A STUDY OF COSTS FOR WOMEN AS UNPAID CAREGIVERS OF YOUNGER ADULTS WITH CHRONIC ILLNESS AND PHYSICAL DISABILITIES:

THE VOICES OF WOMEN CAREGIVERS

BY

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Michelle L.A. Gibbens

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of

MASTER OF SOCIAL WORK

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Abstract

Unpaid caregivers, usually family members, provide the majority of the care required by individuals living with chronic illness and disabilities and face increasing demands. Consequently, policy responses to address caregivers' negative, economic and non-economic consequences are receiving greater attention.

This qualitative research study examined the experiences of women as unpaid caregivers for adults living with chronic illness and disabilities with a focus on understanding the meaning of the women's caregiving-related costs from their own perspective. In-depth, semi-structured interviews were conducted with seven women who are unpaid caregivers for their adult children or male partners. An interpretative phenomenological approach and feminist theoretical framework guided the study.

The women's narratives highlighted elements of the caregiving role and contextual factors affecting their caregiver experience. The meanings derived from their caregiving experiences indicate that: both economic and non-economic costs are integral and interconnected; caregivers' costs can also be addressed through supports for care receivers; their caregiving role exceeds "normal" family roles and deserves support; caregivers' costs are increased by barriers to accessing supports; service enhancements are required to decrease costs; some important factors affect caregivers' service utilization and commitment to their caregiving role continues despite the associated costs.

Policy development and service delivery must simultaneously consider caregivers' economic and non-economic consequences with the objectives of meeting both care receivers' and caregivers' needs and being responsive to individual circumstances. Caregiving must be recognized as a shared, social responsibility so that

women are not disadvantaged by the expectation to assume these roles with little or no support.

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CHAPTER ONE

INTRODUCTION

Rationale for the Study

This qualitative research study examines the experiences of women as unpaid caregivers for younger adults living with chronic illness and/or long-term physical disabilities particularly with respect to their caregiving-related economic and non-economic costs or negative consequences. The current context within which unpaid caregiving occurs in Canada demonstrates the importance and relevance of this study at this time.

The Canadian Caregiver Coalition (2004b) defines caregivers as "individuals who provide care and assistance for their family members or friends who are in need of support due to physical, cognitive or mental health conditions" (p. 1). Similarly, for the purposes of the Statistics Canada General Social Survey, informal caregiving is defined as "the performance of tasks by family and friends, without pay, that helps maintain or enhance people's independence" (Cranswick, 1997, p. 2).

According to the General Social Survey (GSS) conducted in 1996, approximately 2.8 million Canadians or 12% of the population perform informal caregiving roles (Cranswick, 1997; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). The GSS conducted in 2002 identified over 2 million caregivers or one in five Canadians aged 45 years and over who are providing care to seniors with long-term physical disability or physical limitation (Stobert & Cranswick, 2004). Beyond this, the 2001 Participation and Activity Limitations Survey (PALS) on disability in Canada found that there are over

2 million children, youth, working-age adults and seniors with disabilities who need assistance with everyday activities. The same survey indicated that there are a total of more than 7,800,000 family members, friends and neighbours involved in providing this assistance with everyday activities. Meanwhile organizations or agencies were identified as providing this assistance to only slightly less than 500,000 individuals with disabilities (Social Development Canada, 2004). It is estimated that over 80% of the care of the elderly and other family members with chronic illness and/or long-term disabilities is provided informally by unpaid family members (Aronson, 1998; Fuller, 2001). Fast, Eales, and Keating (2001) have estimated that unpaid caregivers save the public health care system over $5 billion a year and perform work that is equivalent to that of 276,509 full time employees.

According to Armstrong and Kits (2001), "most care is informal or self-care and formal services supplement them" (p. 17). Consequently, research and policy discourses have become increasingly focused on identifying the needs of unpaid caregivers and assessing alternatives for meeting these needs. In recent years, there has been increasing attention in research and policy analysis arenas in the negative economic consequences experienced by unpaid caregivers and public policy responses to this issue. On the basis of her analysis of the data from the 1996 GSS, Cranswick (1997) concludes that "there is a group of caregivers whose duties are taking an economic toll" (p. 8). Analysis of the 2002 GSS caregiving data leads to a similar conclusion. According to Cranswick (2003),

> The most profound of the socioeconomic impacts are the financial consequences of providing care. More than one-third of younger caregivers [aged 45-64 years] cited extra expenses due to their caregiving duties (42% of women and 38% of men) as did 27% of senior women and 30% of senior men. (p. 14)

Furthermore, 15% of the caregiver respondents in the 1996 GSS identified financial compensation as a type of support that would be useful for them in maintaining their unpaid caregiving (Cranswick, 1997).

Since the late 1980's, the growth in demand for informal elder care has raised the profile of the issue of economic consequences for those who provide this care. There is evidence to suggest that there is an increasing demand and expectation for unpaid caregiving in Canada that has not been restricted to elder care. Armstrong and Kits (2001) suggest that due to new technologies and health care reforms involving deinstitutionalization and cost-cutting, "the care demands on households have both grown significantly and taken on new dimensions as highly complex care is transferred to the home" (p. 4). Fast and Keating (2000) also suggest that the factors of aging demographics, "increased survival after catastrophic illness and injury", "new patterns of illness and disease" (p. 8) with increases in chronic diseases have resulted in a situation where there are more people requiring higher levels of care, often over many years. Armstrong et al. (2000) and Fuller (2001) also document how government policies have increased the expectations on family members to provide unpaid caregiving to adult family members with chronic disease and disability. For example, health care reform initiatives undertaken since the 1990's have focused on increasing the provision of community-based care. According to Fuller (2001), due to inadequate public funding for home care, the shift to community-based care means that most of the costs for home care are borne by individuals and families (p. 5).

Consequently, the current context for unpaid caregiving is one where the caregivers' burden is increasing as a result of reform strategies and government policies consistent with the international neoliberal agenda to decrease public expenditures and the role of the state while simultaneously increasing expectations of family responsibility for previously publicly funded services. This shift has also been accomplished by promoting community-based, informal care provided by family and friends as the most desirable and best quality option for caregiving (Armstrong et al., 2000; Hooyman & Gonyea, 1995; Neysmith, 2000).

In recent years, the Canadian health care system has been reviewed with the objective of identifying long-term solutions. There have been two major reports for the federal government commonly known as the Romanow report and the Kirby report (Commission on the Future of Health Care in Canada, 2002; The Standing Senate Committee on Social Affairs, Science and Technology, 2002). Both of these reports acknowledge the need for support to caregivers and recommend financial compensation strategies. Additionally, there have also been some provincial government consultations on the future of health care. At this time, it is important that all policy options be examined from a perspective that considers the costs for all stakeholders including the economic and non-economic costs to the unpaid caregivers who are providing the bulk of the care in the community (Fast, Williamson, & Keating, 1999).

This study is also timely given recent caregiving policy development activity at the federal government level. In June, 2000, the Final Report of the Senate Subcommittee, chaired by The Honourable Sharon Carstairs and charged with ensuring the improved provision of "quality end of life care" or palliative care, presented a list of recommendations including "that the federal government immediately implement income security and job protection for family members who care for the dying" (Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology, 2000, p. 28). Then in September, 2000, Bill 493, a private member's bill received first reading in the House of Commons but was ultimately unsuccessful. This bill proposed up to 50 weeks of income replacement from the Employment Insurance Fund (Canadian Palliative Care Association, 2000). The Senate Committee's work provided the impetus for an initial policy response that was launched in January, 2004 with the introduction of the Compassionate Care Benefit through the Employment Insurance program. This benefit is designed to provide family caregivers in palliative care situations with the option of applying for Employment Insurance benefits for short-term, caregiving-related leave from paid employment (i.e., a maximum of six weeks of benefits plus two week waiting period). Additionally, the federal government and several provinces, including Manitoba, have amended labour policy and legislation to provide job protection for employees who take time off to care for a family member in a palliative care situation. However, those providing caregiving support to individuals with chronic illness or long-term physical disabilities are excluded from eligibility for this benefit.

More recently, in August, 2004, the federal government under the leadership of Prime Minister Paul Martin, followed up a Liberal party election campaign commitment of $1 billion over five years for caregiver support by appointing Hon. Tony Ianno as the Minister of State (Families and Caregivers) under the broader portfolio of Social Development Canada. This marks the first time in Canadian history that there has been a designated cabinet minister with the clear mandate to develop a policy response to the needs of unpaid caregivers. Minister Ianno has been conducting consultations across the country that are intended to inform the development of national policy or programs to address the needs of unpaid caregivers.

Subsequently, the federal government indicated its intention to increase income tax-based support for caregivers in the October, 2004 Speech from the Throne (Canadian Caregiver Coalition, 2004a). The federal budget presented in February, 2005 followed up on this commitment by announcing that "family members who provide care for elderly parents or adult children with disabilities will be able to claim $10,000 in medical and disability-related expenses on their Income Tax forms–double the amount they are currently able to claim" (Canadian Caregiver Coalition, 2005). This budget also increases the Child Disability benefit by $300 up to a total benefit of $2,000 (Canadian Caregiver Coalition, 2005). Both of these changes respond to recommendations made in the final report of the Technical Advisory Committee on Tax Measures for Persons with Disabilities released in December 2004 (Technical Advisory Committee on Tax Measures for Persons with Disabilities, 2004).

Given this current context, it is imperative to understand how women who provide long-term, unpaid caregiving support to younger adults living with chronic illness and/or physical disabilities describe and perceive the caregiving-related costs they experience. Some policy initiatives, such as the Employment Insurance Compassionate Care Benefit, have excluded this group of caregivers so it is particularly important that their realities, needs and recommendations be brought forward into the ongoing policy dialogue.

Research Questions

Research has demonstrated that there is a range of negative consequences experienced by many unpaid caregivers as a result of their unpaid caregiving responsibilities. Research studies have consistently demonstrated that a significant proportion of individuals and families experience burden or distress as a result of their unpaid caregiving roles. For many caregivers, this burden includes negative economic consequences due to increased expenses, decreased income from paid employment and/or the provision of many hours of unpaid labour (Hooyman & Gonyea, 1995).

This study used qualitative research methods to examine the costs experienced by unpaid caregivers from the perspective of female unpaid caregivers of younger adults living with chronic illness and/or long-term physical disabilities. This group of unpaid caregivers was selected as the focus of this research because their experiences and caregiving-related costs have not been adequately documented in the current research literature. Furthermore, the voices of these caregivers have been largely absent from the current policy discourse. This study focused on understanding the experience and meaning of their caregiving-related costs from their own perspective.

Due to the gendered nature of unpaid caregiving for adult family members and this writer's personal worldview, a feminist theoretical framework and feminist research principles were incorporated into this study.

This research was guided by the following questions: How do female unpaid caregivers of adults aged 21-55 years living with chronic illness and/or long-term physical disabilities describe the caregiving-related costs they experience? What do these costs mean to these caregivers?

Relevance to Social Work and Social Policy

Understanding the experience and caregiving-related costs of female unpaid caregivers of younger adult family members with chronic illness and/or disability has important implications for theory, social policy and social work practice.

Contribution to Theory

Most of the theoretical development regarding economic and non-economic costs experienced by unpaid caregivers and related policy analysis frameworks for assessing economic impact has been based on research involving caregivers of frail seniors and children (e.g., Fast et al., 2001; Fast et al., 1999; Ferguson, 1998). Through an in-depth examination of caregivers' experience and perceptions, this study provides evidence that these theoretical models are also largely relevant for unpaid caregivers of younger adults with chronic illness and/or disabilities. However, it is also important to recognize that there are some key factors that create some variance between these women's experiences and those of caregivers who are caring for older adults or in shorter term acute or palliative care situations on a shorter term basis.

Contribution to Policy

This qualitative study highlights female caregivers' experiences and perceptions with respect to caregiving-related costs as well as current and potential policies and services intended to address these costs. The study findings were also examined for their implications for the ongoing policy discourse. The study participants themselves also offered their own recommendations on both policy and practice changes that they felt could better address their caregiving-related costs.

Several key factors that affect caregivers' service utilization were also identified. Given persistent concerns about underutilization of services by caregivers and research evidence that caregivers' attitudes, beliefs and perceptions influence utilization (Pedlar & Smyth, 1999), this is important knowledge for policy development and social service administration.

This study also makes an important contribution by highlighting the experience of a group of caregivers whose needs have not been central in current policy research and analysis.

Contribution to Social Work Practice

It is critical for social workers involved in both clinical practice and social policy analysis to understand the experience of unpaid caregivers with respect to their caregiving-related costs.

Firstly, the research findings can be used to sensitize practitioners working with unpaid caregivers and younger adults living with chronic illness and/or physical disabilities to caregivers' experience and the importance of considering caregiving-related costs in assessment and intervention plans. This approach to practice is advocated by Baines and Evans (1992) who suggest that "an analysis of caring in the private sphere, which incorporates both labor and love, broadens the framework so that both family relationships and the material conditions of people's lives are examined" (p. 8). Awareness and sensitivity on the part of practitioners is particularly important given the study participants' contention that social workers' and other professionals' attitudes and actions can have a direct impact on their caregiving experience in either a positive or negative direction.

This research also contributes to the practice of social policy analysis through the use of a qualitative study that brings forward caregivers' experiences and voices in a manner that contributes to policy research and can be used to inform ongoing policy discourse. Wharf and McKenzie (1998) advocate for a policy analysis approach that "will permit more open dialogue and debate about the normative aspects of the policy issue being considered" (pp. 57-58).

Researcher's Experience of Unpaid Caregiving and Related Expectations

I have encountered the phenomenon of unpaid caregiving in both my personal and professional life. Professionally, I have worked with individuals affected by multiple sclerosis (MS) for more than 10 years. This work has included direct service provision and management of programs and services intended to support the person with the diagnosis of MS as well as their family members and friends including unpaid caregivers. For the last 4½ years, I have managed a pilot project testing the use of an individualized funding model as a tool for unpaid caregivers of people with MS to access self-identified services and activities intended to enable them to address their own needs through individualized self care and wellness plans.

Through my paid work in this area, I have become sensitized to the issues facing unpaid caregivers. My experience with the caregiver funding pilot project has particularly increased my awareness of the economic consequences facing unpaid caregivers. The funding provided through the pilot project was intended to encourage caregivers' self care and participation in wellness-oriented activities. Several caregivers attempted to apply to use the funding for cost of living or caregiving-related expenses even though the amount of funding available was quite minimal (i.e., up to a maximum of $300/year per caregiver). Many caregivers also shared their broader economic security concerns. For many years, I had been aware of the fact that a chronic disease like MS can affect the income, employability and overall quality of life of the person diagnosed. However, I had given far less consideration to the fact that family members and/or friends who take on unpaid caregiving roles often also experience negative economic and non-economic consequences.

My personal caregiving experience has involved episodic support to my mother during health crises over several years. As a result of her current health situation, my middle-aged mother has been periodically fairly dependent at an age when she might normally have been independent and providing support to her adult children and their young families. I have also had first hand experience with the economic consequences of caregiving as I have assisted my mother financially with medical and other necessities that she would not otherwise have been able to afford due to her health-related inability to maintain employment. I have also occasionally needed to take time off work to assist her. However, due to the nature of my work, I have been able to make up this missed time rather than take unpaid time off. I can foresee the possibility of my mother's health deteriorating further and my caregiving role becoming more intense on an ongoing basis. If this were to occur, I would anticipate that my quality of life and potentially my own health would be affected as I try to manage a more significant caregiving role with my other family and employment responsibilities.

My experience with unpaid caregiving has led me to the conclusion that a public policy response to the economic consequences faced by unpaid caregivers is desperately needed in Canada. I have had the opportunity over the last few years to be involved with both the Canadian Caregiver Coalition and Manitoba Caregiver Network. These two voluntary coalitions of individuals and organizations, one at the national level and one at the provincial level, are trying to advance caregivers' issues on the public policy agenda including issues related to caregivers' economic security. In order to participate in public policy discussions in a manner that is informed by these caregivers' lived experience, I have felt that there is a need to better understand how caregivers of younger adults living with chronic illness and/or disabilities describe their caregiving experience and their related costs. It is my belief that only public policy responses that are grounded in this reality will make a meaningful difference in the lives of caregivers.

Based on my previous experience, I had expected to hear from the women about the unique aspects of their caregiving situations with younger adults with chronic illness or disability. Additionally, I expected to hear some suggestions regarding the need for a range of flexible supports in order to address their needs in the context of this reality. However, I was struck by the significant degree of consensus regarding general policy and service recommendations that emerged from this group of women who are in relatively diverse caregiving situations.

I had expected the women to talk about direct supports to the care receivers such as home care. Yet the women placed greater emphasis on the role of these supports than I would have expected when they were given an explicit and focused opportunity to identify their own individual needs as caregivers.

I also anticipated that the women would identify both economic and non-economic costs associated with their caregiving roles. However, I expected that economic costs would be emphasized and that the women would focus on measures to better address this negative aspect of their caregiving experience. Instead, the women's stories highlighted a complex interconnection of various economic and non-economic costs with at least equivalent emphasis on the non-economic costs. This led to conclusions and recommendations that differed from what I might have anticipated at the beginning of the study.

CHAPTER TWO

LITERATURE REVIEW

This literature review will address definitions of key constructs from the research questions, the relevant theoretical literature, and relevant information regarding findings and methodology from the empirical literature. The review will conclude with a discussion of the gaps in the current literature and this study's contribution to addressing those gaps.

Definition of Key Constructs

The key constructs from the research questions are unpaid caregivers, the nature of unpaid caregiving, adults living with chronic illness and/or disabilities, unpaid caregiving for adults living with chronic illness, costs for unpaid caregivers, and policy responses to economic consequences experienced by unpaid caregivers. These constructs will be defined through an examination of the relevant literature.

Unpaid Caregivers and Unpaid Caregiving

A common element of most definitions of informal caregivers is that they provide a range of caregiving supports and activities to family members and friends without pay. The terms informal, unpaid and family are often used interchangeably as adjectives to describe this type of caregiver and caregiving.

For the purposes of the 1996 and 2002 General Social Survey (GSS), informal caregiving was defined as "the performance of tasks by family and friends, without pay, that helps maintain or enhance people's independence" (Cranswick, 1997, p. 2). Data collection focused on "the unpaid, informal care being provided by Canadians to people with long-term health problems–that is, any condition or physical limitation lasting, or expected to last, more than six months" (p. 1).

Similarly, the Canadian Caregiver Coalition (2004b), a partnership of individuals, groups and organizations formed in November 2000, defines family caregivers as "individuals who provide care and assistance for their family members or friends who are in need of support due to physical, cognitive or mental health conditions" (p. 1). The term "informal caregiver" is often used in research literature and policy discourse. However, the Canadian Caregiver Coalition and other groups purposefully avoid the use of this term. The Family Caregivers Association of Nova Scotia (2002) (now renamed Caregivers Nova Scotia) explains in their position statement on caregiver language that they do not support the term informal caregiver because "caregivers, nationwide, have expressed concern that the term 'informal' diminishes the importance of their roles as caregivers in today's society" (p. 1).

Consequently, the term caregiver is used throughout this proposal to refer to those who meet the above definition adopted by the Canadian Caregiver Coalition. The adjective "unpaid" is sometimes added to emphasize the economic reality of this caregiving.

The Nature of Unpaid Caregiving Work

Hooyman and Gonyea (1995) outline two primary approaches for describing unpaid caregiving. The first and most predominant approach in research is to describe and document the objective or behavioral dimensions of caregiving (i.e., type, frequency and duration of caregiving activities). Cranswick (1997) describes Canadian caregivers from this perspective. She identifies caregiving tasks as falling into two categories:

"instrumental" activities such as meal preparation, house cleaning, laundry and sewing, yard work, banking and bill-paying and/or providing transportation; and "personal care" activities, such as bathing, dressing or toileting. Similarly, Fast and Keating (2000) categorize caregiving tasks as "personal (bathing, feeding, grooming, toileting, administering medication)", "physical (housework, home maintenance, shopping, transportation)", "organizational (linkage between the care recipient and the formal service sector)", or "emotional (maintaining social interaction, cheering up an individual when she is depressed, reassuring and validating attitudes or perceptions)" (p. 3). Heron (1998) outlines a similar range of tasks involving instrumental, personal care and emotional elements (i.e., "personal care", "health care", "support with mobility", "domestic tasks", "monitoring/supervising", "spending time with the person needing care" and "rehabilitation") (pp. 37-38).

An alternate approach to exploring the nature of unpaid caregiving focuses on the subjective dimensions of caregiving. According to Hooyman and Gonyea (1995), "several qualitative researchers have begun to explore the subjective, cognitive, and emotional dimensions of caregiving in greater depth" (p. 132).

Levine, Reinhard, Feinberg, Albert, and Hart (2003) also suggest that there is a need to move beyond the identification of the specific activities of daily living for which caregivers provide assistance. They identify two domains of caregiving; "direct care provision" and "care management". However, they propose that in order to capture the complexity of the caregiving role, it is also important to take into account four key contextual factors that affect caregivers' experience with caregiving tasks or activities within each of these domains. These contextual features are "timing" (i.e., frequency and predictability), "caregiver proximity" (i.e., on "stand by" for assistance when needed versus providing direct "hands on" care), "caregiver effort" required and, finally, "care recipient response" (i.e., "cooperative, passive or obstructive") (pp. 21-22).

Gendered Nature of Care

General descriptions of the extent and nature of unpaid caregiving often obscure the fact that although some men are involved in unpaid caregiving, women perform most of the unpaid caregiving work. According to Hooyman and Gonyea (1995) "one of the most consistent findings in family research is that, across the family life cycle, the vast majority of carers for relatives with chronic disabilities are women" (p. 120). Morris (2001) provides the following summary of gender-specific caregiving research findings:

> Women are the majority of unpaid caregivers, and the majority of care recipients, and as such are greatly affected by home and community care policies and practices. Women and men experience different socioeconomic contexts and gender role expectations, which result in women giving more hours of unpaid care than men, performing more demanding forms of caregiving than men, traveling further and more often to provide unpaid care, and having responsibility for more than one care recipient more so than men. (p. 1)

According to Stobert and Cranswick (2004), "women dedicate almost twice as much time to their tasks – 29.6 hours per month, compared with 16.1 hours for men" (p. 2). Furthermore, the types of caregiving tasks undertaken vary significantly by gender with women still being primarily responsible for personal care.

Jenson and Jacobzone's (2000) review of the literature on the gender distribution of caregiving responsibilities also confirms that "women provide greater amounts of informal caring work, both qualitatively and quantitatively" (p. 13). Firstly, they report that in Canada, 55% of all caregivers are women. Furthermore, analysis of the data on informal caregiving from the 1996 GSS reveals that not only are women more likely to be unpaid caregivers but also that "women often take responsibility for the tasks involving personal care and emotional support, which may result in a greater burden of caring" (p. 13). According to the 2002 GSS, nearly half a million Canadians over the age of 45 were providing personal care to a senior but three-quarters of these individuals were women (Cranswick, 2003). This gender difference is particularly significant given that negative caregiving-related consequences were reported by a higher proportion of caregivers providing personal care than those providing any other type of caregiving support. Some examples of the rate of negative consequences reported by caregivers providing personal care include: 52% report changes to their social activities, 39% report changes to their holiday plans, 31% report sleep disturbances, 29% report negative effects on their health and 55% incur extra expenses related to caregiving (Cranswick, 2003).

Consequently, it is not surprising that the same survey found that women were more likely than men to report negative consequences for their own health and well-being. For example, female caregivers aged 45-64 years were twice as likely to report caregiving-related disruptions to their sleep pattern (i.e., 2 in 10 women compared to compared to 1 in 10 men). Similarly, female caregivers reported other negative effects on their health more often than men (i.e., 7% of male caregivers aged 45-64 compared to 21% of the female caregivers of same age group and 7% of male caregivers aged 65+ compared to 16% of the female caregivers of that age group) (Cranswick, 2003).

Canadian women are also significantly more likely than men to provide regular, repetitive care such as meal preparation and housekeeping on a daily basis. In fact, the only task that male caregivers in Canada were more likely to perform is home maintenance (Cranswick, 1997).

