consider some of the most common barriers that hinder interdisciplinary team function.

Teams do not function in a vacuum. They occur in politicized work cultures, and the team members bring their own social and professional values to the group. Clark (1994), regards teams in context, and in doing so, distinguishes
himself from the prevailing research on interdisciplinary teams. Clark theorizes that the values we need to work well as a team, directly conflict with the values we learn in society and through our professional development, namely independence and competitiveness. From this perspective, interdisciplinary teams may seem designed to fail, and the abundant literature on team dysfunction would seem to support Clark's premise (Abramson and Mizrahi, 1996; Drinka, 1994, 1996; McClelland and Sands, 1993).

In addition, team dynamics do not always reflect the egalitarian principles underlying interdisciplinary process. In practice, teams are often hierarchical (Wieland et al., 1996). Factors like gender, age, professional affiliation, duration of membership and character sustain the ebb and flow of power among team members. Furthermore, working towards egalitarian team work may be premature when the organization in which they are operating are hierarchical (Siegel, 1994). Medical settings are generally hierarchical both within their organization and in the way they connect to the funding body- the Ministry of Health.

Additionally, power imbalances generate conflict, and unwanted conflict hinders our ability to collaborate fully in caring for the patient. Team conflict receives considerable attention in the literature (Abramson and Mizrahi, 1996; Drinka, 1994; Opie, 1997; Satin, 1994; Siegel, 1994; Toner et al, 1994; Wieland et
al., 1996). Using a different frame of reference, Drinka (1994), considers conflict as a tool for developing team work skills by employing mediation and consensus building to reach a resolution to the problem. Despite the challenges that conflict poses to interdisciplinary work, it may also serve a purpose by elevating discourse and interaction beyond formal, cursory levels to a point of group collaboration.

Language is also problematic to interdisciplinary care teams. Simply the use of the word “team” implies an element of equality—of sportsmanship and getting the job done together. Relying on the rhetoric of interdisciplinary team work is easier than actually doing the process work to make it real. Without standards or a process of team evaluation, the label of “interdisciplinary team” is available to all groups regardless of whether they practice at this level (Siegel, 1994). This may also be a consequence of inadequate training in the model of interdisciplinary practice (Satin, 1994).

Clearly, there are problems associated with interdisciplinary care teams, but most can be balanced with attention to interpersonal dynamics, education, team vision and purpose. Indeed, interdisciplinary practice remains the most popular approach to health care (Wieland et al., 1996).
A Model for an Inclusive Interdisciplinary Care Team

The literature does not address issues relating to home support workers’ membership on interdisciplinary care teams, suggesting that the idea is rarely, if ever, given serious consideration. Walters’ (1996), recommends that home support agencies build team spirit among care staff with the sole purpose of reducing staff turnover: these “teams” consist of only HSWs and their supervisors. This patronizing management approach underscores the lack of credibility afforded HSWs, and the excessive authority bestowed upon the agencies.

Donovan et al. (1993), addressed the need to empower the enormous contingent of home care staff in New York city. Their plan retained the web of home support agencies (comprised of over 6,000 separate offices), but advocated for HSWs to conduct union bargaining directly with the state rather than with the agencies. This is consistent with the abject status attached to their role and discussed at length thus far. As a result, a proposal to bring home support workers on to care teams must extrapolate on data which is affiliated to, but not entirely congruent with, the topic. Research participants’ also expressed ideas that guide the model.

Organizing HSWs to participate on care teams is logistically difficult because numerically they dominate all other community health care providers. There are
too many HSWs for each person to hold permanent team membership, but the use of representative positions denies others the opportunity to participate. The best compromise is an approach developed by Siegel (1994), called Flexible Membership. This model uses a small base of primary team members such as a home care nurse, social worker and physician, and a secondary group of members that shifts depending on the client’s circumstances (Siegel, 1994). Depending on the client that the team is working with, the HSW attending meetings will be different. Informal consulting and collaborating between home support staff and the rest of the team would also be available particularly under the ICHN model.

Because the HSWs attending team meetings would be client specific, it is necessary that the workers have consistent contact with their clients. Schedule shuffling resulting in multiple home support workers caring for a single client is a hindrance towards understanding a client’s needs, strengths and weaknesses. This is a critical problem identified by the research participants, and in the words of one HSW, irregular client contacts prohibited her from providing, “real care.” Its significance to the home support workers and to the functioning of the care team distinguishes this issue as a priority.

Adding the role of “team member” to HSWs already bloated job descriptions and frenetic schedules undoubtedly raises the question of money. Currently,
HSHWs are not paid for breaks, nor travel time to clients' homes; thus, precedence suggests they would not be compensated for meeting attendance. This inequitable practice must be rectified along with increases to the low pay scale for home support staff. As part of this agreement, payment for their participation on the interdisciplinary care team would be secured. Their client specific team involvement would require only a modest time commitment with minimal financial impact. The primary monetary commitment would result from efforts to achieve pay equity. British Columbia's civil service is presently evaluating their employment structure to meet pay equity standards, and thus, if HSHWs were indirectly made government employees via ICHNs, their earnings would have to be considered in this review. If HSHWs are expected to be equals with the other team members, they must be paid commensurate.