Morris et al.'s (1999) examination of the changing nature of home care and its' impact on women concluded that "women family members were expected to supplement home care services without pay and at great personal expense…whereas men were not under as much pressure to do so" (p. vi). This is consistent with Hooyman and Gonyea's (1995) conclusion that men and women differ not only "in their enactment of the caregiving role" but that "gender influences the meaning of caring, the social context of providing care, and the consequences of performing the carer role" (p. 121). They discuss how the predominant cultural ideology identifies women as "natural caregivers" (p.121) and that structural factors and public policies tend to reinforce this ideology. Similarly, Baines, Evans and Neysmith (1998) highlight how the welfare state reinforces women's unpaid caregiving (p. 4).

Given the current reality of the gendered nature of care, several researchers (e.g., Armstrong & Armstrong, 2002; Association feminine d'éducation et d'action sociale, 1998; Baines et al., 1998; Fast et al, 2001; Hooyman & Gonyea, 1995; Jenson & Jacobzone, 2000; Morris, 2001; Morris et al, 1999) have emphasized the need for a gender-sensitive or gender-based approach to any unpaid caregiving research and policy analysis. Despite this widespread recognition of the gendered nature of care, Morris (2001) concludes that there is insufficient gender-sensitive research and analysis in the current home and community care literature including literature pertaining to unpaid caregiving.

Adults Living with Chronic Illness and/or Long-Term Disabilities

In a press release announcing the release of the new *International Classification of Functioning and Disability*, the World Health Organization (WHO) (1999) explained that the new classification system:

> Recognizes the fact that a diagnosis of diseases and disorders, while important for clinical and public health needs, is not sufficient to describe the functional status of the individual and also to predict, guide and plan the various needs of such an individual. (p. 1).

A similar perspective is found in the definition of disability included in *The Social Work Dictionary.* Disability is defined as "temporary or permanent inability to perform 'normal' activities, usually as a result of a physical or mental condition or infirmity" (Barker, 1995, p. 102). The definition of disability used for the purposes of the 2001 Participation and Activity Limitation Survey (PALS) of children and adults in Canada also identifies disability as "an activity limitation or a participation restriction associated with a physical or mental condition or a health problem" (Social Development Canada, 2004). Based on this understanding, it is evident that it is not the diagnosis of disease itself but the functional status of the individual as a result of that diagnosis and "societal opportunities or barriers" that will determine the individuals' care needs (WHO, 1999). These care needs in turn have implications for unpaid caregivers because they determine the type and amount of care required from either the health care and social service system and/or from family members and friends.

Identifying a particular disease or health condition as a chronic illness or disability introduces the concept of chronicity where the condition and the resulting functional limitations are considered to be long term. Although remissions may occur in some diseases, chronic illnesses are generally considered to be those conditions and diseases that are not fatal but for which there is no known cure. Accordingly, following a review of several definitions, Lubkin (1990) defines chronic illness as: "... the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6).

Unpaid Caregiving and Adults With Chronic Illness and/or Disabilities

For the purpose of understanding the degree of similarity and difference among chronic diseases, Rolland (1988) presents a psychosocial categorization of chronic illness based on the four major variables of; (a) onset (gradual vs. acute), (b) disease course (progressive, constant, or relapsing/episodic), (c) outcome (fatal, shortening the life span or nonfatal), and (d) degree of incapacitation (cognitive and/or motor, reduced energy etc.). According to Biegel, Sales, & Schulz (1991), variation in these variables produces different effects in families and has implications for the family caregiving experience (p. 24).

Biegel et al. (1991) propose that caregiving due to chronic illness and disability is different from traditional tasks and activities within a family because it represents "the *increment of extraordinary care* that goes beyond the bounds of normal or usual care" (p. 17). They report that caregiving for a family member who has a chronic illness "involves a significant expenditure of time and energy over potentially long periods of time, involves tasks that may be unpleasant and uncomfortable, is likely to be nonsymmetrical, and is often a role that had not been anticipated" (p. 17).

Additionally, Fast and Keating (2000) highlight the "great variability in the length of the caregiving commitment depending on the nature of the illness or disability, with more family caregivers facing a commitment to many years, even a lifetime, of caregiving" with "vastly different patterns of need across the course of different conditions" (p. 9). Armstrong and Kits (2001) also acknowledge that caregivers providing care for someone living with a chronic and progressive condition face different challenges than those who are providing caregiving for recovery from short-term illness or surgery. In the first instance, "care needs can only increase with time and last until death" (16). Meanwhile, other caregivers can expect the caregiving demands to diminish over time until care is no longer required.

Notably absent from the definition of the key constructs of unpaid caregivers, unpaid caregiving and adults living with chronic illness and/or disabilities is the role and influence of culture beyond gender role expectations. Culture is addressed to a limited extent in some of the empirical literature presented later.

Beyond culture, recent work by Guberman and Maheu (2003) would suggest that there is a need to give greater consideration to the socioeconomic context within which caregiving occurs. They examined the experiences of caregivers from three ethnocultural minorities in Quebec in comparison to those of caregivers from the French Canadian majority and found more similarities than differences. While still promoting the need for cultural sensitivity, these researchers conclude that "socioeconomic conditions are as important as cultural values and traditions" (p. 43). For example, socioeconomic and political factors largely determine the type and extent of supports and service options available to caregivers regardless of their ethnicity.

Finally, while both objective and subjective dimensions of caregiving are important, the current literature is dominated by a focus on the objective dimensions. An increased understanding of the subjective dimensions of caregiving is essential to policy development and analysis.

Costs for Unpaid Caregivers

An extensive body of literature has developed exploring the consequences of unpaid caregiving for those individuals who provide this care. There are some studies that have acknowledged the positive aspects of caregiving. For example, Berg-Weger, Rubio, & Tebb (2001) have identified 14 categories of caregivers' positive feelings regarding caregiving. Other studies have also reported that caregivers find caregiving work rewarding and report positive benefits such as a strengthened relationship with the care receiver. Nolan (2001) highlights a number of studies that have contributed to the identification of these positive aspects and the development of conceptual frameworks for understanding the sources of and factors related to caregiving satisfaction. For example, Keating et al. (1999) found that 90% of female caregivers of seniors and 86% of male caregivers of seniors reported stronger relationships with the seniors as a result of the caregiving. More recently, respondents to the 2002 GSS were asked about the "intrinsic rewards" they may have experienced as a result of their caregiving duties. Stobert and Cranswick (2004) report that "between 80% and 90% feel that helping others strengthens their relationships with the care receiver and repays some of what they themselves have received from others and life" (p. 6).

Despite this evidence, the literature is primarily focused on documenting the negative consequences for unpaid caregivers (Berg-Weger et al., 2001).

Cranswick (1997) concludes that the costs associated with unpaid caregiving for someone with a long-term health problem include "negative feelings the caregivers may harbour and disruptions to the caregiver's life or economic costs" (p. 4). This is consistent with Hooyman and Gonyea's (1995) proposal that there are both subjective and objective elements to caregivers' experience of burden or costs related to caregiving. Similarly, in their examination of eldercare in Canada, Keating et al.'s (1999) review of the literature highlights evidence of social, psychological, physical and economic consequences for these caregivers. Similarly, the Canadian Association for Community Living (2005) proposes that both care receivers and caregivers are at risk when unpaid caregiving takes place in an unsupportive context. They recognize that the risks to caregivers include "lost income, opportunity, health status, increasing disability-related expenditure and future economic security as they withdraw from, or are prevented from entering, the paid labour market in order to provide informal caregiving" (p. 7). At the same time, potential psychosocial or subjective costs are also recognized as including "the loss of what were once caring relationships among family members and the potential of those relationships for self-determination, self-development and contribution of each family member" (Canadian Association for Community Living, 2005, p. 7).

Keating et al. (1999) divide economic consequences into employment consequences and out-of-pocket expenditures (pp. 59-62). In their literature review, Keating et al. highlighted employment consequences ranging from lower productivity and higher absenteeism to reducing hours and turning down overtime and/or other opportunities such as extra projects, meetings, trainings and promotions. Jenson and Jacobzone (2000) conclude that these employment consequences have a "depressing effect on wages". Keating et al. (1999) and Jenson and Jacobzone (2000) also highlight research evidence that some caregivers reduce or leave their paid employment due to caregiving responsibilities thereby reducing their income. Fast et al. (2001) also identify lost current and future income and lost employment benefits as employment-related costs that some caregivers experience (p. 46). They note that "any decisions which reduce current income...will have a lasting effect on future income in retirement" (p. 35).

Jenson and Jacobzone (2000) also add the concept of opportunity costs to the definition of caregiving-related costs for unpaid caregivers. They suggest that these "opportunity costs" include "the costs of foregone earnings and leisure", "the displaced expenditure within the household", and "the health effects and the impact on marriages" (p. 11).

With respect to out-of-pocket expenditures, the literature documents caregivers' additional expenditures due to the purchase of goods and services for the care recipient, increased household expenses and the purchase of services such as respite care, housekeeping and yard work to "buy time" for the caregiver (Fast et al., 1999; Keating, Fast, Connidis, Penning. & Keefe 1997; Keating et al., 1999).

Much of the literature identifying caregivers' burden or costs focuses on individual caregivers and families and does not include discussion regarding how government policies and programs alleviate or contribute to these costs. The failure to extend the discussion to structural factors reinforces societal, cultural expectations based on an ideology that defines unpaid caregiving as private family responsibility. According to Cancian and Oliker (2000), this results in a situation where "the economic and psychological burdens of providing it [caregiving] are substantial and there is little assistance from outside the family to lighten the load" (p. 64). Baines et al. (1998) and Neysmith (2000) arrive at similar conclusions.

Fast and Keating (2000) have been at the forefront of Canadian research which has attempted to link the negative consequences for unpaid caregivers to a larger policy agenda. Based on their own previous work and other related research, Fast et al. (1999) developed a taxonomy of the "hidden costs of informal elder care" (p. 305). Their taxonomy distinguishes between economic and non-economic costs. The non-economic costs are further categorized as physical, social (i.e., relationships and activities) and emotional (i.e., stress, morale and control/independence). They break the economic costs into three additional categories of employment-related (income, benefits and employee productivity), out-of-pocket expenditures (i.e., expenditures on the senior, expenditures on help, money transfers, expenditures on workplace benefits), and unpaid labour (p. 305). In later work focused on the development of a policy analysis framework, Fast et al. (2001) also add the value of unpaid labour provided by caregivers as an important economic cost that should be considered in assessing the overall costs for caregivers and the impact of any policy.

The distinction between non-economic and economic costs is summarized as follows: "economic costs involve money or money equivalents and affect standard of living. In comparison, non-economic costs result from declines in certain aspects of quality of life, such as physical, social and emotional well-being" (Fast et al., 2001, p. 3).

Fast et al. (1999) connect this taxonomy to the policy environment by presenting it as a model for conceptualizing the differential experience of cost by relevant stakeholder groups including elderly care recipients, unpaid caregivers, these caregivers' families, employers of these caregivers and society at large. These authors report that there is evidence that some policy reforms have redistributed the costs of elder care among stakeholders. The end result is that public expenditure reductions do not decrease the overall costs of providing care because the costs have simply shifted to other stakeholders, especially the unpaid caregivers. They purport that "the conclusion that informal care is less costly in terms of public expenditures than formal care is based upon a relatively narrow and short-term view of the formal care system's own costs" (p. 322).

Unfortunately, this work on conceptualizing economic and non-economic costs has been restricted to an examination of unpaid caregiving for the elderly in Canada. Further research is required to understand the relevance of this work for other caregivers such as those caring for younger adults with chronic illness and disabilities.

Gender differences are also relevant to the construct of costs experienced by unpaid caregivers. According to Morris (2001), "caregiving interferes with paid work for women more than men, and although caregiving involves financial costs for men and women, there are more and deeper longer-term costs for women" (p. 2). Neysmith (2000) suggests that recent health care and social service restructuring has exacerbated gender inequity because the "costs that were ejected from the public world frequently landed in the private world of households where women picked them up with little control over the terms and conditions under which the resulting additional work would be done" (p. 3).

Policy Responses to Economic Consequences for Unpaid Caregivers

Keefe and Fancey (1998) propose that it is important to recognize that policy responses to the economic consequences experienced by unpaid caregivers can have either social or economic objectives. They identify social objectives for policies that "recognize the contribution of family members and support them even though the family would continue to provide care if compensation were not offered" (p. iii). On the other hand, they suggest that policies with an economic objective "strive to reduce or delay the institutionalization of elderly persons and thereby decrease the cost to the health care system" (p. iii). Based on a review of financial support programs for caregivers in Britain, Finland and Michigan, Sipila (1995) also notes that programs vary with respect to their intended function. For example, in Britain, the program is intended to compensate for lost earnings while in Michigan the program's function is to purchase care services for low-income care receivers who do not have employment-related insurance to assist with these costs in order to prevent institutionalization. At the same time, Finland's program prioritizes the provision of public home care services and provides compensation only for those who choose not to use these services.

The literature on policy responses to the economic consequences experienced by unpaid caregivers has tended to divide these policies into the two categories of direct and indirect financial compensation (Havens, 1999; Keefe & Fancey, 1998). Additionally, in her recent and continuing international review of financial compensation initiatives for family caregivers of dependent adults, Keefe (2004) also includes labour policies.

According to Keefe (2004), "indirect compensation programs are non-direct cash payments that have a delayed monetary (or economic) value" (p. 2). Tax relief, pension schemes or social security benefits have been identified as forms of indirect financial compensation. Tax relief includes tax credits, tax deductions and tax exemptions intended to offset additional expenses incurred. Keefe & Fancey (1998) define pension schemes as having the intention "to protect caregivers, who cannot seek employment because of caregiving responsibilities, against income losses from future retirement benefits" (p. 24). This generally involves "third party payment of pension credit or insurance premiums" (Keefe, 2004, p. 2). Great Britain and Norway are cited as examples of countries where such schemes exist. Meanwhile, social security benefits are programs that provide caregivers with access to unemployment and sickness benefits while caregiving for dependents. This type of program is connected to national insurance systems in Great Britain and Sweden (Keefe & Fancey, 1998). Keefe (2004) reports that the purpose of indirect compensation programs varies internationally and may be to either recognize the caregivers' caregiving time or their out-of-pocket expenses.

By contrast, direct financial compensation has been defined as "cash benefits that are paid directly to the caregiver or to the care receiver with the intention of compensation the caregiver" (Keefe, 2004, p. 2). Generally, this involves "the transfer of money through either an allowance, stipend, grant or voucher system" (Keefe & Fancey, 1998, p. iii) or even a wage or salary (Keefe, 2004, p. 2). Keefe and Fancey (1998) and Keefe (2004) suggest that direct financial compensation or payment to caregivers can be further divided into three categories; compensation for caring work, compensation for out-of-pocket expenses incurred by unpaid caregivers, and funding to enable caregivers to purchase support services. Therefore, there are generally three types of direct payment programs. These programs are: wage programs intended to provide a replacement wage for unpaid caregiving, cash allowance programs that are seen more generally as a financial contribution to the caregiving situation, and finally, financial support for expenses associated with caregiving including the purchase of support services (Keefe & Fancey, 1998). Havens (1999) also noted that in some jurisdictions self-managed or consumer-directed compensation programs that enable care receivers to hire their own attendant care allow for the possibility of payment to family members. This is then another form of caregiver compensation (p. 11).

Labour policies that can be defined as a form of financial compensation for caregivers are those that "enable an employee to take leave from their workplace to assume or continue caregiving responsibilities" (Keefe, 2004, p. 2). These policies generally enable caregivers to receive income through a national insurance program during a caregiving-related leave. Canada's recent Compassionate Care Benefit administered through the federal Employment Insurance program is one such example. Keefe (2004) proposes that "the purpose of these policies is to enable direct care to occur for a specified period of time which otherwise may not be possible due to work commitments" (p. 2).

Fast et al. (2001) propose that in assessing the economic impact of policy on informal caregivers of frail seniors, it is necessary to consider not only those policies explicitly directed towards financial compensation for these caregivers (e.g., Caregiver Tax Credit) but also health, income security and labour policies that affect them directly or indirectly. Therefore, in their analysis of the current policy context, they consider the availability of health programs (i.e., home care, adult day programs, consultation services, drug plan, equipment plan, home oxygen program, and physician and hospital services). They also include income security programs including social assistance, Old Age Security, Canada Pension Plan, guaranteed annual income programs and income tax deductions and tax credits (p. 31). Finally, similar to Keefe (2004), they also consider the variation in provincial labour legislation with respect to family responsibility leave provisions. Fast et al. (2001) advocate that it is necessary to look at "the collective effect of the complex maze of interrelated polices and policy instruments that exist in Canada" (p.1) rather than focusing only on financial compensation for caregivers since other policies also have the potential to impact caregivers economic well-being.

Internationally, there are many examples of government programs and policies providing for both direct and indirect financial compensation for unpaid caregivers. Several countries in Europe and many states in the United States offer some form of financial compensation (Keefe, 2004; Keefe & Fancey, 1998; Linsk, Keigher, Simon-Rusinowitz, & England, 1992; Stone and Keigher, 1994). The general finding is that there is a very uneven pattern of supports available for unpaid caregivers. Stone and Keigher (1994) highlight this situation in the United States while Glendinning and McLaughlin (1993) describe a similar situation of diversity of response in Europe. Similarly, Fast et al. (2001) find significant regional disparities between regions in Canada. International comparisons conducted by Keefe & Fancey (1998), Keefe (2004) and Jenson & Jacobzone (2000) also emphasize the diversity of policy responses to date.

With respect to Manitoba specifically, unpaid caregivers in Manitoba currently do not have access to any of the forms of direct financial compensation described above. Under some circumstances, Manitoba caregivers may be able to receive room and board payments and even a minimal care allowance from the provincial Employment and Income Assistance program if their adult care receiver resides with them and qualifies for income assistance. Caregiver cash allowance programs have been introduced in some jurisdictions (e.g., Veteran Affairs Canada, Nova Scotia had a program that has been discontinued) (Keefe & Fancey, 1998).

Canadian caregivers, including Manitobans, who meet eligibility criteria have access to an indirect form of financial compensation through the federal income taxation system. According to Young (2000), the taxation system in Canada "is increasingly being used to provide relief for those with physical or mental disabilities and those who care for persons with disabilities" (p. 57). In this regard, the Disability Tax Credit, Infirm Dependent Tax Credit, Caregiver Tax Credit, medical expense and attendant care (expanded to disability support deductions in 2004) are identified as the components of Canadian tax relief for persons with disabilities and/or their unpaid caregivers (Young, 2000). Keefe and Fancey (1998) note that there are strict eligibility criteria and complex rules for the various elements that comprise this tax relief.

Some Manitoba caregivers may also be experiencing positive financial benefits through reductions in out-of pocket expenses they might otherwise incur if some of the home care and other health and income security programs identified by Fast et al. (2001) were not available. Manitoba's provincial labour legislation mandates job protection for family responsibility leave related to maternity and parental leave and now also supports access to the federal Compassionate Care Benefit by providing job protection for this purpose. However, beyond the Compassionate Care Benefit for which only a very specific group and limited number of caregivers are eligible, there is currently no provision for temporary income replacement. For most caregivers, their only option would be applying for provincial income assistance once they exhaust all family income and savings and meet the stringent eligibility criteria.

Relevant Theoretical Literature

The foundational theoretical framework for this study is feminist theory on women's caring. Theoretical models describing the interrelationship of factors that influence caregivers' psychosocial adjustment are also relevant as they illuminate caregiver characteristics and aspects of caregiving situations that may influence caregivers' experience and their perceptions of that experience (Avison, Turner, Noh, & Nixon Speechley, 1993; Biegel et al., 1991). Theoretical frameworks that have been developed to conceptualize and analyze the costs of unpaid caregiving in eldercare in Canada are also relevant to this study (Fast et al. 2001; Fast et al., 1999; Keating & Fast, 1997).

Feminist Theory on Caring

Feminist theory on caring has evolved out of the recognition that women provide the bulk of unpaid caregiving in our society. This unpaid care includes childcare as well as care for adult family members living with chronic illness and disabilities. Several authors have contributed to the development of this theory or stressed the importance of the feminist framework for understanding current issues with respect to unpaid caregiving (e.g., Armstrong & Armstrong, 2002, 2004; Armstrong & Kits, 2001; Baines & Evans, 1992; Baines et al., 1998; Ferguson, 1998; Guberman, 2004; Hooyman & Gonyea, 1995; Neysmith, 2000).

This theory acknowledges that women are disadvantaged by the fact that they provide most of the unpaid caregiving and that they experience negative social, emotional, physical and economic consequences as a result. Authors writing from this perspective suggest that these negative consequences are derived from the social conditions under which unpaid caregiving occurs rather than the caregiving itself (Armstrong & Armstrong, 2002; Baines et al., 1998). According to Baines and Evans (1992), "a feminist perspective, rooted in an analysis of women's caring" draws attention to these social relations and structures and “challenges social work’s traditional separation of the micro and macro perspectives” (p. 8).

Hooyman & Gonyea (1995) discuss the application of a feminist framework to the research and understanding of unpaid family caregiving. They outline the central constructs of this framework as including the recognition that gender is socially constructed and that patriarchy or domination of women within the family persists today. Baines et al. (1998) have also emphasized that feminist analysis of family care requires recognition of patriarchy as a system of social structures and practices in which men dominate women. Guberman (2004) concludes that in this context women often do not have a real choice related to whether or not they will assume unpaid caregiving roles. In their research into why women take on these caregiving roles, Guberman, Maheu and Maillé (1992) found that three of the six factors that were identified as determinants of women’s decisions to provide care were in fact structural constraints that were external to themselves; the inadequacy of institutional or community resource alternatives, their economic dependency and the care receiver imposing the decision upon them.

Hooyman and Gonyea (1995) advance the argument that the dominant ideologies of separate spheres and familialism have led to the devaluation of unpaid caregiving and consequently, women. They link the development of these ideologies back to the Industrial Revolution that led to a separation between the home and family care and the capitalist workplace and paid labour. The home became defined as women’s sphere while the factories became dominated by men. According to Hooyman and Gonyea (1995), “nonmonetized and nontechnological, caregiving became devalued in a society that increasingly defined work in terms of measurable output and wages rather than nurturing and maintenance" (p. 30). Cancian and Oliker (2000) propose that this devaluation led to a devaluation and lack of support for family caregiving that has had negative effects on women's income, well-being and the quality of care in society (p. 10). Baines et al. (1998) describe the current situation as one where caring work has come to be defined as women's "natural responsibility" (p. 9) at the same time that it is devalued. In other words, "the ideals of the separate spheres concept simultaneously extolled and devalued caregiving" (Cancian & Oliker, 2000, p. 24).

Hooyman and Gonyea (1995) propose that the ideology of separate spheres has evolved to include the ideology of familialism which defines caregiving as a private family responsibility. This ideology of familialism also espouses the tenet that the best care is provided by family members in the home. These authors also suggest that current public policies are "based on this individualized approach, valuing self-reliance, independence, and minimal state provision with families assuming most of the burden" (p. 30). Furthermore, this ideology supports neoconservative notions of "traditional family values" (p. 111) and assumes that women will be available to provide free caregiving labour in the home.

Feminist researchers conclude that women's predominance in unpaid caregiving roles contributes to the persistence of gender inequality in Canada (Armstrong & Armstrong, 2002; Baines et al., 1998). For this reason, the feminist perspective identifies the need to conduct research in the field of unpaid caregiving in a manner that acknowledges and seeks to understand the gendered nature of care while bringing to light structures and policies that reinforce gender inequality or present barriers for gender equity. Fast et al. (2001) stress the importance of applying gender-based analysis to assessing the economic impact of policies on unpaid caregivers so that "the differential effects of policies, programs and legislation on women and men caregivers are unmasked" (p. 45). The application of a gender lens or gender-based analysis involves "integrating questions concerning gender throughout the analysis" (Status of Women Canada, 1996, p. 29) for the purposes of understanding differential effects of policies on men and women and highlighting issues related to gender inequality.

Theoretical Models of Unpaid Caregivers' Psychosocial Adjustment

Given the probability that caregivers' psychosocial adjustment will have an impact on their perception of the caregiving experience, the costs associated with caregiving and related policy responses, theoretical models of caregivers' psychosocial adjustment are relevant to the current study.

Following their review of research into unpaid caregiving and specific chronic diseases, Biegel et al. (1991) propose that there is evidence of "some consistencies across diseases in the predictors of psychosocial adjustment for family caregivers" (p. 199). They propose a theoretical model for further empirical testing. This model identifies objective stressors as the characteristics of the person with the chronic illness with respect to illness severity, suddenness of onset, and the degree of change or impact as a result of the illness (pp. 201-204). Their model also includes contextual or mediating variables. These are outlined as demographic factors (gender, type of role relationship with patient, age and socioeconomic status), preexisting psychological factors, relationship quality, family life stage and social support (pp. 204-213).

Based on their research, Avison et al. (1993) propose a stress process model as a conceptual framework for "understanding variations in psychological distress among caregivers" (p. 89). Their research indicates that the social stressors of stressful life events and chronic strain are positively linked to caregivers' levels of distress while there are stress buffering effects from the psychosocial resources of social support and a personal sense of mastery.

These theoretical models essentially ignore the contribution of social policy and other structural factors that may have an impact on the caregiving experience. There is also limited attention to the influence of the realities of the gendered nature of care. Despite these weaknesses, the models do assist in highlighting a number of factors relevant to caregivers' experience of their unpaid caregiving roles and the related costs.

Ecological Policy Paradigm for Care Environment

In order to examine and research policy issues related to eldercare, Keating et al., (1997) developed an ecological model of the eldercare environment. Their model identifies the three key contexts as the client (i.e., the senior), the client's caring environment (including formal and informal caregivers), and the more distant policy environment. Further to this, they suggest that there is a need to acknowledge the interface between informal and formal care providers as one that is complementary. This challenges the assumption underlying some policies that formal caregivers substitute for informal caregivers or vice versa. These authors stress that policies should be developed and analyzed from a perspective that considers and values the economic costs across all "caring partners" including unpaid caregivers, professional caregivers and government. The presentation and discussion of this model is restricted to the eldercare environment but the same three key contexts could also be relevant for policy for younger adults living with chronic illness and disability. However, some of the specifics related to these contexts may vary with this population and the caregivers involved.

Riggs (2003) also proposes that caregiving policy needs to be considered from this type of holistic perspective on “care partnerships”. She states:

> A twenty-first century approach will shift focus from the caregiver in isolation to the individual and the family as the pivot for a care partnership that includes everyone engaged in the care of that individual and particularly the primary care provider. (p. 72)

Theoretical Frameworks for Conceptualizing Costs and Economic Impact for Unpaid Caregivers

Fast et al.’s (1999) taxonomy of the hidden costs of informal elder care with its conceptualization of both economic and non-economic costs was presented in the discussion of the literature related to defining the construct of costs for unpaid caregivers. Fast et al. (2001) have built on this earlier work to develop a theoretical policy analysis framework for assessing the economic impact of health, income security and labour policies on informal caregivers of frail seniors. The four components of this policy analysis framework include: (a) a description of the policy instrument or program under consideration, (b) moderating characteristics of the caregiver, caregiving situation and context, (c) gender of the caregiver, and (d) caregivers’ economic costs.

With respect to the policy instrument, Fast et al. (2001) suggest that it is necessary to first identify the intent or objective of the policy, eligibility criteria, user fees and benefits provided before proceeding with the analysis. They describe the “moderating characteristics” as “a set of caregiver, care receiver and regional characteristics that mediate the effect of any given policy on the economic outcomes affecting informal caregivers” (p. 45).

The key moderating characteristics are identified as the presence of young children, labour force status, geographic proximity, care receiver income and regional economy. It is proposed that not all of these characteristics will act as mediating factors for all programs or policies.

Caregivers' gender is identified in the framework independent from the moderating characteristics. The authors are advocating the need for gender-sensitive analysis due to the fact that women and men are likely to experience different effects from policies related to their unpaid caregiving roles. The authors state that "the gender of the caregiver is a constant filter in the framework because of the ubiquitous nature of gender differences in the social context in which we live"(Fast et al., 2001, p. 45). They acknowledge that this reality has an economic impact.

Finally, based on previous research and their initial application of the policy analysis framework, Fast et al. (2001) propose that in analyzing the potential economic impact of a policy four types of economic costs should be examined. These economic costs are lost current and future income, lost employment benefits such as extended health care coverage and paid vacation, out-of-pocket expenses and unpaid labour (p. 46).

Based on their initial application of this policy analysis framework, Fast et al. (2001) conclude that "the relationship between a given program and types of economic costs incurred are moderated by caregiver and care receiver characteristics, the gender of the caregiver and the interactions among these caregiver, care receiver and regional characteristics" (p. 46).

Despite the fact that the earlier work on the taxonomy of costs stresses the existence and the importance of both economic costs and non-economic costs for unpaid caregivers, this policy analysis framework ignores the non-economic costs to focus solely on economic costs. Consequently, the model does not facilitate an examination of the interaction of economic and non-economic costs and their combined contribution to these caregivers' experience. Furthermore, despite the fact that the authors acknowledge that the economic impact of policies may be different for women with different characteristics (e.g., lone-parent families headed by women, Aboriginal people, and visible minorities), their framework does not include these issues of diversity in the analysis. The potential applicability of this framework is also limited by the fact that it has been developed from research on informal eldercare and is designed to analyze policies only for those caregivers. Therefore, it is unknown whether the identified moderating characteristics are sufficient or accurately reflect the experience of unpaid caregivers of younger adult family members with chronic illness or long-term disabilities.

Empirical Literature – Research Findings

Non-Economic Costs for Unpaid Caregivers

It is important to note that Fast et al.'s (1999) taxonomy of hidden costs of informal elder care was developed based on research evidence that there are significant non-economic costs for many caregivers that coexist with the economic costs. Payne and Ellis-Hill (2001) describe how the non-economic consequences or needs of caregivers have been largely studied through the use of standardized questionnaires or structured interviews with an emphasis on measuring "constructs such as quality of life, perceived burden, and psychological morbidity" (p. 11). They suggest that the advantage of this approach has been that it yields quantifiable data. However, the disadvantage is that it tends to measure the negative aspects of caregiving without consideration for the global caregiving experience including the positive aspects.

Fast et al. (1999) highlight research which indicates that caregivers experience a variety of emotional costs including resentment of their loss of independence and control, psychological stress including symptoms of guilt, anxiety and burden as well as poor morale and depression (p. 310). The Canadian Caregiver Coalition (2002) suggests that in addition to economic costs caregiving can have negative effects on the caregivers' health and physical well-being, social well-being and emotional well-being (p. 2). A recent study of primary caregivers of children with cerebral palsy found that they are more likely to have a variety of both physical and psychological health problems (Brehaut et al., 2004).

Costs related to physical well-being have been found to include physical strain from caregiving responsibilities and declines in general health status over time (Fast et al,, 1999, pp. 310-311). Cranswick's (1997) analysis of data from the 1996 GSS reveals that "the most severe alterations to caregivers' lives were the changes in their own health status" (p. 7). In this survey, "29% of caregivers reported that their sleep patterns had changed and 21% said that their health had been affected" (p. 7). A further finding was that women were twice as likely as men to report that their health had been affected. The same finding is replicated in the analysis of the 2002 GSS, with 1 in 10 caregivers of seniors reporting health problems and this number increasing to 2 in 10 when women's responses are analyzed separately (Cranswick, 2003).

With respect to social well-being, several studies have found that caregiving interferes with some caregivers ability to establish and maintain relationships due to time demands (Fast et al., 1999). The 1996 GSS also found that many informal caregivers give up social, leisure and personal development opportunities (e.g., 45% reported that helping others caused them to make changes to social activities) (Cranswick, 1997). The 2002 GSS data indicates that caregivers 65 years of age and over experience less of an impact in this area. However, for caregivers aged 45-64, 40% of female caregivers and 30% of male caregivers report changes in their social activities (Cranswick, 2003).

Economic Costs for Unpaid Caregivers

There is research evidence that unpaid caregivers' economic costs are significant. Based on her analysis of recent Canadian data, Cranswick (2003) concludes that "the most profound of the socioeconomic impacts are the financial consequences of providing care" (p. 14).

Keefe and Medjuck (1997) interviewed 246 employed female caregivers and found that economic consequences (i.e., loss of income, financial assistance provided to care receiver and restrictions on their ability to save for retirement) contributed significantly to caregivers' stress. They also found that stress level was correlated to caregivers' income. Based on their finding, they recommend workplace and public policies that address short and long-term financial consequences rather than focusing only on short-term stress management.

Glendinning (1992) found that negative financial consequences were experienced by 21 of 29 caregivers interviewed in England. These consequences included drawing on savings, buying more on credit, borrowing money, delaying bill payments, cashing insurance policies, cutting back on previous patterns of saving, and giving up or cutting back on some previous items of consumption. Eight of the caregivers interviewed also reported that they worried more about money now than they used to.

Employment-Related Costs

Recent Canadian statistics indicate that a majority of caregivers of seniors are also employed outside the home (i.e., 77% of male and 63% of female caregivers aged 45-64 years) (Cranswick, 2003). However, there is also evidence to indicate that these employed caregivers are still incurring negative employment-related consequences.

In the 1996 Statistics Canada survey of caregivers of seniors, 55% of women and 45% of men reported that their unpaid caregiving had repercussions for their work. Additional analysis of data from the same survey found that many employed respondents had made job adjustments due to caregiving responsibilities. These job adjustments included: changing hours of work (17.7% of women, 21.9% of men), coming late or leaving early (35.9% of women, 37.2% of men), missing a day or more of work (31.7% of women, 27.8% of men). Additionally, 17.1% of employed women and 16.1% of employed men reported that their caregiving responsibilities had affected their job performance (Keating et al., 1999). Data from the 2002 GSS continues to indicate that caregiving affects caregivers' employment situations with many caregivers making adjustments such as quitting a job, retiring early or reducing their hours of work (Cranswick, 2003; Stobert & Cranswick, 2004).

Opportunity Costs

Several authors highlight the potential impact of opportunity costs on unpaid caregivers but there is little empirical research available about the extent of these costs. In the 1996 GSS, small proportions of caregivers of seniors have reported that they have postponed economic opportunities such as education, job transfers or promotions and job offers as a result of their caregiving responsibilities. For example, 8% of women and 6% of men reported having postponed education plans and 6% of women had turned down a promotion or transfer while only 2% of men reported doing this. While the overall proportions are small, the authors note that women were two to three times more likely than men to report postponing these types of economic opportunities (Keating et al, 1999, p. 90). In 2002, 3% of male and female caregivers of seniors had turned down a promotion as a result of their caregiving situation (Cranswick, 2003).

Loss of Current and Future Income

In their study of rural caregivers in Nova Scotia, Campbell, Bruhm and Lilley (1998) found that many had left paid employment due to caregiving responsibilities and fewer than one-quarter of the participants were currently involved in paid employment. Of those who were not currently employed, almost half had changed jobs or left a job due to caregiving responsibilities.

In their literature review, Keating et al. (1999) highlight research by Martin Matthews and Campbell that found 9 to 11% of employed caregivers relinquished employment because of caregiving responsibilities. According to Fast et al. (1999), research studies have resulted in estimates that "as many as 40% of informal elder care providers are employed and that up to 50% of these relinquish employment opportunities" (p. 312). Two percent of respondents to a recent Canadian survey of caregivers of seniors reported that they had quit their job due to their caregiving-related responsibilities (Cranswick, 2003).

Fast et al. (1999) note that some caregivers may lose current income as a result of some of the job adjustments they make (i.e., unpaid time off for missed days or hours of work or turning down overtime) (p. 312). According to Cranswick (2003), "in 2002, reducing hours of work was common for caregivers aged 45 to 54: 20% of women and 13% of men reported having done so" (p. 16). About 10% of caregivers between 55 and 64 years old also reported reducing their hours of paid work. This reduction in hours of paid work also leads to lower income. According to the 2002 GSS, "approximately 1 out of every 10 women and slightly fewer men lost income due to their care duties" (Cranswick, 2003, p. 16).

Loss of private or public pensions and other employment benefits is frequently cited as an important employment-related cost experienced by many unpaid caregivers (e.g., Fast et al., 2001, Fast et al., 1999; Jenson & Jacobzone, 2000) but no empirical studies of the exact nature and magnitude of this particular type of cost were identified in the literature review.

Out-of-Pocket Costs

Statistics Canada data from the 2002 GSS indicate that more than one-third of caregivers aged 45-64 years incurred extra expenses due to their caregiving duties (i.e., 42% of women and 38% of men), as did slightly less than 30% of caregivers age 65 years and older (Cranswick, 2003). This is fairly consistent with the previous 1996 GSS where 44% of caregivers reported that they had incurred extra expenses as a result of helping others (Cranswick, 1997). In their study of home care in Manitoba and Newfoundland, Morris et al. (1999) also found that the costs of medical equipment, special meals, renovations to accommodate disabilities, repairs and maintenance and sometimes prescription and non-prescription medications were largely borne by care recipients and unpaid caregivers. Glendinning (1992) found that caregivers who were employed full-time and provided substantial amounts of caregiving were more likely to have high levels of spending on substitute care" (as cited in Havens, 1999). No empirical research quantifying the amount of these costs was found in the literature review.

Unpaid Labour

Fast et al. (2001) purport that "the value of unpaid work performed by informal caregivers is a major component of the hidden costs of informal elder care" (p. 4). These authors reference an earlier 1999 study conducted by Fast and Frederick that estimated the replacement value of the more than 2 million unpaid caregivers in Canada to be more than $5 billion a year. Campbell et al. (1998) calculated that if the rural caregivers in their study were paid $10.90/hour for the average number of hours worked they would each receive an income of $92,000 annually.

A significant deficit in the empirical research on the costs experienced by unpaid caregivers is that there is no specific information available on the nature and magnitude of these costs for the specific caregiver population that is the focus of this study (i.e., those who provide unpaid caregiving for adult family members with chronic illness and long-term disability). The research information available is either for the general population of unpaid caregivers or for caregivers of the elderly specifically. Furthermore, none of the studies reviewed presented empirical findings that provided a quantitative summary of the overall costs experienced by any of the caregivers studied. Similarly, there was no study that provided a comprehensive, in-depth, qualitative picture of caregivers' costs from the perspective of the caregivers' themselves.

The current research literature on economic and non-economic costs also does not address the interaction of economic and non-economic costs in caregivers' experience and the related policy implications. This qualitative study provided an opportunity to explore this gap.

Caregivers' Perception of Financial Compensation

The 1996 GSS asked caregivers to indicate the types of supports that they would find useful in continuing their caregiving efforts. Almost half of the caregivers who responded did not identify any type of support that would be helpful. However, financial compensation was the most frequent response from caregivers who identified a need for support (i.e., identified by 15.4% of caregivers). Not surprisingly, over 70% of the caregivers who were in favour of financial compensation also reported that they had incurred extra expenses related to their caregiving. Caregivers with lower incomes were mostly likely to view financial compensation as a favourable support. Almost one-quarter of caregivers with household income less than $14,999 and one-fifth of caregivers with household income between $15,000 and $29,999 identified financial compensation as a useful support compared to 16% of caregivers with household income between $30,000 and $59,999 and 12% of caregivers with household income over $60,000 (Keefe & Fancey, 1998).

In the 2002 GSS, "occasional relief or sharing of responsibilities" was the most common answer (i.e., 51% of caregivers aged 45-64) to the question of what would be the most useful thing to allow them to continue providing help. However, financial compensation was also still suggested by a substantial portion of caregivers (Stobert & Cranswick, 2004).

Adamek (1991) assessed caregivers' perceptions of the helpfulness of financial assistance that was being provided to their care receivers in the form of a supplement to a veteran's disability allowance provided when the veteran is in need of regular assistance from a caregiver. A significant majority of caregivers reported that the benefits were helpful in maintaining the veteran in the community and financial assistance was the type of support most desired by the respondents. However, over half of the caregivers indicated that the benefit amount was inadequate. Furthermore, caregivers who reported lower emotional and financial strain were more likely to indicate that they thought the benefit program was helpful.

More recent research data from the National Cash and Counselling Demonstration and Evaluation in the United States indicates that both caregivers and care receivers report positive benefits from this consumer-directed model. Under this program, care receivers can manage the budget allocation for their care including the selection and payment of their care providers. These demonstration programs allowed care receivers to hire family members and approximately 80% of participants chose this option. The evaluation found increases in satisfaction for both caregivers and care receivers as well as decreased emotional strain for caregivers (Kunkel, Applebaum & Nelson, 2003).

Other Stakeholders' Perceptions of Financial Compensation for Unpaid Caregivers

Simon-Rusinowitz, Mahoney, & Benjamin (1998) obtained the perceptions of home care administrators (via mail questionnaires) and policy experts (via in-depth interviews) with respect to the possibility of a policy of financially compensating unpaid caregivers. They conclude that "while respondents were generally reluctant to support such a policy, their comments reflected contradiction and confusion about the outcomes of paying family caregivers" (p. 4). They found that some respondents identified both benefits and disadvantages to this policy approach. The disadvantages cited included concerns about fraud and abuse as well as increased administrative costs. Similarly, Blaser (1998) presents an argument against compensating caregivers based on her experiences as a manager of a community care program in Illinois. Her concerns include the potential for exploitation of family caregivers, the potential for fraud and abuse as well as increased administrative and program costs.

Impact or Effectiveness of Policies/Programs

Addressing Economic Costs for Unpaid Caregivers

Keefe & Fancey (1998) conducted an international comparison of direct and indirect financial compensation programs as well as an extensive literature review of empirical findings and evaluations for the various programs. Their findings as well as those from other research studies are summarized below. Keefe (2004) is currently conducting a review of some international financial compensation initiatives for caregivers of dependent adults. The objective of this current research is to better determine the various policies' impact and effectiveness and assess their potential applicability to the Canadian context.

Indirect Financial Compensation

Keefe and Fancey (1998) conclude that "little empirical evidence exists to interpret the usefulness of these initiatives for informal caregivers" (p. 26).

With respect to tax relief specifically, Young (2000) and Keefe and Fancey (1998) note that tax relief programs are not fully utilized due to a lack of public awareness and understanding of the complex rules and eligibility criteria involved. Keefe and Fancey also note that strict eligibility restricts the numbers of caregivers who are entitled to the benefit even when they are aware of it. Based on their analysis of the economic impact of current policies on unpaid caregivers of frail seniors, Fast et al. (2001) conclude that the Caregiver Tax Credit and other income tax credits "provide little economic benefit to informal caregivers" (p. 44). Keefe (2004) argues that additional financial compensation measures are necessary for Canadian caregivers because "tax initiatives are often only beneficial to certain income groups and are delayed in actual compensation for costs/expenses incurred by the caregiver" (p. 3).

Keefe and Fancey (1998) report that indirect financial compensation programs are generally inadequate because the amount of financial benefit provided is either too small (e.g., tax relief) or too long in coming (e.g., pension schemes). Furthermore, they conclude that little evidence exists that such initiatives result in increases in informal caregiving or in fewer personal care home placements (pp. 27-28). They suggest that these programs exist despite the lack of data because they "represent a way of recognizing and legitimizing the important role of family caregivers using a public policy framework" (p. 28).

Direct Financial Compensation

Keefe and Fancey (1998) report the general finding that most direct compensation programs, such as caregiver allowances and wage allowances, offer an extremely low level of benefit that is insufficient to provide meaningful financial support to caregivers. Previous research by these authors examined the Nova Scotia Home Life Support program that offered either in-home support services or a caregiver allowance. They found that the financially compensated caregivers reported the highest time dependence burden or were responsible for a greater number of caregiving tasks that occupied a greater proportion of their time. They speculate that this is due to the fact that the benefit level was inadequate to allow them to purchase support services to relieve them of some of their caregiving responsibilities (Keefe & Fancey, 1997).

By contrast, recent demonstration projects in the United States have actually found a slight reduction in the number of hours of care provided by family caregivers when they are paid (Kunkel et al., 2003, p. 76).

Vinton and Kim's (1996) evaluation of a Florida program that provides a small financial subsidy in addition to case management services found evidence of positive assessment of this program by care receivers, caregivers and case managers. They conclude that caregivers' financial subsidies improve the quality of life for the caregiver and care receiver while providing cost-savings for the formal health care system.

Based on recent evidence from the National Cash and Counselling Demonstration and Evaluation in the United States, Kunkel et al. (2003) conclude that:

> Empirical evidence from well-designed research demonstrates that recipients of paid family care are more satisfied, as are the caregivers. Anecdotal concerns about neglect, safety and negative effect on family relationships have been dispelled in the studies now available… caring for love *and* money is possible, and for some desirable. (p. 80)

Jenson and Jacobzone (2000) express concern that there are indications that some short-term financial compensation programs may have long-term negative financial implications, particularly for women who leave the paid labour force to take on caregiving responsibilities with only token compensation provided (p. 34). Guberman (2003), Jenson and Jacobzone (2000) and Keefe and Fancey (1997) all stress the importance of the provision of adequately funded public support services simultaneous with any direct compensation programs. It is explained that this is necessary in order to ensure that unpaid caregivers have real choices regarding their unpaid caregiving. Additionally, Guberman (2003) stresses that any financial compensation for caregiving should include remuneration at market value and the provision of employment-related benefits in order to ensure that the caregivers, primarily women, are not further economically disadvantaged.

Keefe and Fancey (1998) also report that there are few evaluations of existing direct compensation programs that contribute to an understanding of whether these programs meet the objective of "sustaining the caregiving relationship and thereby delaying or reducing the high costs of institutionalization" (p. 38). A small number of studies have indicated that direct compensation programs may help sustain the caregiving relationship even when the benefit level is low. However, there is no evidence that financial support encouraged or increased unpaid caregiving by family members.

Economic Impact of Home Care and Other Policies

Morris et al.'s (1999) study of current home care policies and practices concluded that these policies have a negative financial impact on unpaid family caregivers, especially women. Their findings highlight the fact that women are expected to supplement home care services "without pay and at great personal expense in terms of their own health, incomes, benefits, career development and pension accumulation" (p. vi) while men are not faced with the same pressures or expectations.

Fast et al.'s (2001) analysis of the economic impact of health, income security and labour policies for caregivers of frail seniors in three Canadian jurisdictions led to the conclusion that some programs reduced caregivers' out-of-pocket expenses by subsidizing health supplies and services while others increased the out-of-pocket expenses with user fees. They also found that "few programs have an impact on the employment-related costs of informal caregivers" (p. 34). Guberman (2004) references several studies that indicate that attempts to reduce caregivers' negative economic and non-economic costs have been largely unsuccessful. She states that "the varied fragmented measures and programs that do exist have not been shown to have any major impact on caregiver well-being" (pp. 81-82).

Underutilization of Existing Services/Programs for Unpaid Caregivers

Although the literature does not provide information about the rate of utilization of existing direct and indirect financial compensation programs, a persistent concern of other caregiver-related programs and services has been underutilization in spite of apparent need (Parris Stephens, 1993; Zarit, Parris, Townsend, Greene & Leitsch, 1999). Montgomery (1995) and Chappell (1998) have noted significant patterns of underutilization with respect to respite care programs in spite of the fact that Canadian caregivers have indicated that occasional relief would be helpful in continuing to provide care (Cranswick, 1997; Stobert & Cranswick, 2004). Similarly, a survey of 345 caregivers of persons with multiple sclerosis, a chronic disabling disease affecting younger adults, found that 60% of caregivers had not used any services at all. Only 4% of the respondents had used some form of respite care in the past two years despite the fact that the majority of respondents were reported to be providing high levels of care and had been providing care for more than 9 years (Aronson, 1995).