How realistic is it for HSHWs to be accepted as professional equals when historically, they have been banished to the lowest rank of the health care hierarchy. Guiding this question is Clarke's (1994), premise that teams reflect the social and systemic forces present in our lives. In this way, the lack of respect afforded HSHWs in the current health care structure transfers over to any future work relationships. Merely adding HSHWs to the care team will not legitimize their position to fellow members. Transcending prejudices against home support staff begins with the deconstruction of current perceptions, and the
reconstruction of an identity which more accurately represents HSWs. This is one function of team building.

As I alluded to previously, a substantial body of literature contends that interdisciplinary health care teams are as effective as their internal dynamics, and most teams are stymied for this reason (Drinka, 1994, 1996; Opie, 1997; Satin, 1996; Siegel, 1996; Wieland, 1996). This wasted productivity is a drag on the already lean health care dollar, and thus, it is in the public's best interest to support team building initiatives. Training is a fundamental need. Just as HSWs will require education about how interdisciplinary teams function, so will the other members. Ironically, many teams are never trained on how to work as a team, and those fortunate enough to have received this education are challenged by staff turnover, and a continual need to increase their knowledge about interdisciplinary team process (Opie, 1997; Siegel, 1994).

Integrating new team members like home support staff is a convenient opportunity to bring all the members up to the same level of knowledge. In addition to aiding communication and professional practice, education is an equalizing measure with the potential to reduce power imbalances among team members. This shared learning can then stand as the foundation for day-to-day team building which Opie (1997), regards as a crucial element of interdisciplinary efficacy.
Flexible Membership provides HSWs and less traditional disciplines an opportunity to participate in interdisciplinary collaboration. Likewise other professionals secure access to the knowledge and skills HSWs possess. Although the team risks some efficacy from lack of membership continuity, it gains the insights of others, and ideally results in better care for the client.

Community based care relies heavily on the efforts of home support workers. They work directly with elderly and disabled people living at home, and provide personal care and support to enable clients to live independently. Their services delay or prevent more costly institutional base care, and thus, are of crucial importance to the health care system (Aronson and Neysmith, 1996; Neysmith and Aronson, 1996). Despite, their enormous social and economic contributions, and the availability of a structural framework, HSWs are not members of the community base care team. Our choice not to integrate HSWs into collaborative teams is indicative of our prejudices.

**IMPLICATIONS FOR SOCIAL WORK**

Despite providing essential services, HSWs are at the bottom of the health care hierarchy. Inequities in wages and value of work are important to the social worker's role as advocate. In addition, the majority of HSWs and their clients are women: this gender disproportion identifies the area as a 'women's issue'.

As discharge planners and case workers in the community, social workers often
arrange and rely upon home support services for their clients. Awareness of the systemic exploitation of HSWs may facilitate a shift from their role as "outsiders," to members on the health care team. Furthermore, as members of the interdisciplinary care team, social workers, are in a position to facilitate the inclusion of HSWs and to seek their feedback on client care.

In addition, HSWs have an untapped knowledge base gained by working with many clients in a direct care relationship. Such insight can help academics, policy makers and health care professionals to understand manifestations of aging and dementia that are identified from daily observation.

Although HSWs perform their duties in isolation, there work has larger social implications. An organized, stable home support industry is necessary to support the increasing care needs of our aging population. Given the current poor working conditions for HSWs and an already rapid rate of staff turn over, the industry is already jeopardized. Health care policies that promised a redirection of funding to home care services have left an entire work force of caregivers and care recipients stranded, in the home, alone. These points raise important questions about the value our society places on the lives of women and the aged.
LIMITATIONS AND FUTURE RESEARCH

The findings are limited by the degree to which they can be generalized to other HSWs' experiences. A larger, specialized sample that adequately reflected the mostly ethnic minority work force would be beneficial in this regard. Ethnic minority workers have special circumstances associated with cultural differences and language barriers that render them particularly vulnerable in a profession which is already marginalized. The HSWs who participated in this study have the skill and confidence to speak convincingly about their caring work and their profession; however, their competence in this regard makes them the exception, not the norm.

Although nearly every province is initiating some form of home care focused health reforms, the policy discussed in this study is specific to British Columbia. The literature suggests that HSWs are confronted with similar problems regardless of their home base, but the policy framework for integrating them into the care team will not exist in every province. In this way, the team model I propose must be adjusted according to the policy nuances in each province or state.