A special issue of *The Journal of Applied Gerontology* (Vol. 18, No. 2, June, 1999) presented recent research on caregiver attitudes, beliefs and perceptions about service use. In their introduction to this special issue, Pedlar and Smyth (1999) identify the challenge for researchers and practitioners as being "to account for little or no use of supportive health and social services by care recipients and their family caregivers despite high levels of professionally assessed service need" (p. 142). They conclude that the empirical research indicates that an understanding of caregivers' attitudes toward, beliefs about, and perceptions of services can help to reduce the disparity between assessment of need and service use. As in other areas of the caregiving literature, most of the studies are focused on unpaid caregivers of the elderly. However, there are some important findings that may apply to unpaid caregivers of younger adults with chronic disease and/or long-term disability. For example, Stommel, Collins, Given and Given (1999) found that attitudes toward services were associated with caregiver gender, age, and the care receiver's diagnosis. In their study, men appeared to favour family independence over seeking government services. Older caregivers were also less likely to seek out government services. With respect to the care receivers' diagnosis, they found that caregivers of persons with dementia were least likely to reject services while caregivers of physically impaired elders were least confident in the service system. Additionally, Kosloski, Montgomery, and Karner's (1999) study concludes that "perceptions of need were generally found to vary according to ethnic group membership in predicting the use of discretionary services" (p. 252).

Smyth and Pedlar (1999) conclude that current research confirms the necessity of taking caregiver attitudes, beliefs and perceptions into account in planning and implementing service programs to meet their needs. Mullan (1993) drew a similar conclusion from his finding that education was positively related to increased service use among Alzheimer's caregivers. He concluded that education "is an omnibus variable that may be a surrogate for a set of interconnected characteristics such as knowledge, attitudes, beliefs, and norms about using formal services" (p. 251).

Dobrof and Ebenstein (2003) suggest that the issue of underutilization of existing services by caregivers is connected to individuals' process of self-identification as caregivers. They note that individuals are often reluctant to acknowledge the caregiver role and may not readily identify as caregivers. Consequently, they suggest that the related challenge is "how do healthcare and social service providers reach those caregivers who may be in need of support and resources but are not even aware that the caregiver support group…is relevant to their situation?" (p. 33).

Smyth and Pedlar (1999) conclude that "much work still needs to be done to adequately conceptualize and operationalize caregivers' service-relevant attitudes, beliefs, and perceptions" (p. 258). The findings from a study of the health of caregivers in Manitoba indicate that factors external to the caregivers themselves may also affect service utilization. According to Hawranik and Strain (2000), "there was a general consensus that resources were limited in availability, were difficult to discover and obtain, and frequently excluded the caregiver" (p. iv). This study provided an opportunity to explore a different group of caregivers' perceptions and experience with respect to services intended to address their caregiving-related costs.

Empirical Literature – Research Methodology

The majority of the research on costs experienced by unpaid caregivers and the economic impact of related polices has been conducted using quantitative methodology.

Payne and Ellis-Hill (2001) also report that the situation is essentially the same with respect to research on caregivers' non-economic costs (p. 11).

Several years ago, Linsk, Keigher, Simon-Rusinowitz, and England (1995) concluded that "there are almost no studies revealing the voice of consumers and family caregivers on the family compensation issue" (p. 69). At that time, they indicated that a 1992 study by Keigher and Murphy was a notable exception. This study involved structured, qualitative interviews with families receiving financial compensation through a program in Michigan. The purpose of the study was to understand how families utilized and perceived the funding. Since that time, there have been additional studies that have captured caregivers' perception of financial compensation (e.g.. Adamek, 1991; Cranswick, 1997; Keefe & Fancey, 1997, Vinton & Kim, 1996). However, all of this work has been quantitative in nature and has either involved self-administered, mailed questionnaires (Adamek, 1991, Vinton & Kim, 1996), structured interviews to collect quantitative data (Keefe & Medjuck, 1997) or secondary analysis of larger databases of information (Cranswick, 1997; Keefe & Fancey, 1997). Some qualitative studies have attempted to shed light on caregivers' experiences and needs including those related to the economic costs resulting from unpaid caregiving (e.g., Campbell et al., 1998). However, there has been no qualitative study that provides an in-depth examination of caregivers' experience of costs.

In their work, Fast et al. (2001) created several "typical" caregiver profiles and used a case study methodology to apply their policy analysis framework for the economic impact of various policies on unpaid caregivers. They suggest that this approach is necessary because of the complex interaction of moderating characteristics that can influence the relationship between a given program and the types of economic costs incurred by unpaid caregivers. They conclude that in order to understand the economic impact of a policy, it is necessary to consider relatively in-depth information about the nature of various caregiving situations including caregiver, care receiver and regional characteristics based on the local geography and the economy.

Gaps in the Literature

Gaps in the current literature identified in the preceding review include inadequate empirical data on the nature and magnitude of caregiving costs for unpaid caregivers of younger adults, insufficient information from caregivers themselves regarding their experiences and perceptions, as well as limited gender-sensitive research and analysis.

Data on the Nature and Magnitude of Costs and Impact of Current Policies on Unpaid Caregivers of Younger Adults

While it has been suggested that "the extent and consequences of elder care are well documented" (Fast et al., 2001, p. 1), there is a lack of research regarding the specific nature and magnitude of the economic consequences for unpaid caregivers of younger adults with chronic illness and long-term physical disabilities. The research literature describing the costs experienced by caregivers has presented data on caregivers generally or caregivers of the elderly specifically. Most notably, the caregiving data collected through the 1996 and 2002 GSS, provide only a limited profile on caregiving in Canada since the only respondents are caregivers over the age of 45 years who are caring for someone 65 years or older.

Information is also lacking regarding the perceptions and experiences of caregivers of younger adults living with chronic illness or disability with respect to their caregiving-related costs and addressing their economic costs.

Further to this, Canadian researchers have concluded that, "while the potential for policies to affect the consequences of informal caregiving is now recognized, little is *known* about how individual policies actually influence caregivers' costs" (Fast et al., 2001, p. 3). Fast et al. have developed a policy analysis framework for assessing policies' economic impact on unpaid caregivers of the elderly but it remains to be seen how relevant this is to the experience of other unpaid caregivers. Consequently, there is both a theoretical and empirical gap in the literature with respect to unpaid caregivers of younger adults with chronic illness, their caregiving-related costs and the economic and non-economic impact of current and potential policies for them.

Lack of Caregiver Voice

The fact that the majority of research in this area has used quantitative methodology has created a situation where the research information available has focused on describing and counting caregivers' costs and policy responses from the perspective of the researcher. As previously noted, there is very limited research documenting caregivers' perceptions of the costs they experience and their attitudes, beliefs and perceptions about policy responses to address their caregiving-related costs. Research that has sought caregivers' perceptions of financial compensation programs has been limited to caregivers in jurisdictions where these programs are available and those caregivers who have utilized the programs. The one exception to this is the one item on the 1996 GSS that asked caregivers which services they would find helpful. Financial support received the most frequent, positive response to this question. Given the persistent finding of underutilization of other caregiver services and research evidence that service use is linked to caregivers' attitudes, beliefs and perceptions, this is a significant gap. This lack of knowledge also has implications for the development and implementation of a successful policy response in an area where the Canadian public policy response has been very limited to date.

Lack of Gender-Sensitive Research and Analysis

A number of authors have noted the lack of gender-sensitive research and analysis in the caregiving literature (e.g., Fast & Keating, 2000; Hooyman & Gonyea, 1995; Morris, 2001). Most of the research literature reviewed presented research on caregiving-related costs and/or the impact of and perception of financial compensation policies without any gender-based analysis. According to Morris (2001), "the majority of home and community care literature does not take gender into account, apart from occasionally pointing out that most family caregivers are women" (p. 48). Important exceptions include reports on the analysis of the 1996 and 2002 GSS that highlighted gender differences in a number of important areas particularly with respect to the consequences of caregiving (Cranswick, 1997, 2003; Keating et al., 1999; Stobert & Cranswick, 2004). Since these data are only from unpaid eldercare caregivers, researchers have acknowledged the need for further research to develop our knowledge about "gender differences among caregivers to other adults in need" (Fast & Keating, 2000).

Contribution of This Study

Fast and Keating (2000) propose that an important question for future research is "How do the provision of informal care, and the needs of informal care caregivers, vary across population groups and conditions?" (p. 18). A primary contribution of this research study was to explore and document the experience and perceptions of unpaid caregivers of younger adult family members living with chronic illness and/or long-term physical disabilities. This is a group of caregivers that is significantly underrepresented in the caregiving literature generally and in research on caregiving-related costs specifically.

Research on caregivers' use of services designed to meet their needs highlights the importance of understanding the complexity of caregivers' experiences and their attitudes, beliefs and perceptions regarding caregiving-related costs in order to inform policy development and implementation. This study provides some important insights in this regard.

The use of qualitative methodology and in-depth interviews with caregivers adds to the largely quantitative research that is already available. It is also the methodology best suited to an in-depth exploration of caregivers' experiences, attitudes, beliefs and perceptions regarding their caregiving role and caregiving-related costs.

Additionally, Fast and Keating (2000) acknowledge the need to bring forward the voices of caregivers and other community stakeholders in caregiving research "given the nature of policy reform, which increasingly is emphasizing community care over institutional care" (p. 20). Harlton, Keating and Fast's (1998) study of stakeholder perspectives regarding eldercare policy and practice issues highlighted the importance of understanding the potentially varied perspectives of stakeholders involved in policy discourse. They found that stakeholders agreed that the purpose of eldercare policy was to enhance seniors' independence but there were significant differences of opinion about which types of services and service providers (i.e., public provision versus provision by family) would best achieve this purpose. For example, policy-makers favoured provision of services by family members while care receivers and other stakeholders emphasized the importance of the availability of public service delivery.

Up to this point, the voice of unpaid caregivers of younger adult family members living with chronic illness and/or physical disabilities specifically has been largely absent from both research and policy discourse on public policy responses to the economic and non-economic consequences of unpaid caregiving. This study provided a forum for the expression of these caregivers' voices.

CHAPTER THREE

METHODOLOGY

Based on the preceding literature review, it was determined that the focus and purpose of this research study would be to develop more in-depth knowledge about how women who are unpaid family caregivers for younger adult family members with chronic illness and/or long-term disability describe the costs they experience as a result of their unpaid caregiving responsibilities and the meaning these costs have for them in their everyday lives.

Feminist Paradigm

Out of recognition of the gendered nature of unpaid caregiving, feminist theory on caregiving as well as this writer's feminist worldview principles of feminist research were incorporated into this research study.

With respect to the research design, this meant that the sampling strategy involved recruiting a sample of women only. It was my intention to bring forward the voices of these female caregivers whose voices have not been adequately documented in the current literature. Consequently, the study design included the application of a gender lens or gender-based analysis involving a process of "integrating questions concerning gender throughout the analysis" (Status of Women Canada, 1996, p. 29).

The four themes in the epistemology and methodology of feminist research identified by Fonow and Cook (1991) were particularly emphasized in this study. These themes are "role of reflexivity", "action orientation", "attention to the affective components of research" and "use of the situation at hand".

The role of reflexivity was incorporated into this study in two primary ways identified by Fonow and Cook (1991). First, the identification of a methodology that would facilitate a gender-sensitive approach had been a primary consideration in decisions regarding the research design for this study. This is consistent with Fonow and Cook's perspective that reflexivity means "the tendency of feminist researchers to reflect upon, examine critically, and explore analytically the nature of the research process" including "the assumptions about gender relations underlying the conduct of inquiry (p. 2). Second, I was cognizant that this study could have a "consciousness-raising effect" on the participants especially if they have not previously had the opportunity to reflect on their experience as unpaid caregivers and the caregiving-related costs that they are experiencing. In fact, when recontacted regarding the validity check, one participant emphasized how being involved in the research study had provided her with an opportunity to reflect on her caregiving experience. As a result, approximately one year after the interview, she suggested that she was "not as vulnerable" because she is always questioning and not just accepting things related to her husband's care and her caregiving role. Kirby and McKenna (1989) encourage the use of this type of approach that "will enable people to identify and examine how living on the margins affects their lives, their opportunities, the way they think and act" (p. 64).

This study was also intended to have an "action orientation" because I am interested in making connections between this research and the ongoing policy discourse regarding public policy responses to unpaid caregivers' negative economic and non-economic consequences. As a social worker engaged in both volunteer and paid work in this area, I hope to find opportunities to bring forward the findings from this study and the related policy implications. This approach was consistent with Kirby and McKenna's (1989) recommendation that research methods consider the use of the findings beyond the study itself and be "grounded in a political awareness of the need for change" (p. 63).

The methodology was selected for this study based on its ability to yield research data that reflected the complexity of caregivers' experience on both practical and emotional levels. The affective dimensions of the women's caregiving experience were certainly evident in their individual stories and the themes identified in the findings chapter. Fonow and Cook (1991) identify this type of attention to affective dimensions as a feature of feminist epistemology and feminist research.

Finally, this research was conducted in a manner that enabled caregivers to share their experiences in a way that facilitates the study of "the taken-for-granted, mundane features of everyday life" (Fonow & Cook, 1991, p. 11). The qualitative research design enabled the women to provide detailed examples of their daily caregiving realities. This approach was very important to this study of unpaid caregiving because "for women, these routine aspects of everyday life help to sustain gender inequality" (p. 11).

Qualitative Research Methodology

Rationale

Qualitative research methodology was identified as being most appropriate for this research study. Maxwell (1998) advises that qualitative studies are useful for research studies with the intended purpose of:

> Understanding the meaning, for participants in the study, of the events, situations, and actions they are involved with, and of the accounts that they give of their lives and experiences…how the participants make sense of these, and how their understandings influence their behavior. (p. 75)

Maxwell (1998) also proposes that qualitative research can contribute to "understanding the particular context within which the participants act, and the influence this context has on their actions" (p. 75). This study has yielded findings in both of these areas by highlighting unpaid caregivers' experience and the meaning of this experience for them as well as the related implications for the policy, practice and social service administration contexts.

The use of qualitative methodology in this study is also supported by Fast and Keating's (2000) recommendation that both qualitative and quantitative methods are needed in addressing unpaid caregiving research questions. Their rationale for this recommendation centres around the fact that "there is great variability in how much is known about the various aspects of the phenomenon in question" (p. 20). The caregiving-related costs experienced by unpaid caregivers of younger adults with chronic illness and physical disabilities required more in-depth exploration through qualitative research methodology because very little is known about this group of caregivers and this aspect of their experience. In my opinion, this approach was particularly warranted due to the issue of caregivers' underutilization of services and policies intended to benefit them.

Interpretive Phenomenology

Interpretive phenomenology was selected as the qualitative research strategy that informed the research design for this study. Benner (1994a) and Creswell (1998) are two authors who acknowledge the usefulness of phenomenology in understanding phenomena and experiences related to caring.

According to Benner (1994b), in the tradition of interpretive phenomenology, "the interpretative researcher creates a dialogue between practical concerns and lived experience through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds" (p. 99). Similarly, Creswell (1998) describes phenomenology as "an approach to studying the problem that includes entering the field of perception of participants, seeing how they experience, live and display the phenomenon; and looking for the meaning of participants' experiences" (p. 31). Phenomenological studies emphasize "lived experience" or "the importance of individual experiences of people as conscious human beings" (Creswell, 1998, p. 236). Consequently, this study focused on describing and understanding the daily life experiences of a small group of unpaid caregivers.

Furthermore, Benner (1994b) suggests that interpretive phenomenology can contribute to public policy through "its power to make the concerns, voice, habits, and practices of people visible and in recommending public policy that is attentive to differences and cultural concerns" (p. 123). Therefore, this approach was consistent with the focus and purpose of this study as previously described.

The theory of interpretive phenomenology guided all aspects of the research design including the formulation of the study's research questions, selection of data gathering strategies and data analysis procedures.

The Study

The Participants

This study focused on a subset of the general population of unpaid caregivers, those women who provide unpaid caregiving for adult family members with chronic disease and/or long-term disabilities of a predominantly physical nature. Defining a more limited population for this study was warranted by gaps in the current literature as well as the recognition that caregiving tasks and responsibilities can vary. Cranswick (1997) acknowledges the variability in caregiving situations and concludes that "the help needed by an elderly parent may be quite different than that required by a child with a developmental disability or by a terminally ill friend or relative" (p. 4). Hooyman and Gonyea (1995) also propose that differences such as the nature and degree of disability as well as the timing of the onset of disability and the caregiving role can have an impact on the intensity and duration of family caregiving (p. 125). The women who participated in this study identified a similar range of factors that they felt had particular effects on aspects of their caregiving experience that differed from the experiences of other caregivers. These factors, highlighted in the next chapter, support the original premise that there is a need to better understand the experiences of this particular group of caregivers since caregiving policy development to date has been largely informed by data from caregivers of seniors.

For the purposes of this study, Lubkin's (1990) definition of chronic illness was utilized to identify care receiver populations and subsequently caregivers for the study sample. Lubkin defined chronic illness as "the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6). Additionally, the definition of disability utilized in the 2001 Participation and Activity Limitation Survey was also employed to operationally define disability for the purposes of identifying potential caregiver participants for this study. Disability is defined as "activity limitation or participation restriction associated with a physical or mental health condition or problem" (Social Development Canada, 2004,

p. 1). At the study design stage, it was anticipated that caregivers of individuals living with cerebral palsy, arthritis, diabetes, multiple sclerosis, kidney disease and potentially other types of chronic diseases or disabilities would participate in the study. The final sample included caregivers who were providing care to individuals with cerebral palsy, Huntington Disease, muscular dystrophy, Parkinson's disease and post-stroke disabilities.

In consultation with thesis advisor, Dr. Lyn Ferguson, it was decided that I would be unable to include caregivers of people with multiple sclerosis in the study due the nature of my employment with the MS Society of Canada. My role as project manager for a caregiver funding pilot project included making funding eligibility and approval decisions. Unfortunately, this is a significant group within the larger population of younger adults with chronic illness and physical disabilities and excluded some caregivers from the study who might otherwise have been interested in participating.

Sampling and Recruitment

A purposeful sampling strategy was used in order to recruit a sample of women who shared the experience of providing unpaid caregiving for an adult family member between the ages of 21 and 55 years who is living with a chronic disease or long-term physical disabilities.

The rationale for limiting the caregivers included in the study by the age of the care receivers for whom they provide care was to ensure that the population in the study is distinguished from both caregivers for the elderly or for children and adolescents with chronic illness and/or disability. In the end, two of the care receivers were in their sixties. However, in consultation with my thesis advisor, their caregiving experiences were determined to fall within the scope of the study. In both cases, the women considered their care receivers to be younger than most individuals experiencing their type or degree of illness or disability. Additionally, the onset of the care receivers' illness or disability and the women's subsequent caregiving roles occurred prior to or very shortly after age 55. The earlier age of onset of the care receivers' current condition and the fact that the caregivers self-identified as caring for someone whom they considered to be a younger adult were considered in deciding to include these women in the study sample. In retrospect, it may have been beneficial to define the recruitment criteria as women providing unpaid care for an adult family member with a chronic illness or disability over the age of 21 with an onset of the condition prior to age 65.

Additionally, given the unique issues facing caregivers of adults with mental illness and dementia described by Biegel et al. (1991) and others, this study focused largely on caregivers for individuals who are primarily experiencing physical limitations and/or disabilities. However, a number of the care receivers were also simultaneously experiencing cognitive or intellectual impairments.

Furthermore, only individuals who identified themselves as primary caregivers or the person who is primarily responsible for the care and support of the care receiver were included in the study.

Finally, Maxwell (1998) suggests that purposeful sampling is often used to ensure heterogeneity so that the sample and conclusions represent a range of variation (p. 87). In the identification of organizations to assist in the recruitment process, efforts were made to try to ensure that caregivers of individuals with a range of different conditions and with diversity in terms of ethnic background and other sociodemographic characteristics were invited to participate in the study. This is particularly important given evidence from previous research of the importance and differential impact of some of these factors on the caregiving experience (Baines et al., 1998; Fast et al., 2001; Tirrito & Nathanson, 1994).

Study recruitment was ongoing between January and December, 2004. During that 12 month time period, various recruitment efforts were undertaken.

Several chronic disease, disability, community service and home care provider organizations were contacted and provided with study information in the form of information memoranda for staff, newsletter/website announcements, and/or posters, leaflets and letters for distribution to potential study participants (See Appendix A for copies of the recruitment materials). The organizations that were contacted and participated in the recruitment process included the ALS Society, Arthritis Society, Cerebral Palsy Association, Community Respite Service, Epilepsy Association, Huntington Disease Resource Centre, Parkinson Society, Muscular Dystrophy Association, Stroke Recovery Association, Society for Manitobans with Disabilities, Aboriginal Health and Wellness Centre, Jewish Child and Family Services, Winnipeg Regional Health Authority Home Care Program. Some of these organizations were contacted on a few occasions with requests to continue to share the study information with potential participants.

Additionally, study recruitment information was provided to social workers at the Health Sciences Centre and Misericordia Health Centre. Some adult day programs were also contacted with recruitment materials provided to staff at two programs that have contact with caregivers who would fall within the scope of the study. Posters were also displayed at several community health clinics around Winnipeg. Recruitment materials were provided and/or phone contact was made with a total of 13 private and not-for-profit home care provider organizations. Unfortunately, most of these organizations indicated that they did not have a process for distributing the study information to caregivers. Attempts were also made to identify additional participants through the snowball sampling technique. All women who were interviewed were asked to share recruitment material and/or my contact information with other female caregivers who they thought might be interested in participating. However, this strategy did not lead to the identification of any additional participants.

In all cases, the recruitment materials directed caregivers who had questions about the study and/or were interested in participating to contact this researcher directly. This was done in order to eliminate any potential for perceived or real pressure or threat of consequences for caregivers related to their participation in the study and their ongoing service from the various organizations. In an effort to preserve confidentiality, staff members of the various organizations were not advised if someone known to their organization chose to participate in the study.

Sample Size

In accordance with Benner's (1994b) advice that sample size in interpretive phenomenological studies will be limited by the anticipated size of the text generated during data collection and the number of researchers available to do the analysis, a relatively small sample size of approximately 8-10 caregivers was projected at the beginning of the study. In this study, there was a single researcher conducting all data collection interviews and data analysis.

Despite the range of recruitment strategies utilized, the study concluded with a sample of seven women. In the use of an interpretive phenomenological approach, it is recommended that a sample size be projected at the beginning of the study but that this sample size may be adjusted as warranted based on the quality of data gathered (Benner, 1994b). The ongoing data analysis conducted throughout the project justified the conclusion of the study with a sample of only seven women due to the fact that the quality and amount of data were sufficient to address the research questions posed for the study. The seven interviews varied in length from 1¼ hours to 2¾ hours with five of the interviews having a duration of more than 2 hours. All seven interviews were professionally transcribed and have yielding a total of more than 250 pages of data.

The Interview Process

Due to the fact that qualitative research involves working primarily inductively from the data up, Rothery, Tutty and Grinnell (1996) suggest that qualitative researchers "do not require rigorously defined questions and hypotheses before they can get to work" (p. 12). Similarly, Benner (1994b) proposes that:

> The design of interpretive research is created by establishing lines of inquiry and considering how to study both smooth functioning and breakdown situations... Lines of inquiry, while phrased as questions, should be sufficiently broad and open so that they can be altered, shaped and examined by the dialogue with the actual text. (p. 106)

Additionally, in a phenomenological study, Creswell (1998) proposes that the researcher starts with an orienting framework or philosophical perspective that focuses the research towards studying the meaning of experiences for individuals. With this in mind, the research questions that were developed to guide this study were:

- How do female unpaid caregivers of adults aged 21-55 years living with chronic illness and/or long-term physical disabilities describe the caregiving-related costs they experience?
- What do these costs mean to these caregivers?

The data collection instrument for this study consisted of face-to-face semi-structured interviews with female unpaid caregivers.

According to Kirby and McKenna (1989), "intensive interviews seek to discover information about the experiences of the interviewee in the language and gesture of that person" (p. 68). Semi-structured interviews were used to facilitate a balance between the need for open-ended responses that capture the essence of the caregivers' experiences in their own words with the need to gather data that is not too general and focuses on the original research questions. Rogers and Bouey (1996) describe semi-structured or guided interviews as using some predetermined questions or key words as a guide for the interview while asking questions in an open-ended manner and at a time that fits with the narrative of the respondents. Kirby and McKenna (1989) also recommend the development of an interview guide with a series of questions organized around the central research questions.

The research questions previously identified were used as a framework for the development of a semi-structured interview guide that was used in all the study interviews (Appendix B). The development of the interview guide took into account Benner's (1994b) recommendation that questions be asked in conversational language and in a manner that facilitates narrative storytelling rather than a more structured question and answer dialogue. It has been advised that narrative accounts are best generated when the interviewer actively and intently listens with as little interruption as possible while still using probing questions to ask for clarification or additional detail (Benner, 1994b). According to Benner, “narrative accounts are essential to gain access to the participants’ ways of understanding and structuring the situation” (p. 118).

Consistent with this advice and the interpretive phenomenological research methodology, the interview guide provided a framework for each of the interviews but the questions were not necessarily asked in the same order or with precisely the same wording in each interview. Furthermore, if I felt that the woman had spontaneously addressed one or more of the questions as her narrative unfolded, I did not directly ask the question but only probed for clarification or more in-depth understanding.

The interview guide also included some closed-ended, structured questions to gather sociodemographic information relating to caregiver and care receiver characteristics, socioeconomic status and other demographic information in order to create a profile of the caregivers involved in the study. In order to not interrupt the flow of the caregivers’ stories, these questions were only asked directly if the answers did not emerge in the course of the caregivers’ narrative accounts.

All of the interviews were conducted face-to-face and were arranged at times and locations chosen by the participants. Four of the interviews were conducted in the participants’ homes, two of the interviews took place in an office space organized by the researcher and the final interview took place in the caregivers’ own office at her place of employment.

Written informed consent was obtained from all study participants with respect to both their agreement to participate in the study and for audiotaping of their interview for the purposes of producing a verbatim written transcript to be used in data analysis (a copy of the consent form is provided in Appendix C). Additionally, when a participant became emotionally upset and/or identified some unmet needs for which resources are available, a brief listing of relevant community and government resources was provided following the interview for the caregiver's information and voluntary follow-up (a copy of this resource list is provided in Appendix D).

The women who participated in the study were willing and often eager to share their stories. For the most part, they were quite open and candid in sharing both their positive and negative experiences. In some cases, the women's narratives of their experiences quite naturally covered the questions outlined in the semi-structured interview guide with only probing and relatively little direct questioning by the researcher. There was an emotional intensity to most of the interviews too. The women talked about the difficult emotions they experience in response to the care receivers' condition and the difficulties they have encountered in having their own and the care receivers' needs adequately met.

Most of the women also talked about being motivated to participate in this study in the hope that their contributions derived from their own caregiving experience might be able to benefit other caregivers. Some of the women also expressed their desire to see the study findings used to influence positive change in the policy and practice arenas that they identified as affecting their caregiving realities. The women's interest in the study was also evident in the fact that all of them were interested in participating in a member validity check.

Strengths and Limitations

The use of qualitative research methodology within a feminist paradigm facilitated an in-depth exploration of a small group of women's caregiving experience including their caregiving-related costs. This provided the opportunity to develop a thorough understanding of these women's experiences and the meaning and implications that they have for their lives. Furthermore, this understanding also contributed to the identification of some concrete implications and recommendations for the policy, practice and social service administration contexts within which these women's caregiving realities are situated.

At the same time, it must be acknowledged that there are also some limitations with respect to the potential transferability of the study's findings to other caregivers who provide care to different care receivers with different needs and under different circumstances.

Firstly, while the decision to recruit a sample of women only is consistent with the gender-sensitive approach required by the application of the feminist paradigm, the exclusion of the voices of male caregivers is one of the limitations of this study. In keeping with a gender sensitive approach, it will be important not to assume that the voices of the women in this study can accurately represent the experience and perceptions of male caregivers. Similarly, although there was some diversity in the women's ethnic backgrounds, none of the women identified themselves as a member of a visible minority group. This researcher had hoped for greater diversity in this regard but was unsuccessful in recruiting women from visible minority groups including Aboriginal women. Finally, all of the study participants were recruited through their contact with a chronic disease or disability organization in the voluntary sector either through a website or newsletter advertisement or through a recruitment letter. Consequently, there is some concern that the women in the sample may differ in some way from other caregivers who are not in contact with these organizations. However, the contextual factors that the women described as affecting their caregiving role and the elements of the caregiving role that they identified are consistent with previous research with caregivers providing care to other care receiver populations (e.g., elder care). This is an indication that the study's findings are potentially relevant to these other caregivers as well.

Analysis

Qualitative Data

All seven interviews were transcribed by a professional transcriptionist and the resulting transcripts were the basis for the qualitative data analysis.

Coleman and Unrau (1996) state that "the central purpose of analysis in qualitative studies is to sift, sort and organize the masses of information acquired during data collection in such a way that the themes and interpretations that emerge from the process address the original research problem(s)" (p. 90). Creswell (1998) suggests that this is accomplished by utilizing a combination of some common data analysis strategies used in qualitative research regardless of the specific approach and then some strategies particular to phenomenology. The data analysis plan for this study utilized both more generic strategies and those from the tradition of phenomenology.

Interviews were sent for transcription as soon as possible following each interview. Data analysis was conducted on an ongoing basis over the 12 month period in which data collection occurred. Following each interview, I recorded my immediate observations of the interview itself as well as of the major points or issues emphasized by the woman being interviewed. This was done in order to identify both ways to improve future interviews and potential themes for consideration later in the data analysis process. For example, this process of reflection following the first couple of interviews led to the identification of the need to make note of and/or inquire about the role economic considerations played in the women's caregiving-related decision-making. Consequently, this approach was consistent with Benner's (1994) advice that the data analysis process should begin with the first interview so that the researcher can pursue "lines of questioning" that arise from the analysis in future interviews.

Throughout the data analysis process, I also maintained documentation related to all aspects and stages as well as my own thoughts and conclusions that emerged.

Prior to any further data analysis, I wrote a full description of my experience of the phenomenon of unpaid caregiving and caregiving-related costs and my related assumptions. This bracketing was done to clearly identify the bias that I was bringing to the data analysis process. The description of the researcher's experience of unpaid caregiving and related expectations that was presented in Chapter One outlines the biases that I brought to this work and that had to be bracketed in the analysis process.

Once a transcript was prepared, data analysis proceeded with a global review of the text of the written transcript from the interview. Then the transcript was read a second time and notes on my initial impressions were made in the margin of a printed copy of the transcript.

The next step involved writing the initial findings into the form of reflective notes or meaning unit summaries for each of the interviews. In accordance with the phenomenological tradition, the intent of these summaries was to highlight key aspects of the respondents' experience and the meaning of this experience for them. In reviewing the text, I was particularly looking for statements about how individuals are experiencing their caregiving role generally and their caregiving-related costs specifically. According to Benner (1994b), "the interpreter seeks to identify the everyday reasoning and associations made by the participants" (p. 113). The intent was to develop a list of "nonrepetitive, nonoverlapping statements" (p. 113).

Then the process of reducing the data was initiated by identifying the common categories emerging across the interviews. Once all of the interviews had been completed, these categories were organized into a handwritten visual display and outline. This was done in order to summarize the analysis to that point and look for additional interconnections and overlap between the categories. The text from each of the interviews was then sorted into these categories with categories being revised and new ones added as the data analysis proceeded. After several revisions and attempts to appropriately categorize the data, several key themes emerged.

Then the next level of analysis consisted of "interpretive commentary" where "the interpreter moves to a level of commentary that considers the first level of presentation from various interpretive vantage points" (Benner, 1994b, p. 101). This involved writing a description of the women's experience with each of the key themes including specific examples of what happened and how they described and made sense of it. At this stage, I also included interpretative commentary to clarify the meanings of the participants' voices as they were emerging through the data analysis process. Creswell (1998) describes this as "constructing a description of how the phenomenon was experienced"

(p. 150). The process of writing the description and commentary on the key themes and meaning units also resulted in the identification of additional areas of overlap and interconnection. This led to further revision through relabelling and reducing the number of key themes and highlighting the relevant interconnections in the descriptions and commentary. By reducing the data to descriptions of several themes that capture the common or shared experience of all of the participants, "essential invariant structure or essence" of the caregivers' experiences was documented (Creswell, 1998).

According to Benner (1994a), understanding is the goal of this approach rather than "explanation or prediction through causal laws and formal theoretical propositions" (xiv-xv). Consequently, the consideration of the theoretical connections of the emerging findings did not explicitly inform the data analysis process and in fact, was not undertaken until the end of the data analysis process.

Quantitative Data

The purpose of the quantitative analysis of the sociodemographic information collected as a component of the caregiver interviews was to present a summarized profile of the caregivers involved in the study. Although the information provided was quantitative in nature, statistical analysis was neither appropriate nor possible for most items. For many items, only a sum total of responses could be presented (e.g., identification as a visible minority, care receiver gender, marital status, employment status). Other items were modeled after similar sociodemographic questions in other research (Department of Sociology, University of Manitoba, 1989) and provided response categories with a numerical range (e.g., income, caregiver and care receiver ages).

Consequently, for these items, only a sum total of responses for each category is included in the profile.

The questions related to the length of time since the care receivers' diagnosis and the length of time the caregiver has been in their caregiving role were also presented in this manner in the interview guide. However, for these two questions, the caregivers each provided a precise number of years in the context of telling their caregiving story. Consequently, basic descriptive statistics of minimum, maximum and mean are presented for these two characteristics of the profile presented in the findings chapter.

Research Quality Considerations

Lincoln (1995) suggests that the quality of a qualitative research study should be evaluated by assessing the "trustworthiness" of research in a manner that considers both methodological and ethical issues.

The principles of the feminist paradigm outlined earlier in this chapter provided the ethical framework for this study. The involvement of participants beyond the research interview (i.e., the member validity check) combined with the intention to apply the research results to influence ongoing practice and policy discussions are factors that contribute to the study's quality (Lincoln, 1995).

The credibility of explanations generated, researcher bias and reactivity are all issues related to the validity of this qualitative study that must be addressed.

According to Janesick (2000), "validity in qualitative research has to do with description and explanation and whether or not the explanation fits the description. In other words, is the explanation credible?" (p. 393). Janesick, Creswell (1998) and Coleman and Unrau (1996) suggest that validity can be tested by doing a cross-check.

This involves having an outsider review transcripts to see if they can derive similar meaning units and explanations from the same data. My thesis advisor, Dr. Lyn Ferguson, provided this cross-check for two of the interviews in this study. She reviewed the transcripts as well as the meaning unit summary for each of these interviews. The results of her review concurred with the themes derived from my analysis. Additionally, she provided suggestions regarding the style of the presentation of the themes in order to more effectively enhance the report, particularly with respect to the emotional tone of some of the findings.

As recommended by Creswell (1998), Maxwell (1998), and Coleman and Unrau (1996), member checking was also utilized to solicit the views of some study participants regarding the data and the conclusions drawn. This was intended to assist in ruling out the possibility that participants' meaning has been misinterpreted and provides evidence of validity (Maxwell, 1998, p. 94). All participants were asked at the time of the interview if they would be interested in participating in this process and all seven women indicated that they were interested. Each of the women was contacted again as the data analysis process was concluded and reiterated their interest in participating in the validity check. They were each mailed a copy of the meaning units summary derived from the analysis of their interview as well as a point form overview or outline of the key themes emerging from the study overall. The participants provided feedback by telephone regarding their perception of the accuracy of the meaning unit summary based on their experience and recollection of the interview. They were also invited to ask questions or comment on a findings overview. This process was very useful as some of the women further clarified aspects of their experience captured in the meaning units and/or reemphasized the importance of some of the key themes outlined in the findings overview. Overall, the women confirmed that the analysis and key themes were accurate and consistent with their experience.

Researcher bias is another consideration that had to be addressed in this study. Maxwell (1998) defines bias as "ways in which data collection or analysis are distorted by the researcher's theory, values or preconceptions" (p. 92). He suggests that it is neither possible nor desirable to eliminate or control for researcher bias. Instead in qualitative research the main concern is "with understanding how a *particular* researcher's values influence the conduct and conclusions of the study" (p. 92). I have previously described my personal worldview as being consistent with the feminist paradigm. I have also acknowledged how this has shaped my interest in the research topic as well as decisions related to research methodology and design. From the perspective of interpretative phenomenology as a research strategy, "the researcher's own background practical knowledge is considered as part of the perceptual lens, enabling skills and limits for conducting the study" (Benner, 1994b, p. 103). The data analysis process included a clear documentation of my own experience with unpaid caregiving and caregiving-related costs so that researcher bias could be readily identified and acknowledged. This in turn facilitated the "bracketing" of my own views so that the analysis could rely on the respondent's statements (Benner, 1994; Creswell, 1998). As key themes and meaning units were identified during the analysis process, the original transcripts and exact wording of participants' statements were repeatedly reviewed to ensure that findings were based directly on the participants' own descriptions and were not a result of researcher bias. The participants' validity check also helped to reconfirm this.

Researcher bias was also addressed during data collection and analysis by engaging in reflexivity and regular reflection independently and through periodic discussions with my advisor regarding the study's progress and my personal reactions to my direct interaction with the participants and the themes emerging during data analysis. This was particularly important due to the emotional nature of some the interviews. An example of a personal reaction that was reflected upon and resolved through discussion with my advisor was my concerns related to contacting one of the participants for the member validity check. Despite the fact that she had indicated that she wanted to participate, I was reluctant to contact her because I thought that the process might add additional burden or pain during a particularly difficult time in her caregiving journey. Once I had worked through my own emotions and reactions, I was able to contact the woman, remind her of the emotional nature of the material that she would be reviewing and appropriately leave the decision regarding her participation in her hands. According to Lincoln (1995), "such reflexivity is absolutely required to understand one's psychological and emotional states before, during, and after the research experience" (p. 283).

Finally, reactivity is another threat to validity that involves the influence the researcher has on the study participants and their responses in the context of the study. This is particularly relevant given that face-to-face interviews were used for data collection in this study. Maxwell (1998) concludes that "the interviewer has a powerful and inescapable influence on the data collected; what the interviewee says is *always* a function of the interviewer and the interview situation" (p. 92). I tried to minimize reactivity through techniques such as avoiding leading questions. I also carefully reviewed transcripts to identify any aspects of the interview that may have increased reactivity. This included identifying new ways of posing questions in future interviews to further reduce the potential for reactivity. During data analysis, only data that emerged from or could be verified through the women's detailed narratives of their experiences were included in order to minimize any researcher bias or reactivity resulting from the researcher's questions. I also followed Benner's (1994b) recommendations regarding conducting the interview in a manner that facilitates the development of a narrative with minimal interruptions and questions from the interviewer. Given the interest with which these women approached these interviews, this occurred quite naturally in almost all the interviews.

Summary

This study was designed to illuminate the voices, experiences and caregiving-related costs of women who are unpaid caregivers for younger adults living with chronic illness and/or disabilities of a primarily physical nature.

The qualitative methodology of interpretive phenomenology was selected in order to provide an opportunity for an in-depth exploration and increased understanding of these women's caregiving-related costs with a particular emphasis on the meaning these costs have for them in their everyday lives.

The application of a feminist theoretical paradigm informed the selection of a sample of women only. It also guided the development of a semi-structured interview guide that facilitated the participants' identification of both the emotional and practical aspects of their daily caregiving realities including economic and non-economic costs. The methodology also provided an opportunity for caregivers to describe their experiences in a holistic manner that captured the complexity of their situation and the influence of both the micro and macro level contexts within which their caregiving experience occurred.

Careful consideration was also given to validity and reliability issues in the design and conduct of this study in order to increase the strength and relevance of the findings for influencing positive changes in support of unpaid caregivers.

CHAPTER FOUR

FINDINGS

The study findings are presented in this chapter beginning with an overview profile of the study participants and their caregiving situations. The next section outlines the findings with respect to the first research question of how female unpaid caregivers of younger adults living with chronic illness and/or long-term physical disabilities describe their caregiving-related costs. The chapter concludes with a discussion of the key themes emerging from the women's stories that address the second research question of the meaning their caregiving costs have for these women.

The Women and Their Caregiving Situations

This study was focused on a subset of the general population of unpaid caregivers, those women who provide unpaid caregiving for adult family members with chronic disease and/or long-term disabilities of a predominantly physical nature. The multiple sources and methods used in the previously outlined recruitment strategy were intended to recruit a study sample that reflected as much of the diversity of caregivers and caregiving situations as possible given the limitations of small sample size. Fast et al. (2001) have identified characteristics that research has indicated are important differences in caregiving situations (e.g., presence of children, labour force status, geographic proximity to care receiver, income of care receiver). It was also hoped that the sample would include caregivers who provide varying amounts and types of unpaid caregiving support since these differences could potentially affect their perception of caregiving-related costs. Attempts were also made to recruit women who represent the experience of "lone-parent families headed by women, Aboriginal peoples, members of visible minorities and individuals with disabilities [who] tend to have less income than their peers" and who may consequently experience a greater negative economic impact" (Fast et al., 2001, p. 45).

The final sample of the seven women who were interviewed for this study reflects diversity on most but not all of these characteristics. For example, there were unfortunately no Aboriginal women in the sample. One Aboriginal woman did contact the researcher but was unable to attend the interview and attempts to reschedule were unsuccessful.

The following is an overview profile of the study participants including sociodemographic characteristics of the caregivers and the people they provide care for as well as a description of their caregiving situations.

The Caregivers

Five of the seven women identified themselves as falling within the age category of 50-64 years. One woman was in between the ages of 18-29 years and the final woman was between 65-74 years of age.

With respect to the caregivers' relationship to their care receivers, four of the women are mothers caring for their son or daughter with a chronic illness or disability. The three other women are providing caregiving support to their husband or male partner.

Three of the women are married while another woman is engaged to be married to her common-law partner. All but one of the women who is married or engaged was caring for their male spouse or partner rather than their son or daughter. In other words, only one of the women caring for their son or daughter living with a chronic illness or disability had the support of a male partner in this caregiving role. Two women had been widowed many years ago and had remained single while another woman had been single for more than 20 years following a divorce.

At the time of the interviews, four different types of living arrangements were identified among the participants. Two of the caregivers were currently living alone following the placement of the person for whom they provide care in a long-term care facility. One woman was living with her husband for whom she provides care. There were also two women who were living with their spouse and at least one child. However, their situations varied significantly. In one case, the adult child was the care receiver. Meanwhile, in the other case, the husband was the care receiver and the child was an infant recently born to the caregiver and care receiver. Finally, two women were living with their adult children for whom they were the primary caregivers; one for her daughter and the other for her son.

With respect to location, five of the study participants resided within the City of Winnipeg while the other two participants resided in two different small towns in rural Manitoba.

The women also varied in terms of their current employment status. At the time of the interviews, three of the women were unemployed and not currently looking for employment. Two of these women identified themselves as retired. One of the retired women reported that she had taken early retirement due to her caregiving responsibilities for her husband and aging and ailing parents. The third woman suggested that she was essentially retired because she had been unable to find other employment following the onset of her husband's illness and disability when it became apparent that their early retirement was not going to proceed as planned. Three other women were employed, two full-time and one part-time. The remaining study participant had been employed full-time but was currently on parental leave following the birth of her infant daughter. At the time of the interview, she was beginning to question the feasibility of returning to her previous employment given her combined child care and caregiving responsibilities. In fact, five of the seven women indicated that their caregiving responsibilities had affected their current employment status. The one woman who was working part-time indicated that she had held part-time positions over the years in order to accommodate her caregiving role and her daughter's schedule and needs. Similarly, one of the women indicated that due to her caregiving responsibilities, she had just recently returned to full-time paid employment through a combination of two part-time positions. This was after approximately 20 years of either not working outside the home or working on a very part-time basis.

Six of the seven women responded to questions regarding their current income category and income sources. One woman chose not to answer the income category questions. For the caregivers' own individual gross annual income, all of the women fell into the two lowest income categories. Two women reported earning less than $14,999 and four women reported the income in the category of $15,000-$29,999. According to 2001 census data, this places at least some of the study participants below the median income of $20,469 for all Manitobans aged 25 years and over and $16,602 for Manitoba women aged 25 years and older (Statistics Canada, 2004). This places at least some of the study participants below the median income for Manitobans. Depending upon where the four women fall in the $15,000-$29,999 category, it is possible that the entire sample is below Manitoba's median income. The sources of the women's personal income ranged from Canada Pension Plan retirement pension, Old Age Security, workplace pension plan benefits and/or private investments for the retired women to income from full or part-time employment. One woman's employment income was also currently being supplemented with child support payments from her ex-husband that would continue until her daughter transitioned to a more independent living situation. One woman was receiving Employment Insurance maternity leave benefits at the time of the interview but had previously had income from full-time employment.

Once the income of other family members was taken into account, gross household income was reported as being slightly higher but still relatively low. Four women reported household income between $15,000 to $29,999 and two women reported household income in the category of $30,000-$59,999. The median household income category was $15,000 to $29,999. This means that at least two-thirds of the study participants (i.e., 66.7% of participants responding to this question) had a household income below the median household income of $41,661for Manitobans as reported in the 2001 census (Statistics Canada, 2004). The additional sources of household income identified by participants included care receivers' employment-based disability insurance and/or CPP Disability benefits or care receivers' Income Assistance (i.e., welfare). Beyond this, there were a couple of more unique sources of income. In one case, the family was also living off some proceeds from the sale of a business. Another woman's household income included her husband's income from paid employment and minimal room, board and mileage payments from the Department of Family Services Income Assistance Program for some of her son's expenses.

This sample of female caregivers lacked some diversity in that all study participants were Caucasian. None of the women identified themselves as being a member of a visible minority group except for one woman who suggested that her female gender could qualify her as a visible minority group member. However, there was still some diversity in the women's ethnic backgrounds.

Two of the women reported that both they and their parents were born outside of Canada. One woman emigrated from Italy as a child while the other woman had emigrated from Russia as a young adult. All of the women were fluent in English, although it was a second language for three of the women with two of them indicating that they also still regularly spoke their first language.

In response to the interview guide questions on ethnic background, each of the women identified the ethnic group to which their mothers and fathers belonged with the following groups being identified: German Russian, Ukrainian, Mennonite, Ukrainian/Polish, English/German, French Canadian, Danish, Scottish and Italian.

Regarding their own ethnic identity, five of the women identified themselves as belonging to one of the following ethnic groups: Russian Mennonite, French Canadian, Italian Canadian and "Canadian with a mix of Ukrainian". One woman did not identify an ethnic identity while the seventh woman described herself as having Mennonite heritage but not currently involved in that culture or religion.

When asked if they felt that their ethnic background had had any effect on their caregiving experience, four of the women indicated that there was no effect. One of the other women suggested that her parents participation in a Mennonite cultural and religious community prior to her own birth influenced the values they taught her regarding what it meant to be “a good person”. Two other women reiterated the importance of their respective faiths and religious communities (i.e., Mennonite and French Canadian Catholic) and the positive impact on their caregiving experience.

The Individuals for Whom They Provide Care

Six of the seven care receivers were male including three sons and three male spouses or partners of the women who were caregivers. The one female care receiver was the daughter of her caregiver.

Three care receivers were between the ages of 21-29 years with two being adult children and one being the male partner of the women who were their caregivers. The age of the remaining two adult son care receivers was between 30-39 years old for one and between 40-49 years for the other. The final two care receivers were 63 and 66 years old and were husbands cared for by their wives. These two care receivers fell slightly outside the original age parameters of the study but were included because the caregivers’ self-identified as women providing caregiving support for a younger adult.

There was also some variation in the primary diagnosis that was responsible for the care receivers’ disabilities and care related needs. In four of the seven situations, the care receivers’ disabilities were primarily physical in nature. However, in three situations, there was either cognitive impairment or a diagnosis of an intellectual disability that accompanied the physical impairments.

Three of the care receivers had a diagnosis of cerebral palsy. Two of these young adults had very high physical care needs and were dependent upon wheelchairs and lifts for mobility in addition to having intellectual disabilities. The third person with cerebral palsy required less assistance with physical and personal care but still required some occasional personal care and mobility assistance. The caregiver in this case also provided support with advocacy. A fourth care receiver who had had a stroke was experiencing a range of physical and cognitive impairments.