In addition, this study considered only one side of the caregiving partnership. Uncovering the experiences of care recipients is essential for understanding the symbiotic caring relationship, yet there is a dearth of literature from the care
recipient perspective. Further study in this area would advance the body of caregiving research to a new depth.

In summary, the research findings portray how governments use health policy to deliberately encumber HSWs for immediate gains: their far reaching caregiving work for inferior wages. Although the health ministry saves money with this arrangement, their shortsightedness places every citizen at risk. As a consequence of the poor treatment HSWs receive, there is rapid staff turnover, and their growing animosity is evident. In effect, the government is losing the work force necessary to sustain the health care system and its increasing reliance upon home base care. The cost of improving work conditions for HSWs is nominal in comparison to the enormous tax burden that would result from a return to a focus on institutional care.

Politically, governments would be wise to take this cue and avoid the backlash sure to ensue when the public is denied basic health services coupled with steep personal tax increases because of a lack of HSWs to support the system. However, time is running out for political damage control. The HSW union is gaining strength, and the impact of the enormous health care reforms is incentive for activism. An angry workforce will be harder to appease in negotiations. Health policy must change to make allowances for HSWs including: scheduling input, pay equity, a restructuring of the fractured system
of home support agencies, and a means for professional consultation and
collaboration outside of the home environment. These changes would
demonstrate the government's willingness to move beyond rhetoric by actively
investing in the future of health care.
CONCLUSION

As governments recognize that our aging population and dwindling tax base will overwhelm an institutional based health care system, they have urgently restructured. Home base care is the outcome, and in theory it shows promise for both elderly health care consumers and the future of universal health care. However, in practice the frenzied reform has fallen short of transferring adequate funding from the hospital to the home.

Caught in the middle are home support workers. This predominantly female work force cares for people in their own homes; thereby, reducing the burden on more costly institutional health care resources. However, in their position at the bottom of the health care hierarchy, HSWs are supporting the weight of the entire health care system. Given their poor status, it is not surprising that the industry’s high rate of turn over threatens the availability of enough workers to meet the growing service demands. Without the workforce to support it, home care will flounder and the public will be denied health care.

An insufficient body of literature addresses the home support profession, despite a growing reliance on their work. Moreover, society’s narrow construction of caregiving work serves to undermine the extent of HSWs’ labor.
From a poststructural view, our understanding of the home support profession is largely manufactured, and does not represent their actual experiences. With the few studies about HSWs, their voices have been almost completely absent.

Employing qualitative methodology, this study considered the experiences of home support workers caring for elderly people. Through interview and focus group formats, HSWs discussed how they understand their caring work. More than just physical labor, their work includes the creative thought and emotional support that occurs under the surface of nearly every action. Outside of the public’s view, however, this hidden caring work is neither recognized, nor rewarded. Compounding the complexity of their work is the impact of home care policy reform. Greater demands on their services, but insufficient time and supplies with which to meet the need, is taking its' toll on the underpaid caregivers. Furthermore, conducting their work independently, in isolated apartments and houses throughout the province denies HSWs the opportunity to consult and collaborate within their own profession and with other health care providers.

Health policy is doing nothing to improve working conditions for HSWs, on the contrary, it serves to maintain their marginalized status and to perpetuate the myth that their work is easily defined by outside forces. Nevertheless, being in the process of health care reform is also a helpful resource to HSWs. With change
happening in every aspect of the health care system, HSWs have an opportunity to carve out their own identity for themselves. In particular, the integration of community health care resources under single umbrella organizations lends a suitable template for bringing HSWs out of the fringes and into the inner circle of health care service providers. In the company of other professionals, they are well positioned to join the interdisciplinary home care team in collaborating on client care. In this context their caregiving knowledge could be recognized and compensated, their isolation lessened and ultimately care for the mostly aged clients would improve. Team membership holds considerable potential for improving the work conditions and status of HSWs.

In the process of caring for their aging clients, home support workers exercise more than muscle. Sylvia, Anne, Heather, Rita, Sue, Kate and Beth demonstrate that their knowledge and skills are a blending of the abstract and concrete, and their application is complex. Their stories are a window to a rarely seen part of life, but one that ultimately impacts us all.
REFERENCES


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Appendix A

Unstructured Interview Guide

1. Please describe what you typically do at a client's home from the time you arrive until you leave.
   a) How does this experience differ if a client suffers from dementia?
Appendix B

Semi-Structured Interview Guide

1. Please describe what you typically do at a client's home from the time you arrive until you leave.

2. What do you feel is the most important work you do as a home support worker?

3. What do you need in place for you to accomplish your work?

4. How do you see your work fitting into the larger continuing care system?

5. In the course of performing your work, who do you interact with in the continuing care system?

6. How do you relate to those people?

7. Please discuss how or if you think home support workers could work with the continuing care system.

8. What, if any, barriers do you feel prohibit this involvement with the continuing care system?