The other three care receivers had diagnoses of muscular dystrophy, Parkinson's Disease combined with another condition, and Huntington's Disease that to date had resulted in exclusively physical impairments and disabilities.

There was also considerable variation in the length of time that had passed since the care receiver had been diagnosed with their current condition. This period of time ranged from 2 to 44 years with a mean of 17.6 years and a median of 12 years since diagnosis.

The Caregiving Situations

As might be expected, the caregivers' length of time in their caregiving role also varied from 2 to 44 years with a mean of 20.5 years and a median of 20 years. All but one of the women identified themselves as having been a caregiver for the full length of time that the care receiver had been diagnosed with their current condition. The woman who was the exception had just met and became involved with her partner 2½ years ago but he had been diagnosed many years ago. This situation highlights another source of difference in the women's caregiving situations in that there are also differences in the timing between the beginning of their relationship with the care receiver and the initiation of their caregiving role. For three women, their relationship with their care receiver had been well established for many years before these care receivers' diagnosis and the onset of the caregiving role. In three other situations involving mothers caring for their adult children, the onset of the illness or disability had been at birth so the caregiving role had been a feature throughout the relationship.

Another woman identified herself as having been a caregiver for over 30 years now even though the current care receiver was only diagnosed ten years ago. In her case, she had had a serial caregiving experience of providing caregiving support to first her husband and now two sons diagnosed with the same hereditary disease. At one point, prior to the death of one of her sons, she was caring for two of them simultaneously for a period of time. Two other women had also had the experience of simultaneously providing caregiving support to other individuals while caring for the care receiver who was the main focus of the interview. In one case, the woman was caring for her husband and two sets of aging parents, while another woman found herself providing support to her aging mother and episodic support to her daughter for her health concerns for periods of time during her 44 years of being her son's primary caregiver.

All of the women were asked to quantify on average how much time they spent doing caregiver-related activity by responding to a close-ended question that provided response categories ranging from 0-2 hours a day to 24 hours a day. The women generally had difficulty arriving at an estimate of the actual amount of time. Although the question was asked in a quantitative manner, most of the women provided a more qualitative answer whereby they itemized some of their daily caregiving activities or expressed their difficulty in sorting out what was caregiving versus activities related to other roles and responsibilities such as general home maintenance. In the words of one woman, "it's hard to decide where the caregiving ends and where the responsibility for home making and so on [begins] which is part of that". Armstrong and Armstrong (2004) have noted the same difficulty in previous research. They explain the difficulty as follows:

> … counting care time is problematic. Care time is difficult to count in part because it is hard to define and the boundaries are so unclear. This is especially the case when it overlaps in households with other kinds of work, paid or unpaid. (p. 36)

Levine et al. (2003) have also recognized the difficulties inherent in trying to document and quantify caregiving tasks and activities when they occur in the context of personal relationships.

The few women who were able to quantify time spent in some aspects of their caregiving role indicated that they spent between 2 and 10 hours per day in physical caregiving tasks. However, a few of the women emphasized that this was really only one aspect of their caregiving role and that if the mental and emotional aspects were taken into account the number of hours would be considerably higher. In the end, one woman concluded that the only appropriate way to quantify it was as 24 hours a day. She felt that there was not really anytime in the day when she was not her son's caregiver even though she might not be with him or directly providing care to him every minute of the day.

The Women's Description of Their Caregiving-Related Costs

These women did not describe their caregiving-related costs in isolation from their caregiving experience as a whole. In fact, their discussion of costs was very much embedded in their overall caregiving story. Therefore, addressing the first research question of how these women describe their caregiving-related costs requires a presentation of some important aspects of their overall caregiving experience as described by the women. Through their narratives, the women highlighted a range of factors that provide important background for understanding their description of their caregiving-related costs. The relevant factors presented here include a description of the important elements and activities of their caregiving role and contextual factors affecting the caregiving experience and caregiving-related costs. These contextual factors include those related to characteristics of the care receiver and their condition as well as internal and external sources of support that influence the caregiving experience and related costs. This section concludes with a presentation of the women's description of their economic and non-economic caregiving costs.

Important Elements of the Caregiving Role and Experience

A general description of their role was used as an entry point for interview participants to begin telling their caregiving story. These caregivers' descriptions of their caregiving roles are consistent with previous research that has documented the fact that caregivers generally take on a multifaceted role involving a range of caregiving tasks and activities (Cranswick, 1997; Fast & Keating, 2000; Heron, 1998; Hooyman & Gonyea, 1995).

All the women identified themselves as engaging in physical caregiving activities. These activities included assisting with or fully providing the care receiver's personal care such as bathing, toileting, dressing and feeding/food preparation as well as assisting with mobility through lifting and transfers and pushing a wheelchair. However, all of the women also particularly emphasized the emotional and mental aspects of caregiving as central to their role. According to one woman, "it's really the emotional, mental piece".

All of the women's descriptions of the mental aspects of the caregiving role included seeking out information about the care receiver's condition and available services, coordinating care, including formal services, for the care receiver and advocating for access to resources to address the care receiver's and their own needs. The women used phrases like "learning to be the squeaky wheel", "going through the chain of command" and "we have to fight all the time for things" to describe their ongoing advocacy role with respect to accessing adequate supports. Three of the seven caregivers also emphasized their role in proactively facilitating short and long-term planning for the care receiver's changing needs. Five of the seven women talked about having to educate others (i.e., school staff and students and home care service providers) about the care receiver's needs and abilities. Four of the seven caregivers talked about taking responsibility for ensuring that the care receiver continues to be mentally stimulated in accordance with his or her abilities in order to maximize their potential and functioning. Two of the seven caregivers also talked about the mental task of deciphering the care receiver's verbal communication and interpreting it for others. All of the women identified their caregiving role as involving the need to be physically present or to ensure that someone else is in order to provide general supervision or monitoring to ensure the care receiver's safety. In most cases, the care receiver could not be left alone at all but two of the care receivers could be left alone for short periods of time.

These women's descriptions of the emotional aspects of the caregiving role included having to manage and cope with the difficult emotions that can arise from the realities of their situations. Some of the women emphasized the pain involved in watching someone you love struggle as a result of changes in their functional abilities. Other emotional aspects that were identified included dealing with their frustration over lack of support or resources to meet care receivers' and their own needs, dealing with the care receiver's anger and other difficult emotions and behaviour, and feeling overwhelmed by the demands of the multitude of caregiving responsibilities faced on a daily basis. One woman expressed the opinion that "I think the physical part is maybe 10%, the emotional is 90%".

The experience of two of the women whose family members were relatively recently placed in a long term care facility also highlights the fact that the mental and emotional aspects of the caregiving role continue to be demanding even when the primary, day-to-day responsibility for the physical caregiving tasks shifts to formal service providers.

Two other women also found this to be the case when home care service providers assumed some of the physical caregiving tasks. Even when these services are in place, they have an ongoing role in coordinating, monitoring and educating in order to ensure that the service is adequately meeting the care receivers' needs. This in turn affects the degree of relief that the caregiver experiences when someone else takes on aspects of this care.

Overall, these women described their caregiving experience as having some difficult and challenging aspects but also some positive aspects. One woman summarized her experience as "I mean it's hard. It's hard in one way, yea… It's been difficult but has blessed too…" Benner and Wrubel's (1989) research has also highlighted this duality in caregiving experiences since "involvement and caring may lead one to experience loss and pain, but they also make joy and fulfillment possible" (p. 3). Morris (2004) indicates that previous research studies have also reported that women find the work rewarding. The more negative aspects of the women's experiences are captured in the discussion of caregiving-related costs presented later. However, it is also important to highlight the positive aspects identified by six of the seven caregivers in the study.

The primary positive aspect described by these women was the fact that they had highly positive or improved relationships with the care receiver and/or other family members. Similar findings have also been reported in other research studies (Morris, 2004). Six of the seven women suggested that the care receiver's illness or disability and their caregiving role had created opportunities to spend more time with the care receiver and/or have greater emotional intimacy with the care receiver or other family members. In one situation, the woman suggested that she has a close relationship with all of her adult children and that these relationships are probably even closer because of the illness in the family and her caregiving role. As evidence of this closeness, she described the importance and priority that her children assign to coming together quite regularly for family celebrations. She also said that they are always there for each other. Similarly, another woman talked about how she has enjoyed close family relationships and good times with her children in spite of the caregiving demands that she has juggled over the years. Another woman also described the positive relationship that she and others are able to have with her care receiver and suggested that one of the benefits of this has been "she just reminds me of what's important in life, you know".

In another situation, both the female caregiver and her husband retired early as a result of her husband's condition and her caregiving role. Consequently, they have been able to spend more time together. She said that they have really enjoyed this time and their relationship has become closer as a result. In her words, "a lot of time together has been actually wonderful… I just think of, uh, the opportunity for a couple to be really close".

Another woman recognized a similar benefit in stating that:

> I guess I get to spend a lot of time with [care receiver] which is kind of nice and I know him like really, really well so I can anticipate, uh, his needs and his wants and what he's thinking a lot of times… Yea. I think it helps sort of bring us together and we understand each other better.

The same woman talked about experiencing the additional positive consequences of developing a better understanding and appreciation of people with disabilities generally as well as better planning and organizational skills.

Contextual Factors Affecting the Caregiving Experience and Related Costs

The relevant contextual factors identified by the women include those related to characteristics of the care receivers and their conditions as well as internal and external sources of support that influence their perception of their caregiving experience and related costs. The women drew attention to the fact that all of these factors had the potential to affect their caregiving experience in either a positive or negative manner.

Characteristics Related to the Care Receivers and Their Conditions

These factors included the chronic, long-term nature of their caregiving situation, the type of onset of the care receivers' illness or disabilities, the age of both the care receiver and caregiver at onset and the nature of the disability itself.

Chronic, long-term nature of caregiving. Firstly, the chronic, long-term nature of these women's caregiving situations was certainly highlighted in their stories. The chronic or long-term nature of the care receivers' illness or disabilities means that they all anticipate continuing to have a caregiving role for the foreseeable future. In some cases, there was also the potential for the amount and type of caregiving responsibilities to increase as the care receivers' condition progresses or needs change as a result of age or an increase in body size. The one exception to this was one woman who felt that her son may die of complications from his disease within a year or so because his condition had deteriorated significantly within a relatively short period of time. Another woman also indicated that if her husband's care needs progressed that they may have to consider the possibility of a long-term care placement. This would be a change in rather than an end to her caregiving role. Another woman contrasted her caregiving role with her one son with her parenting experience with her other children;

> It is different where the care support when, after a while, the other kids can do on their own... And so all these things that you normally do to teach these kids to do [care receiver] couldn't. There's no, physically he could not do anything on his own. So it, yea, there is quite a difference.

She and others also emphasized the fact that the caregiving-related financial and other costs that they experienced were also consequently of a very long-term nature and cumulative over time.

Type of onset. Two of the women described how the type of onset of their family members' illnesses and subsequent disabilities had dramatically affected their caregiving experiences in opposite directions. In one case, the care receiver's disability had progressed quite slowly over a number of years so that they had an opportunity to anticipate and adjust to changes. This woman believes that this has helped her cope and manage her caregiving role better. In her words:

> We've been very lucky to see things unfolding and they've unfolded somewhat predictably. I always think of people that have, have had a stroke. I mean one day it's this and one day it's that. And you don't even talk to the person in advance about, you know, you might need a walker whereas we've had a chance to kind of predict those things.

By contrast, the illness and subsequent disability of the other woman's husband had a very dramatic and sudden onset. Consequently, she faced a lot of uncertainty and grief combined with a lack of information regarding the sudden changes in her husband's functioning and the related treatment and management options. Throughout the interview, she repeatedly highlighted the need for more support to caregivers who are faced with this type of sudden onset and a need for information and support services to help them find their way through the crisis and beyond.

Care receiver's and caregiver's age at onset. Additionally, two caregivers shared their experiences that indicate that the age at which one becomes a caregiver and the care receiver becomes ill or disabled is an important factor in the caregiving experience. They felt that it had implications for the available options for appropriate care as well as the caregiver's options and choices with respect to their own livelihood and potential sources of income. Firstly, one woman suggested that resources such as the Home Care and Handi-Transit (i.e., public, accessible transportation for people with disabilities) programs are designed primarily with the needs of older adults in mind. She suggested that their needs are very different from those of younger adults with disabilities, particularly those who are employed and raising young children. According to her, the systems need greater flexibility to respond to their employment and family-related needs.

Although their ages and situations are quite different, another caregiver reached similar conclusions about her family's experience. She identifies herself as a relatively young caregiver (age 59 at the time of onset of her husband's disability) and her husband as a man in his sixties who was faced with his current condition a few years ago at a comparatively young age. She described her frustration with the limitations of a personal care home placement for her husband where his fellow residents are generally in their eighties with interests and abilities that differ significantly from his own. She also talked about being at a point where she would like to re-enter paid employment since her early retirement dreams are no longer accessible and she could use additional income. However, despite the fact that she feels that she is young, she has been advised by a potential employer that she is too old.

Nature of the illness or disability. Two of the women also felt that the nature of the care receivers' illness or disability had had an effect on their caregiving experience, one positively and one negatively. One woman suggested that she had been able to cope quite well because her husband's symptoms and disability were all physical in nature. She indicated that she may not have been able to cope as well if her husband's mental health or cognitive abilities had been affected. By contrast, another woman felt that the fact that her son's disabilities are largely invisible has had negative consequences for both of them. She described the main effect of her son's condition as being awkward and slowed mobility and experiencing slowed information processing. It was her perception that the nature of her son's disability limited his eligibility for certain services that could have been beneficial (e.g., home care services even for respite purposes only). She also talked about how others did not understand some of the difficulties her son has and the amount of support that he requires.

The experience of the women in this study has reinforced previous evidence that the experience of younger adults with chronic illness or long-term physical disabilities is different from that of caregivers providing care and support to seniors or family members requiring acute or palliative care (Armstrong & Kits, 2001; Biegel et al., 1991; Fast & Keating, 2000).

Internal and External Sources of Support that Influence Caregivers' Experience and Costs

As an extension of their description of their caregiving-related costs, caregivers were asked to share examples of when they felt their caregiving experience and caregiving-related costs had either been positively or negatively affected. The women revealed how their use of personal coping strategies as well as informal and formal support has affected their perception of their caregiving experience and their caregiving-related costs. In addition to describing their direct experiences, several of the women went on to share their ideas about what could make a positive difference for them.

Personal coping strategies. Some of the women identified personal coping strategies that they have adopted to improve their well-being and caregiving experience. These personal coping strategies include spirituality, positive attitudes towards accepting disability and change, planning ahead including seeking out information and resources, and, finally, a commitment to adequate self care.

Two of the women mentioned their involvement in and connection to organized religion through community churches as something that was connected to their caregiving experience. One of these women suggested that having her family regularly attend church with their disabled son was an important part of staying connected to the community and keeping their family life as normal as possible. The other woman suggested that faith and prayer provided her with strength to face the challenges caregiving presents, as well as a way of understanding and accepting her situation. She said that she did not know how she would have managed without prayer and her love for and faith in God. She also talked about how she has asked God why all of this has happened to her. She believes that it has happened for a reason and that there have been several times when God has intervened to make sure that she did not have more than she could handle. One example of this was the placement of one son into a long-term care facility just weeks before her second son became ill and was diagnosed with the same disease and also required her caregiving support. In her word's, "it was just happening to you and the only thing we can do now, pray to God for strength and for help, that God will help us through this hard and difficult time".

A few of the women talked about the importance of positive attitudes in coping with their caregiving situations. One of the women mentioned that she did not feel overwhelmed by her caregiving role and emphasized the fact that she felt that her personal perspective and attitude have made a difference in this regard. She described how previous work experience with people with disabilities made her more comfortable or accepting of this experience in her family. Similarly, she suggested that her attitude has been about making the best of what they have and using available resources to cope and maintain quality of life. She describes her perspective and attitude as follows:

> I haven't found it that difficult. Like it's not overwhelming… I've never had any illusions. I worked with disabled people when I was 20 and I've had no illusions at all about what life would bring and I, I never asked why us or why me or. This is the way it is. And what can you do best with what's available. And what can you plan ahead to do. You can't plan ahead for everything. But it's, it hasn't been overwhelming, surprisingly… I think it's perspective. It's not necessarily faith. It's just perspective that I was fairly well grounded and fairly secure.

Another woman expressed her attitude as:

> You can't go forward, you can't, you know, you can't, um, jump the hurdles and move on if you haven't accepted it. Once you've accepted it, then you can move on. Then you can grow, then you can grow. Otherwise you stay the same. And/or you go backwards. But you have to accept it and say, OK, this is, this is where it's at. Let's see, we have that to work with and so we move on.

One of the other women suggested that exposure to two individuals with disabilities in her family of origin made her more willing to accept and be comfortable with managing her daughter's disability over the years. Additionally, both she and one other woman talked about how their caregiving role and relationship with the care receiver helped them focus on what is important and positive in their lives. According to one of these women, "it helps me appreciate what I have and focus a little bit more on the positive aspects of life rather than being negative about what I don't have".

Two of the caregivers talked about their use of planning and organizational skills as important to managing their caregiving experience. One of them described what this has meant to her:

> A lot of the success we've had in making this go has been a lot of solitary thought... What was going to be the next challenge and, um, thinking ahead. So when he started needing a walker for instance, um, I was thinking to myself, OK, eventually he's going to need a walker, now how do we introduce this idea?... We didn't wait for the crisis... But still it's a challenge to keep thinking ahead and it still is, you know, and I still have to, I have to think ahead. Now we're kind of settled physically but I'm thinking, there are probably some tough decisions coming because we don't know how long this arrangement is going to last.

All of the women also talked about seeking out information and resources as an important aspect of their caregiving role and responsibilities. Some of the women particularly emphasized this as a proactive coping strategy on their part. One woman described in detail how she proactively developed a network of contacts and formal supports within the health care system (i.e., out-patient client staff, general practitioner, specialist, home care staff, and occupational therapy) and voluntary sector organizations (i.e., exercise program, information and referral and counselling services). She explained how this was essential to her ability to maintain quality of life for herself and her husband;

> I've always done that… that's part of my personality you know. There's that, there's something out there that will make life easier and that quality of life is really important if you can use these resources for improving your quality of life, use them.

She also provided a detailed description of how this network of supports led to a speedy and successful resolution of a crisis situation when her husband's abilities deteriorated literally overnight at one point.

While self care was clearly not a priority for some of the woman interviewed, a few of them did emphasize the importance of self care as a necessary coping strategy to ensure that their caregiving experience did not result in further negative consequences. For example, two of the women emphasized the importance of maintaining their own physical fitness so that they would not end up with injuries from their physical caregiving tasks (i.e., lifts and transfers, etc.). Two other women also talked about how they have prioritized having time for themselves for relaxation and enjoyable activities by making regular use of replacement care for a respite break from the caregiving responsibilities. They suggested that this was important not only in maintaining their quality of life but also their ability to continue in their caregiving role.

Informal supports. All of the women reported receiving some informal support from family and friends or other members of their informal support network. However, their experience ranged considerably. For example, one woman received quite extensive practical assistance and emotional support from a few different family members on a regular basis. On the other hand, another woman described her relationship with her adult children living in another community as her only source of very limited support. One of the women summarized her significant amount of informal support by saying that "we're lucky in that we both have a lot of family in the City that are very helpful for us. And help contribute what they can when we, if we ask for it, or if we need something, they're always there to help support us".

The primary type of support provided by the women's informal networks was psychosocial support. However, some of the women talked about receiving some practical assistance that temporarily relieved them of some of their responsibilities or helped reduce some of their financial costs. For example, one woman described how family members regularly helped out in this way by providing assistance with such things as child care, occasional transportation for the care receiver, income tax preparation and home renovation services. If she had not received this support, she would have had to do more herself or try to find money to pay someone else to provide these services. Beyond this, a couple of caregivers also talked about receiving direct financial assistance from family members in the form of irregular payment of money to the caregiver to assist with general household expenses and/or caregiving or disability-related costs. In one case, it was another adult son living a long distance away who occasionally sent money because he felt that was one way he could help from a distance. In another case, the caregivers' parents assisted with purchases on an occasional basis.

The women described three main types of psychosocial supports provided by family members and friends: providing emotional support, providing recreational or socialization opportunities for the care receiver, and assisting and supporting the caregivers' advocacy efforts.

All of the caregivers identified receiving emotional support from their informal networks although the extent of the support varied. On one end of the spectrum, there was one woman who identified her adult children living in another community as her only source of emotional support. She also indicated that they were limited in their ability to emotionally support her due to the fact that they were still struggling themselves with emotionally coming to terms with their father's illness and resulting disabilities. By contrast, another woman described having a significant level of emotional support from her family as well as from a variety of other members of her informal support network in her neighbourhood, workplace and church community. She summarized the extent of the support and its importance to her:

> And we are kind of a close family. We support each other… We are there for each other. I mean if I'm ever in the need of anything, my daughter, she's always there for me too. Even with two little children… Like I work at [place of employment]. I have a support group there too. Any time I'm really low I go to my, one of the [colleagues]. Just go and talk with them… I have my support group and I'm glad… I have my daughter. And I have my children. I have my church group and my very good neighbour here I can talk to any time…

The other woman who experiences very little emotional support reflected on what this has meant for her and the difference it could make if it were available to her.

> I care. Uh, huh. Makes a huge difference. It's a thing you go through a point, and you go through it often, like nobody cares. And I don't know if. I don't think that's feeling sorry for yourself but it's, um, whether because you're alone and then there is sometimes the phone doesn't ring the whole day and you think gee nobody really cares. So, so I think if I was able to help somebody I would set something up for that person to get a phone call at least once every two days or. How are you doing. I care. I'm thinking about you. That kind of stuff… That would have been very important… It's four years later and it still would be important to have

> that follow-up call saying, how are you doing today. Do you want to go for coffee. That's important to the caregiver.

A couple of the women highlighted how family members and other members of informal networks can relieve the caregiver of some of their responsibilities by taking the initiative to provide a recreational or socialization opportunity for the care receiver. According to the women, this gives them some time for themselves or to take care of other responsibilities. It also relieves them of being exclusively responsible for ensuring that the care receiver has adequate recreation and social opportunities. One of these women was looking for this type of support but it had not been forthcoming while the other woman described the benefits to both her and her husband as a result of having friends who regularly provide this type of support. In her words:

> But I think what has happened in fact is that the support that we've gotten has been in the general community. I'm just in total awe of the people that provide support for my husband that, on just sort of a normal basis. For instance, there's a group of guys… that meet at [location] every Wednesday. And they, you can go any Wednesday. Nobody phones around and says, are you going for lunch today. They're just there. And whenever he can go, I drop him off because I think he needs the time away from me. Like what he's lost is he never, I'm there all the time. Uh. So, and they look after him and they feed him. And they just treat him like, you know, there's no special.

Additionally, three of the women identified how members of their informal support networks (i.e., family, friends, neighbours and/or members of their church community) had supported them by assisting them with their advocacy efforts related to securing necessary services or other supports to address the care receivers' or their own needs. One woman talked about this support as being important in equalizing the numbers and the power imbalance in meetings with various government program staff. Two of the other women talked about how someone from their informal network had stepped forward to make telephone calls or write letters in support of the caregiver's request after they themselves had been unsuccessful and had essentially given up. In one case, the additional advocacy eventually yielded positive results. In the other case, it was evident that the support had been important to and appreciated by the caregiver even though nothing further had come from the family member's letter writing. She had even kept copies of the letters sent several years ago.

It is evident that the women's experience with respect to the type and amount of support provided by family members and friends varied considerably. These differences also appear to have resulted in differences in the meaning and impact of their caregiving experience for them. For a couple of the women, their caregiving experience appeared to be a fairly solitary and isolating one despite the fact that on the surface they would appear to be situated in communities that are often thought of as providing extensive informal supports to their members. One of these women lived in a small rural community where she knew many people. However, when her husband's illness and subsequent disabilities struck, none of the community members offered any support to her or her husband. This included individuals that she thought of as friends and previous work-related contacts. No one even came to visit either of them or ask how they were doing. The pain and isolation that she experienced as a result was evident throughout her interview:

> Well I would have thought that there would have been more people concerned about [care receiver] and myself. They could see that I'm struggling with getting him in and out of the van but it was just [care receiver] and myself just going out for coffee. You'd think that somebody would come along and say, well can I take him out for coffee today or can I take him for a walk today or (). You have to hire somebody to do that.

Another woman had chosen to relocate to be near her extended family and the large ethnocultural community to which they are connected. However, this woman's description of her caregiving experience left the impression that it had been by and large a fairly solitary one. When probed, she indicated that she received important emotional support from one cousin and her spouse and that another extended family member had attempted to provide some advocacy assistance by writing letters to politicians. She indicated that she was reluctant to ask other family members or friends for help. According to her:

> They're very supportive but I mean they all have their own family and I don't expect it. I'm very independent. But this cousin of mine and her husband they're wonderful. If I didn't have them, I would feel really isolated, you know. Because the other relatives, they say, oh well call if you need help. But they all have their own problems and illnesses and everything and I don't expect it. No. I'm very, very independent and private. Like I don't, I don't like to bother everybody.

In contrast to these two women, all of the other women talked about having a community or network of positive, informal support although the composition and size of their networks varied. For one woman, this network of support was comprised of her adult children, neighbours and friends, her church community and a small group of colleagues at work. Another woman talked about having support from adult children but also consciously reaching out to develop or renew friendships through volunteer work and other interests to ensure that there were supports in her life that were not directly associated with her caregiving role or her husband's disability. Another woman identified her own and her partner's parents as her primary sources of support. Another woman talked about having a very supportive group of friends who had essentially become family. She talked about how they regularly included both her and her daughter in their everyday activities and milestone events in a manner that anticipated and accommodated her daughter's disability-related needs. This meant that the caregiver had times when she was not fully responsible for anticipating and planning for her daughter's needs. Additionally, they ensured that she and her daughter were not left out or isolated because her daughter's needs could not be accommodated. Finally, another woman who also resided in a rural community indicated that she had received support from the community and intentionally ensured that she stayed connected within her community in spite of her intense caregiving role. She talked about volunteering as leader with a youth recreation program when her son was participating, regularly attending church with her family and socializing with friends.

Formal supports. All of the women who participated in this study and/or their care receivers were either currently using some type of formal support service or program within the health, education and/or social service systems or had previously accessed some type of formal support. With the exception of one woman who described her experience in exclusively positive terms, the women generally described their experience in accessing formal support as very mixed. All the women identified some benefits that they and/or the care receiver had received from programs or services within the health, education and social service systems. However, as with informal supports, there was considerable variation in the women's experience. Some of them felt that there had been relatively limited impact from the few supports that they had been able to access while others felt that they had experienced some fairly significant benefits. However, the women were unanimous in their opinion that there should be additional supports available to caregivers and their families from the health, education and/or social service systems. Some of them were quite adamant in stating that government needs to do more to support caregivers and decrease the caregiving-related costs they experience.

The women's descriptions of their caregiving-related costs are outlined in the next section of this chapter. It is evident from the women's caregiving stories that although caregiving-related costs are a part of their daily reality, a combination of personal coping strategies and external support from informal and formal support networks can make a positive difference to the financial and psychosocial costs they experience. These findings are consistent with previous research and theoretical models of unpaid caregivers' psychosocial adjustment that have identified a range of similar factors as influencing psychosocial adjustment (Avision et al., 1993; Biegel et al., 1991). Moreover, these informal and formal supports are an important part of their caregiving experience with the potential to either positively or negatively affect their caregiving-related costs depending upon the amount and type of support that is available to a particular caregiver. Most importantly, regardless of the current experience, the women were unanimous in their belief that more and better support to caregivers is required.

Caregiving-Related Costs

In order to address the first research question and obtain the women's description of their caregiving-related costs, all interview participants were asked to identify any costs that they felt they had experienced as a result of their caregiving role. The questions pertaining to caregiving-related costs were general and open-ended to allow participants to identify what they perceived as costs regardless of whether they were economic or other types of costs.

Data analysis revealed that the women were identifying both monetary or financial costs as well as other negative consequences with respect to their other aspects of the caregivers' well-being and quality of life. These other aspects cannot be easily monetized or presented in economic terms but can still be construed as costs. Cranswick (1997) espouses this broader conception of caregiving-related costs and states that "some significant costs can be associated with caring for someone with a long-term health problem. These can include negative feelings the caregiver may harbour, disruptions to the caregiver's life and economic costs" (p. 5).

The following presentation of the women's description of their caregiving-related costs has been organized in accordance with the "taxonomy of hidden costs of informal care" proposed by Fast et al. (1999) which broadly distinguishes between economic and non-economic costs. Fast et al. (2001) have described this distinction as "economic costs involve money or money equivalents and affect standard of living. In comparison, non-economic costs result from declines in certain aspects of quality of life, such as physical, social and emotional well-being" (p. 3).

The decision to label some of the women's negative consequences or costs in this report as non-economic is not intended to devalue or minimize their impact. It is my intention instead to reflect the reality that there is not currently a way to assign a dollar value to these types of health and quality of life consequences. In this regard, non-monetized consequences may be a more accurate term than non-economic costs. However, I have chosen to use the latter term in order to be consistent with the related literature as well as to acknowledge the fact that these negative consequences truly do cost women even when they can't be translated into a dollar value.

All the study participants identified economic costs as well as a range of non-economic, primarily psychosocial costs. Clearly, the meaning of caregiving-related costs to these women is comprehensive with both economic and non-economic costs being integral to their caregiving experience. It should be noted that the women did not often use the term "cost" themselves during the interview. Most often, the women provided detailed narrative descriptions of the various aspects of and examples from their caregiving experience without labeling them. They appeared to frame and characterize their consequences of caregiving in terms of good and bad experiences with positive or negative outcomes for themselves and the care receivers. During the analysis process, this researcher categorized and labeled their experiences as either economic or non-economic costs with subcategories within each of these.

Overall Economic Impact

All of the women identified having experienced some financial or economic costs related to their caregiving situation. The women shared their perspective on their current financial circumstances and the economic impact that their caregiving role has had and/or will continue to have into the future. All but one of the women described their current financial situation as one where they have to plan carefully to cover cost of living expenses. This means that money is "always tight" and that there is very little or no money at all left over for "extras". One woman stated that "finances is always a problem… You have to wonder if you can go out to a restaurant to eat". Another woman describes a similar scenario:

> I had to save and scrimp to get by, yea. That's why I only, like for myself, to pay all the bills and everything… I have a house and I have a car. Mind you I don't have like extra. I don't have money for going on vacation, for going somewhere.

Another caregiver described her ongoing efforts to make ends meet:

> Yea, it is, it does become a financial burden… And because I think because I stay home, because I do some gardening, and canning and I think that's one way of why, not really survive but we were able to keep

> on top of things. Otherwise there's no way you could afford, you know, what we have today, you know. If I would have bought everything, you know, made, made everything that. And we did with a lot less, lot less of things that, this, this table and chairs I just got it last March.

A few of the women talked about how the financial impact of their caregiving role and their family member's disability or chronic illness has meant that they are not where they had anticipated they would be from a financial perspective at their current stage of life. One of the women had expected greater financial stability and money for travel etc. by the time her children were all adults. Similarly, another woman also thought that she would have greater financial resources to use for her own leisure and enjoyment during her retirement. Yet another woman is working longer than she anticipated because in her words, "I can't even go on early retirement because I won't survive".

Some of the other women also talked about their financial concerns for the future. Two of the women expressed concern and disappointment that they would not be in a financial position to leave an inheritance for their children. Three of the women were also concerned about upcoming or potential changes that could have a further negative effect on their financial situation. One woman describes what she anticipates when her income is further reduced upon her retirement within a few years:

> When I retire that will be a different story which will be in 4 and a half years. Probably going to be more difficult. In time I will have to give up the house and go in apartment.

Another woman is also anticipating having less money to cover her current cost of living expenses when her adult child transitions to a group living situation and child support payments from her ex-spouse cease. Yet another woman was facing questions about the feasibility of maintaining her current paid employment position and what alternatives might be available to her. Finally, the woman who felt that she and her husband currently had adequate income from a combination of his disability pensions and her employment-related pension is anticipating that this will change if and when her husband requires long-term care placement. She is aware that the costs of continuing to maintain a home for herself are not fully factored into the assessment of their income used to determine the fees that they will be required to pay for his placement. At the time of the interview, one of the other women was in the process of trying to sell her house for exactly this reason.

While six of the seven women described the limitations and challenges presented by their financial situation, the remaining woman described how being in a secure financial situation has been a factor in enabling her to cope well in her caregiving role. She recognized that there have been financial costs related to her husband's disability and her subsequent caregiving role. However, she indicated that her husband's employment benefits (i.e., extended health insurance and disability pension) combined with publicly funded benefits and services such as home care and home care equipment as well as her own retirement pension have enabled them to maintain a secure financial situation. This woman recognized that many other caregivers have more difficult experiences because they do not have the same type of financial security that she does. According to her:

> Finances are key to making a situation work… if you're struggling to look after somebody, and you know, you're just wondering if you're having macaroni today or whatever. And how are you going to pay the rent and you really can't afford an apartment that might be or a house that might be better equipped you can't afford. That must be really difficult.

She has been able to cover cost of living expenses and access all necessary equipment and services for her husband and still have sufficient income to continue to pursue recreation and hobbies such as gardening. She is aware of how this differs from the experience of others:

> I could see, this hasn't been our situation and like in just strictly financial terms, um, I could see that, um, a family might have to put so many resources into just the maintenance that they would, that they would give up a lot of things that they would have spent money on otherwise and that could always be from food to and necessities to, uh, you know, a trip or whatever. I really haven't had to give, we haven't had to give, not having had to give up too many of those things because the financial situation was insecure.

Types of Economic Costs

There was consensus in the women's caregiving stories that they are incurring extra costs compared to families without chronic illness and/or disability in their midst. They shared detailed information regarding the specific types of financial costs that they have experienced with two general categories emerging; out-of-pocket costs and employment-related opportunity costs resulting in decreased current and future income. The economic costs identified by these women reflect the two general cost categories previously identified in the research literature. For example, Keating et al. (1999) divide caregiver's economic consequences into employment consequences and out-of-pocket expenditures (p. 59-62).

Out-of-pocket expenses. The caregiving-related out-of-pocket expenses identified by these women included a range of services and items directly related to the care receivers' care needs resulting from their disability or illness as well as more general contributions to the care receiver's cost-of-living expenses. Therefore, the women's description of their caregiving-related out-of-pocket expenses is consistent with some of the Technical Advisory Committee on Tax Measures for Persons with Disabilities' (2004) assumptions related to disability-related costs. A significant reality is that "for persons with disabilities, normal activities bring extraordinary costs that are involuntary". Furthermore, "some of these costs are general and intangible and others can be supported by receipts for expenditures" (p. 4-5).

Most of the women interviewed identified a comprehensive range of expenses related to the care receivers' care needs. The services and items identified included; equipment for mobility, lifts, transfers etc., medical and personal care supplies, medication, home renovations to increase accessibility and/or facilitate installation of equipment, service fees and other costs for work placement and/or specialized education programs, private extended health insurance premiums, travel costs related to care receivers' medical appointments or for caregiver to be present to continue to provide caregiving support following long term care placement and/or during hospitalizations.

The women reported that there is some reimbursement for some of these expenses via income tax deductions or up-front coverage or direct payment through government or voluntary sector programs for people with disabilities. However, in their experience, these measures do not provide complete reimbursement or cover the full range of services and items required so caregivers still experience significant out-of-pocket expenses. Additionally, caregivers described situations where publicly funded programs only provide the most basic coverage regardless of their specific situation and needs. This means that standardized equipment deemed as a necessity may be covered but the specific type or piece of equipment that is best suited to the care receiver and their needs may not be covered. In some cases, caregivers chose to purchase the most appropriate equipment and incur the associated additional cost. However, in other cases, they either went without equipment that would have been helpful or settled for the less suitable but publicly-funded model.

Beyond public funding, one caregiver found that her household's private extended health insurance was significantly beneficial in covering costs that could not be covered through publicly funded programs. However, another caregiver was surprised to find out that her family's private extended health insurance policy had significant restrictions and provided very minimal coverage for the types of services and equipment her husband required. One caregiver also talked about the care receiver having accessed funding for equipment from a disease-specific voluntary health organization.

In addition to these specific expenses related to the care receivers' disability or illness related needs, the four women who were providing caregiving support to their adult children all indicated that they were supplementing their son's or daughter's income from the provincial government's Income Assistance program by paying for some of the care receivers' general cost of living expenses. These women talked about paying for clothing, food, toiletries and/or recreation costs for their adult children. In one case, the caregiver indicated that she was partially compensated for some of these costs through a minimal room and board payment from the provincial income assistance program. However, the amount of money provided did not come close to covering the full cost of the food, clothing, transportation, etc. that she and her husband were regularly paying for their son. A significant issue related to this particular cost for these women is that it is an ongoing cost that they expect to continue to incur over the long-term and for which they do not anticipate any compensation or reimbursement either from the care receiver or the government. Consequently, the overall impact is quite significant. One of the women had documented some of the financial assistance she had provided to her son over several years.

> I was writing it all down what he owed me. So at the end, what he borrowed from me money and what, what I had, what he couldn't pay me, it was 10 thousand dollars which I never could get back from him.

It is interesting to note that none of the women who were caring for their spouses identified assisting with the care receiver's general cost of living expenses as one of their caregiving-related costs. It could be surmised that this difference is related to the nature of the relationship with the care receiver. In a spousal relationship, all parties are more likely to anticipate sharing cost of living expenses. Whereas, in the normal course of events, parents would anticipate that their adult children would become financially independent over time. One woman describes the difference:

> It's costing us something. Because he's now 24. So 18 to 24 he should have, if it was a normal situation, if I can say normal. If he was at home, like my youngest does work and we do insist on him paying a little bit.

Generally, the women expressed appreciation for the services and/or equipment that had been either publicly or privately funded. They acknowledged that this had helped to reduce some of the financial costs that they may otherwise have had to incur and provided them with assistance in their caregiving role that they may otherwise have had to do without.

Employment-related opportunity costs resulting in decreased current and/or future income. The women's descriptions of these employment-related consequences are also similar to the consequences that have previously been documented in the research and theoretical literature. Although not specifically mentioned by these women, Fast et al. (2001) have suggested that lost employment benefits and their unpaid labour are other costs inherent in the employment-related opportunity costs that the women described (p. 46).

Some of the women described how the time spent in their caregiving role reduced the time that they had available for paid employment, training for career advancement and/or generally affected their ability to maintain or seek employment. According to some of the women, there was a connection between this aspect of their reality and their current financial situation. They are not as financially secure as they might have otherwise expected due to the fact that their caregiving role had essentially limited their income earning potential over the years. The combination of the women's experiences highlights how this reduction in income can be a factor both over the shorter and longer term.

Three of the women talked about how pursuing a full-time paid employment position had not been an option for them due to their caregiving responsibilities. For example, one woman described how she had only worked in part-time positions in order to accommodate her child's school or work placement schedule and care needs. Since the care receiver has never been able to be left alone, full-time work has not been an option because paying someone else to provide the type of before and after school/work care required would have been cost-prohibitive. She also talked about needing to find employers and positions with enough flexibility to accommodate the exact hours that she could be available for work. Another woman caring for her child with a disability described a similar experience:

> I didn't go out and have a fulltime job, um, until, well. And not even a fulltime job. Like when he was a full day at school and it's, I don't know, when he was about 10, 12 years old, I babysat for my sister-in-law for a couple of years… So that worked fine. Like that worked not too bad. What

> I would do is I would bring some stuff here from work, from home to work and stuff and do some stuff at her place. So it would balance things out, you know… But it was not a fulltime job.

Another woman acknowledged that when she returned to work several years after her son was born, she worked in a part-time position until her retirement. Consequently, her income was limited then and continues to be now due to the fact that her pension is calculated on her previous part-time employment income. Another woman was currently in the process of considering either reducing her hours or leaving her paid employment in order to accommodate the demands and related schedule of her combined child care and adult caregiving responsibilities at home. She was wondering how this could be financially feasible without being somehow compensated for at least some of her caregiving time.

One of the women also talked about the opportunity costs involved in not being able to pursue additional training in a timely manner. This caregiver did manage to complete a continuing education certificate. However, she could not complete the course work within the regular time frame and had to apply for an extension. It took her significantly longer because she had to plan to find both the time and money to be able to take each course rather than just being able to move from one course to another.

Types of Non-Economic Costs

The types of non-economic costs identified by these female caregivers fall into the two general categories of negative impact on caregivers' own physical health and psychosocial costs. These negative effects are also consistent with what has been documented in previous research, although the labeling and cateogorization varies somewhat across studies (Cranswick, 1997. 2003; Fast et al., 1999).

Negative impact on caregivers' own physical health. Most of the women recognized that their caregiving role had already or had the potential to negatively affect their own physical health or at least had the potential to do so if they did not take care of themselves with adequate precautions to prevent injury and burnout.

One of the women talked about how she had become "sick" in recent years and was now facing chronic health conditions of her own including diabetes, high blood pressure and other heart-related problems. She suggested that her current health situation is the result of having "too much stress". Another woman described her situation similarly. She had been injured a few times over the years due to difficulties lifting her daughter and now has been diagnosed with arthritis in her joints. She directly attributes the development of this condition to her long-term physical caregiving. She also talked about more subtle physical consequences related to repeated movements involved in dressing her daughter and pushing her manual wheelchair. She described how she had learned from other caregivers with adult children who have the same disability as her daughter that many of them also suffer from the same physical ailment (i.e., a sore thumb). This is a result of the repetitive nature of some aspects of their physical caregiving responsibilities. Overall, this woman described herself as tired all the time and feeling that she is aging faster as a consequence of her caregiving role. Additionally, she feels that she is showing physical signs of aging earlier than her friends of a similar age who do not have caregiving responsibilities.

Two of the other women talked about being aware of the potential for injury due to the physical demands of their caregiving role such as lifting and transferring the care receiver. One woman described how she takes responsibility for addressing this reality by stating “I have to keep myself in shape too because, you know, lots of work is physical so I have to be careful not to hurt myself in that way as well”. Another woman who had previously experienced a caregiving-related injury described how she addresses this aspect of her reality:

> I didn’t want to wreck my back. I was, if I wreck my back, nobody else will be able to come and do my work. Who will I have? So I had to take care of myself. Like I did do exercises and reinforcement exercises along the way because I had to take care of myself because, I mean, nobody else does that. And in doing so, like I did the best I could.

A few of the women also suggested that they had purchased additional equipment such as lifts and transfer systems in their home and vehicle to make some aspects of the physical caregiving easier. However, despite their attempts to reduce the demands and potential negative consequences of the physical aspects of their role, most of the women associated a potential or actual toll on their own physical health as part of their caregiving reality.

Psychosocial costs. The two general categories of psychosocial costs identified from the women’s caregiving narratives are emotional pain and loss and decreased opportunities to address their own needs.

For most of the women, telling their caregiving story in the interview was an emotional experience and they displayed their emotions throughout the interview in tears or expressions of pain, anger or frustration. They clearly identified the emotional aspect of their caregiving role as very central to their overall caregiving experience. Consequently, it is not surprising that they also indicated that they had experienced emotional costs related to their caregiving role. Some of the women talked about emotional costs in terms of the “emotional pain” involved in watching someone you love suffer through a long term illness. One woman described the intense emotional pain involved in her serial caregiving experience with her husband and sons as:

> Just pain in my heart. Deep, deep pain that never goes away… If they die, I don't have them and if they live I see them suffer, I don't want it, it's hard to see them suffer. And in one way they worse when they die. It just, just gives you physical pain. But would never, that never goes away.

Some of the women caring for their spousal partners who experienced onset of the disease or disability many years after the initiation of their relationship also described their emotional costs in terms of losses. They referred to losses that stemmed from functional limitations that the care receiver has experienced as a result of their illness or disability and the subsequent changes to their relationship with that person. One woman whose husband had had a stroke described how this type of loss had affected her:

> …it's like a death. You've lost the person that you've, um, and you've had goals with and you had dreams, all of it… you're exposed to somebody that you don't know.

This woman further described how she had had to come to terms with the fact that these changes also meant a very real loss of her opportunity to fulfill previously established dreams and goals such as travel. According to her, this lost opportunity was due to a combination of her husband's inability to participate, the time demands of her caregiving responsibilities and the negative impact that the situation had had on her financial security. The significant emotional impact of this new reality and the associated loss for her is evident in her words:

> Before we had different plans. We hadn't planned for sickness. We had planned on doing things, planned the goals when we're going to retire and we were going to travel and we were going to, uh, pursue things that we, um, once we sold the business and we could just, um, enjoy our lives. We didn't travel much because we were waiting until he retired to do it then to do these things. And just never happened.

The nature of the disability or illness appeared to affect the types of changes and losses the women described in their relationships with the care receivers. For example, another woman suggested that she and her husband whose disabilities are exclusively physical in nature had a close emotional relationship that had become closer through his illness and her caregiving experiences. However, she mentioned that there had been some changes and losses in terms of their sexual relationship. In a similar yet different example, another woman talked about how her son is no longer able to hug her.

Due to the specifics of her experience, one of the women also talked about loss in terms of actual death. In addition to dealing with deterioration in her son's current condition, she is still grieving the complete loss of other family members who had previously died from the same disease.

Overall, all but one of the women described facing times when they were emotionally overwhelmed by the demands of their caregiving situation. As one woman stated, "I guess it sort of costs me emotionally as well. At times I do feel overwhelmed". According to another woman, "the emotional is 90%... this is the hardest thing that I've ever had to go through in my entire life".

As a result of their caregiving role, all of the women described themselves as having decreased opportunities to address their own needs related to their own personal development and social well-being. Generally, the women described themselves as being in situations where they had very little time for themselves since the physical, mental and emotional aspects of their caregiving combined with their other family and/or work responsibilities consumed most of their time. One woman stated that "a lot of times I feel sort of, well, kind of costs me my private time that I like. I don't get a lot of time to myself as I'd like". Another woman talked about wanting to find a more appropriate long term care placement for her husband so that she could be assured that his needs were adequately met. She felt that only then would she have an opportunity to think about her personal needs and goals. This contrasts sharply with her current experience:

> ...what I would like to do and I have no idea what that is because there's no time to think about it. So it's, it is about my life is about [care receiver] and I can't help but be because it's, it seems to be there.

Another woman talked about being unwilling or unable to focus on developing a life for herself or pursuing her own interests when she knows that her son is not able to achieve his goal of employment and is unhappy with his situation. She said that she did not feel right about going out and doing things for herself when her son did not have something meaningful to do.

One of the other women caring for her son with disabilities since his birth described how she had lost a lot of time over the years. From her perspective, some of the time spent in caregiving-related activities is time that she might have chosen to spend otherwise if her situation was different. She mentioned time for paid employment and time for herself and her own activities as examples of how she might have used this time. Similarly, one of the women also talked about how her caregiving situation has meant a loss of independence for her since she needs to be available for her husband all of the time except during scheduled breaks. She contrasts this with her observation of the experience of other women of her age and stage of life but who do not have caregiving responsibilities for their spouses:

> Not that we keep any secrets but I have to work very hard to be myself and I find that women at my age, um, if their husbands are retired, they're often leading very separate lives, you know, not totally. But they have

> continued their own interests and/or they have their own friends where I have to work very hard at that to maintain that kind of, that kind of thing.

This woman suggested that her decision to take early retirement also meant a loss of independence for her because she gave up a job she enjoyed earlier than she may have otherwise in order to manage her caregiving responsibilities. She talked about how she has used the public home care services for her husband's daily care as well as twice weekly respite breaks when replacement care providers come to their home so she can go out and engage in her own activities. These services have enabled her to maintain some independence and her ability to continue to pursue some of her own interests but have also come with a cost of their own. She described this cost as a loss of privacy for both her husband and herself resulting from the fact that care providers are coming in and out of their home on a daily basis. However, she did indicate that to her surprise this is something both of them have accommodated to quite easily. According to her, all of this has meant that she finds herself in a situation where "you really have to work hard to be yourself".

A few of the women also talked about how their opportunities to address their own needs and interests were affected by a general loss of spontaneity due to their caregiving role. They talked about the amount of preparation and planning that goes into planning outings with the care receiver or alternatively, the restrictiveness of having to plan any recreational or social activities for themselves around their scheduled respite breaks when replacement care providers are available. One woman describes what this has meant for her.

> Making, oh as simple as making friends that I can see on those days. I can't say to my husband, you know, like somebody else might, you know, oh yea, I'm going curling or I'm doing this, you know. If I'm taking a

> class or whatever, it's always got to fit into this Tuesday and Thursday. People know. Tuesday and Thursday you can reach me. So that then limits some kinds of things.

Additionally, three women also acknowledged that the combination of lack of time and spontaneity had had an impact on their relationships with friends and other family members. According to one of the women:

> On occasion I do miss, you know, like I said, being able to sort of pick up and go without having to plan anything. And, you know, it makes it a little bit difficult with obviously with my friends. They don't always understand either the fact that I've got to take care of him before I can go out or make plans or anything.

Another woman acknowledged that she would have liked to have been physically present more often and generally more involved in the lives of her now adult children and grandchildren. This is particularly challenging now since some of them live thousands of miles away. In her words, "the connectionism is there, there hasn't been a loss in the connection. There has been a loss of physically being able to go". Another woman talked about how she had to be creative in identifying opportunities for quality, one-on-one time with her other children given that her son's disability-related needs consumed so much of her time. She talked about using trips to the city for her son's medical appointments as special time with each of her other children on a rotating basis. They also planned family weekends at hotels where her son's needs could be accommodated so that none of her children would feel that they were missing out on her attention or opportunities to enjoy themselves.

Romantic relationships were also affected. Two of the women, one of whom was divorced and the other single, indicated that the time that they spent focused on the needs of their children with disabilities over the years and the associated lack of spontaneity had decreased their opportunities for romantic relationships and/or for finding another long-term partner. One of these women said that she had not been involved in any romantic relationships in more than 30 years while the other had had only one significant relationship in approximately 20 years. The latter women found that in her experience it was difficult to date when she could not be spontaneous and had to plan weeks in advance to arrange respite so that she could go out without the care receiver. She said that she had been in a relationship that ended when her partner grew tired of the restrictiveness of the situation.

Another aspect of the women's experience of decreased opportunities to pursue their own interests related to their recreational opportunities. All of the women acknowledged that due to a combination of their lack of time, money and ability to be spontaneous that they had experienced significant limitations on their ability to engage in regular recreational activities and/or have regular vacations. For example, one of the women talked about only recently returning to a women's group after a lengthy period of not being involved. This had occurred in spite of the fact that it had been an important source of support and socialization for her over the years. Once the care receiver had settled into a personal care home, she once again time and energy for this activity for herself. Another woman described how even once she had respite services, she was still limited in her recreational opportunities and vacation choices because money for these activities was very limited. This was also related to the fact that she prioritized the care receiver's recreation and other needs before her own. She also talked about how choosing to use her replacement care allotment in blocks of two to three weeks in order to have a longer break meant that she did not have as many opportunities for shorter breaks on a more frequent basis. Even when finances were adequate, time and a lack of flexibility or spontaneity in scheduling recreation opportunities also resulted in limited opportunities for other women.

The Meaning of the Caregiving-Related Costs

The remainder of this chapter is structured around the key themes that emerged from the aspects of the women's narratives that addressed the second research question by illustrating the meaning their caregiving-related costs have for their daily lives.

These themes are interrelated with one another as all of the aspects of the women's caregiving experience were interconnected in their stories. There are seven key themes that emerged from the data analysis that describe the meanings that the caregivers derived from their caregiving experience overall and their caregiving-related costs specifically. A discussion of each of these themes is presented below. Firstly, the women experience both economic and non-economic, primarily psychosocial, caregiving-related costs with both types of costs being interconnected in their experience. Secondly, caregivers' needs and costs are also addressed through adequate care and disability-related supports for people living with chronic illness and/or disability. Next, these women recognized that their caregiving role exceeds 'normal' family roles and consequently, feel that they deserve related support. However, a predominant and related theme is that caregivers' costs are increased by barriers that they encounter in identifying and accessing external supports. Yet another key theme was that the women felt there was a significant need for improvements in the currently available supports in order to adequately address their psychosocial and economic costs. Furthermore, they also identified some important factors that limit or otherwise affect their utilization of available services. Finally, the women are committed to their caregiving role despite the associated costs.

Economic and Psychosocial Caregiving Costs Are Interrelated

All of the women described economic and non-economic caregiving-related costs that they were experiencing. Each woman's relative emphasis on each of the two types of costs varied but it was evident that both economic and psychosocial costs are integral to their caregiving reality. Clearly, they could not share their caregiving story without discussing both types of consequences and they could not easily be discussed in isolation from one another. In fact, the women's description of their experiences and the meaning for their lives regularly vacillated between the two types of costs, often to the point of an interwoven rather than a separate presentation of each type of cost. For example, one woman talked about her interest in having the option of being paid for some of her caregiving time. From her perspective, being paid for caregiving work could at least partially address some of the financial costs by valuing her time as the paid home care workers' time is currently valued for doing the same work. However, she also recognized that being paid to provide care or at least making that option available through self-managed or family-managed care programs may lead to some additional psychosocial costs as her caregiving responsibilities increase and she has even less time for herself. In her words:

> I mean, for us, or me particularly to have to take over the role of hiring and firing and taking care of a staff and being in charge of, you know, organizing the hours and pay and issuing cheques and all that, I mean that's a lot more work and it's tough. Do I want to consider adding that on to my, on to everything.

In other examples, the women highlighted how the financial consequences have had both economic and psychosocial meaning for them and how their economic and non-economic costs are interconnected in their experience. For instance, one of the women described the caregiving-related financial costs as being a significant contributing factor in the loss of her ability to fulfill her retirement dreams for travel. Similarly, she and other women also felt that their access to socialization and recreation opportunities were affected by both the lack of 'free' time for themselves and the amount of money they had available to pursue activities of interest to them. This in turn has emotional costs since they are unable to adequately address their own needs. Additionally, some of the women were clearly emotionally upset about the impact of their caregiving-related economic costs as they expressed frustration, anger and a sense of being treated unfairly in their current situation.

Theoretical Connections

This finding regarding the interrelationship between economic and non-economic caregiving-related costs of women's caregiving is consistent with previous research on the impact of caregiving which has clustered the negative consequences of caregiving into categories such as "subjective burden" or the "psychological effects of caring" and "objective burden" or "practical difficulties such as loss of income or having to undertake additional household tasks" (Heron, 1998, p. 43). According to Heron, "the difficulty of any categorization is that factors are generally interconnected; practical problems result in emotional distress, while this in turn makes it harder to cope with practicalities" (p. 43). The distinction between economic and non-economic caregiving-related costs that was used to frame this study also appears to be inadequate in capturing the complexity and interconnection of the women's various caregiving-related costs. Rather than describing their costs in categories, the women seemed to be more comfortable talking about a more general and less distinct division between positive and negative aspects of their caregiving experience.

Caregivers' Costs Are Also Addressed Through Adequate Care Receiver Supports

In the women's caregiving stories, there was a significant focus on the care receivers' needs and programs and services intended to address their needs. Generally, these women experienced their own needs and those of the care receivers as being interconnected. Due to this interrelationship, they were also suggesting that the availability of care and disability-related supports that adequately address the care receivers' needs also benefits them as a caregiver.

Interconnection of Care Receivers' and Caregivers' Needs

For the most part, these women appeared to have difficulty isolating their own caregiving-related needs from their care receiver's support needs. Both types of needs were enmeshed in their discussion.

As one example, one woman focused her caregiving story almost exclusively on her unsuccessful efforts to meet her adult child's needs with respect to employment and financial security. She essentially discounted her needs as a caregiver as unimportant given that from her perspective, her son had such significant, unmet needs. Only after direct probing did she acknowledge that some additional financial support for herself and some respite or attendant care services could be helpful. However, she had never sought out these types of resources because she was more concerned about locating services to address the care receiver's needs. She had also assumed, based on some of her experiences in trying to access services for her son, that she would likely not be eligible for any support that might exist for caregivers. Her experience as a caregiver seemed to be very interconnected with her son's experience of living with a disability. Consequently, she could not or did not want to separate her needs or make any request to have her needs addressed as long as her son continued to have unmet needs. She summarized her perspective as "well, yea if I had a little support, you, know financially. Sure, that would be great, you know. But the main thing, the, the solution is if he would get a job, you know".

Another woman shared how this interconnection of her experience with the care receiver's experience occurs at an almost subconscious level. In describing an experience with a health care clinic related to her husband's care needs, she repeatedly used "we" rather than "he". She acknowledged sometimes having difficulty sorting her experience from the care receiver's experience.

> When he had ulcers on his legs from tape somebody has put on to it, she was the person I saw or we saw and, sometimes I don't know the difference. Sometimes I have difficulty sorting him from me. OK. I realize that. And that's not uncomfortable for me entirely, you know, it is a little bit but not seriously.

In a similar vein, another caregiver demonstrated the interrelationship of her needs with her husband's needs by describing how a long-term care placement with more age-appropriate recreation and social opportunities for her husband would ease some of the demands of the mental and emotional aspects of her caregiving role.

> I think for me what I'm searching for is a community for him that he would be comfortable in, surrounded like with people that he would be comfortable with. So when, when that happens, then I could say, well this is working... would, as a caregiver will lessen my, my worry, my burden. Would help me with my emotions because, and would help me in, OK, now he's comfortable there, now I can step aside as a caregiver and maybe

> now I can do where, what I would like to do and I have no idea what that is because there's no time to think about it. So it's, it is about my life is about [care receiver] and I can't help but be because it's, it seems to be there.

Supports for Care Receivers Affect Caregivers' Experience

The women's description of and recommendations regarding supports to decrease their caregiving-related costs focused heavily on formal supports for which the care receiver was the primary target client. The women talked a lot about services within the health, education and social service systems that are intended to address the medical, personal care, education and social/recreational needs of persons living with a disability or chronic illness. By comparison, the women spoke much less about their experience with supports intended to directly benefit them as caregivers. It was apparent from the women's stories that they feel that when available supports adequately address the care receivers' needs, this in turn provides them with some relief or makes some aspects of their caregiving role easier. On the other hand, when these supports are inadequate there can be a negative effect on caregivers. The women shared both positive and negative examples of how care and disability-related supports for the care receivers have affected their caregiving experience.

Positive Experiences With Supports for Care Receivers

The women's experience highlighted the fact that formal services for the care receiver can benefit the caregiver by alleviating some caregiving demands. Additionally, the availability of formal supports can help to ensure that not all aspects of the care receiver's care are the sole responsibility of the unpaid caregiver all of the time. One woman talked about the sense of relief that comes from knowing that it is not all up to her:

> I mean Home Care is just essential. And we are so, um, blessed to have it, have it available… it has alleviated the stress of thinking what happens if I can't do this. … I remember that feeling when he first came home from hospital and thinking, OK, so I can, I can do this but what if I can't. I've got a cold or I've, you know, hurt myself, whatever. So that's really alleviated that stress, knowing that there's a long way to go in the amount of home care or the kinds of home care they can provide.

Another woman suggested that in addition to feeling supported as a caregiver, having some support with physical caregiving tasks was also helpful in maintaining a positive relationship with her partner outside of their caregiver/care receiver roles.

> Well we have the Home Care program. And I need to go over a lot of the daily tasks that are a lot of work for me. Such as dressing him and bathing him, and helping him, you know, his personal grooming and things like that. And that, well helps keep our relationship a little more stable I think just because I'm not taking care of his every single need and I can sort of focus on him more as a partner, more than just somebody I have to do something for. And I mean they've also, they're also on our side trying to get more funding for equipment and the new bed and things like that so they're trying.

In the context of describing what has made a positive difference for her as a caregiver, another women commented on improvements that she has noticed in areas such as inclusive education, accessible transportation or better income assistance for persons with disabilities who are not employable. The examples that she gave would not usually be considered as caregiver supports. However, she was presenting them as not only improving the quality of life for people with disabilities but also having a positive impact for the caregivers who support them.

Negative Experiences With Supports for Care Receivers

On the other hand, the women also gave examples of situations where the benefits to them as unpaid caregivers were negated or minimized when the available supports and services were not dependable or did not adequately meet the care receivers' needs.

One woman talked about the stress she experienced as a result of home care workers who could not be counted on to arrive when scheduled. The benefits and support for her as a caregiver were also further limited when the home care staff increased expectations regarding the amount of care the unpaid caregiver should provide since she was coming home for her lunch break. From this woman's perspective, only the care receivers' needs were being taken into account and not her needs as a caregiver with multiple, additional responsibilities:

> I was coming home for lunch and that I was supposed to give him lunch. And then I said, so instead of make it easier for me, you're making it harder for me. I mean, my lunch hour, I work very hard at [place of employment]. I need to eat myself and I need to rest a little bit.

Another woman described the impact on her as a result of the sometimes less than adequate and dependable home care services:

> We have a lot of problems with Home Care... A lot of workers that, you know, take a really, really long time to do something... sometimes it's not as if they're being helpful because I have to watch over and make sure that they're not forgetting anything or. So I spend more time watching them making sure everything's getting done or that they've had everything they need.

In another situation, the caregiver often felt solely responsible for her husband's care despite the availability of home care services because the service providers could not adequately deal with some of his care needs and difficult behaviour. She indicated that she did not always use respite services because her husband would become so upset before, during and after these breaks that the staff would ultimately not want to return. Consequently, she felt that she was left with no choice but to have periods of time where she was providing twenty-four hour care, seven days a week without any break.

Another woman encountered similar difficulties with both government and voluntary sector employment programs for her son with disabilities. Her son has completed a few programs but from her perspective, the service was not adequate because service providers did not direct him to training that appropriately matched his abilities. As a result, they also did not find appropriate and long-term employment opportunities for him.

Beyond issues related to the adequacy, dependability or quality of the services provided, the caregivers also talked about their experiences when programs and services did not have sufficient flexibility to respond to their specific situation and needs. Generally, the women felt that the benefits to both caregivers and care receivers were not what they could have been if there had been both the ability and willingness to respond to their individual needs or their needs as a family.

For example, the woman with concerns regarding employment programs for people with disabilities talked about encountering eligibility criteria that excluded her son even though he could likely have benefited from the services being provided. In her words:

> Like it seems every time that they bring out some program, he never seems to fit the criteria. He's either a year older or a year younger or whatever. Never seems to fit. Like he's been given the run-around, you know.

Another example of inflexibility was apparent in another women's experience with school system policies that prevented communication between her as her son's caregiver and the teaching assistants who were largely responsible for his care during school hours. She talked about how this had significantly increased her stress as she did not receive information about care related needs that may have arisen during the school day. In turn, she could not share information about how to best manage some of her son's care needs in the school environment. She shared examples of a few situations where her son suffered potentially preventable injuries at school as a result of this "communication gap". Consequently, she became increasingly concerned about his safety and well-being in the school environment quite aside from any issues related to his individualized education plan.

Another woman talked about encountering programs and services that did not respond to her family situation with an employed partner with physical disabilities and a young child. As one example, she summarized her experience with a lack of flexibility in home care service provision:

> Sometimes it feels also that when we call the office… we're not getting the help that we need because the Home Care system is not designed for young people with disabilities. It's designed for people who don't go to work and who have all day. They have a hard time sending us people at the times that we need… They don't seem very flexible to help us in our specific situation. They say, this is our rules and this is this.

She encountered similar difficulties with trying to secure accessible housing because access to certain units requires advance participation in independent living training regardless of the person's family situation, abilities and prior experience with independent living. She also found similar inflexibility in equipment funding programs that would only fund basic equipment deemed as a necessity and excluded funding for more specialized equipment that would have meant significant quality of life improvements for her family. Two specific examples that she gave were a specialized crib for her daughter so her partner can hold her independently and two ceiling track systems so that transferring to the sofa in the living room in order to participate in family life would be as much of an option as transferring to bed and the toilet.

Two of the women also talked about encountering a lack of flexibility and related difficulties when their care receivers' service eligibility, programs and service providers changed with their transition to adult services at age 18.

By contrast, another woman talked about the increased benefits and decreased difficulties when, for a period of time, she was able to access home care services that were publicly funded but provided by a private agency. From her perspective, the private agency appeared to have greater flexibility to respond to their needs and requests with respect to scheduling of service as well as both gender and continuity of the direct service providers. This caregiver talked about how this made a positive difference for her because it better met her needs and enabled her to decrease her own and the care receiver's stress related to service delivery. This was due to the fact that she had to do less reeducating of staff, and her family member's negative stress reactions to change were reduced.

Theoretical Connections

The fact that the women placed greater importance on supports to the care receiver for their needs than on caregiving-related supports for themselves could be interpreted as another example of the women's self-sacrifice and putting others before themselves in the context of their commitment to their caregiving role. Ellis-Hill and Payne (2001) note Smith's finding that "family caregivers' stories are often embedded in patients' stories and that they do not expect to talk about themselves or their feelings" (p. 162). There was some evidence that most of the women in the study often neglected their own self care or in other ways put the needs of the care receiver before there own. However, the women's emphasis on support to address the care receiver's care and disability-related needs seemed to stem mostly from the fact that there were direct benefits to them as the caregivers when these supports were effective in addressing the care receivers' needs.

According to Benner and Wrubel (1989), "in our modern era, when care and caring are devalued, it can seem that caring is a problem or *the problem*" (p. 5). It was very apparent that these women did not want their caregiving role to be identified as the problem. Instead they were suggesting that a lack of supports for them in their caregiving role including supports directed towards meeting the needs of the care receiver is the problem. This issue seemed to be central to their experience and directly responsible for many of the caregiving-related costs that they identified. This is consistent with the feminist theory on caring and its proposition that negative consequences of women's unpaid caregiving experiences result from the social conditions under which it occurs rather than from the caregiving itself (Armstrong & Armstrong, 2002; Baines et al., 1998). Similarly, in a recent discussion paper on developing a "family supportive policy agenda", the Canadian Association for Community Living (2005) recognizes that:

> For families, "caregiving" is not the issue. Instead, it is the difficulties that arise because their family member cannot access needed disability-related support; because barriers to inclusion in the community persist (in childcare, education, after-school care, recreation, transportation, etc.); and because of a lack of economic and other support when they are expected to become a major provider of personal care services. (p. 6)

Additionally, this finding is also consistent with Fast et al.'s (2001) argument that in order to determine the economic effects of a particular policy intended to benefit caregivers, it is necessary to look at "the collective effect of the complex maze of interrelated polices and policy instruments that exist in Canada" (p. 1). These authors suggest that in addition to looking at caregiver-specific policies, it is necessary to consider the impact of health care, income security and other policies and programs.

Recognition That the Caregiving Role Exceeds 'Normal' Family Roles and Is Deserving of Support

Caregiving Role Exceeds Care Provided in 'Normal' Family Roles

These women identified themselves as having a personal, family relationship with the care receivers (i.e. spouse, common-law partner, parent). However, they also recognized that their caregiving responsibilities went beyond what would normally or usually be expected in these family relationships. These women see their caregiving role and related activities as different from the roles and activities that family members undertake to support each other when there is not a chronic illness or disability involved. For instance, one woman describes her caregiving role with her common-law partner as being different from what one would usually expect "mainly because I spend a lot of time taking care of him rather than just caring for someone".

The differences in the family as a result of the illness or disability-related needs were also apparent in the women's descriptions of family life. For example, a few of the women also talked about the extraordinary effort required to plan fairly routine or regular family activities such as children's recreational activities, family outings or vacations. As one of the women stated: "you know, so when we want to plan a vacation, for instance, a lot more work, a lot more work and sometimes it just doesn't seem worth the work to do it..." On the other hand, one of the other women suggested that in her experience it has all been worth it. Despite the physical effort required on her part to take her son on a camping trip with a children's organized recreation program, she emphasized that "it was a lot of work but I don't regret it because he, he was, the experience was that he would have never gone through, you know".

Some of the women also talked about the importance of trying to maintain 'normal' family relationships in spite of their caregiving role and the efforts that they make in this regard.

In some cases, they talked about the importance of maintaining a relationship with the care receiver outside of the caregiving role. One woman, in particular, emphasized how important it was to her that she maintain a separation between her "working" or caregiving relationship with her partner and their relationship as a couple. She said that this is something that she and her partner consciously work at but that it is not easy. She said that there can be a tendency for frustrations or other emotions from one aspect of their life together to spill over into the other. However, she feels it is essential to maintain a healthy relationship as intimate partners and parents that is independent of their caregiving relationship as much as possible. She describes how they try to manage the two different aspects of their relationship:

> …we sort of don't spend all our time that we have together me doing things for him as well so that we take time out to do something fun or, you know, as a regular couple would do such as, you know, get a movie or spend time talking together. Not just me spending time doing things for him. We just sort of keep our times a little separate.

In other cases, the women emphasized the importance of maintaining positive and 'normal' relationships with other members of the family. For example, one woman emphasized the importance of balancing her intensive caregiving role with her one son with her parenting role for all of her children. She described strategies that she has used to do this including proactively creating opportunities for special times with her other children. Additionally, in order to instill them all with the same values and sense of right and wrong, she also disciplined all of her children similarly including her son with disabilities and involved them all in regularly attending church as a family.

The women's perspective is consistent with previous findings indicating that caregiving due to chronic illness and disability is different from traditional tasks and activities within a family because it represents "the *increment of extraordinary care* that goes beyond the bounds of normal or usual care" (Biegel et al., 1991, p. 17).

Caregivers Deserve Support

These women also appear to share the belief that as caregivers they are deserving of more support due to the fact that they have extraordinary responsibilities and incur related economic and non-economic costs.

One of the women mentioned several different types of extra expenses that she and her partner faced as a result of his disability. She suggested that in her ideal scenario all personal care and equipment costs would be covered based on what provides the best quality of life rather than just meeting basic necessities. She stated that "I think they should be all covered to help him get as normal a life as possible". She gave examples of equipment that would not currently be covered, but in her opinion, should be so that they did not have to be financially disadvantaged in order to have a comparable lifestyle to young families without an adult with a disability.

As a result of their experiences, some of the women were quite adamant in asserting that governments need to do more to support caregivers and families. One woman emphasized government's role in addressing financial costs and suggested that "if government wants more parents to take care of their own, definitely they have to help out financially much more than they do now. Because it is very, very, it's getting more and more expensive". Another woman caring for her husband also expressed the opinion that government could be doing more to decrease the financial-related stress and worry that caregivers such as her have experienced. Another woman emphasized the need for government to adequately fund equipment and other types of supports such as attendant care services and replacement care for caregivers' respite breaks. In the early days of her close to 30 year caregiving experience, this woman had had to explain to program staff and administrators that "I'm really trying hard to be a good parent to do the responsible thing here". She talked about the struggle to get government staff to understand that if she did not get some help that she would reach a point where she would be physically and/or emotionally unable to care for her daughter thus leaving her no one to care for her.

Although most of the women focused their discussion on the need for more government support and formal services, one of the women also talked about how she felt her neighbours and friends could have been more supportive. As a result, she intended to offer support to other caregivers so that they did not feel as isolated as she has.

For some of the women, their belief that there should be more support was also connected to their perception that they had been treated unfairly by government and others. For example, one of the women talked about the amount of financial support and replacement care services for respite breaks that foster parents of children and young adults with disabilities received. She compared this to the very limited support she had received in both of these areas and concluded that "something is not right". Another woman described how it was difficult to understand how a home care service provider could be paid to do the same caregiving tasks that she did at other times of the day or when they did not show up. She said that she had been advised that it was a "conflict of interest" to pay family caregivers for their caregiving-related work. Another woman also described how government has actually contributed to her caregiving-related financial stress due to the fact that the income tax system does not take into account and deduct the full amount of her caregiving-related and cost of living expenses from her income in calculating the amount of income tax she owes. Another woman shared this sense of unfairness as she expressed her frustration at the fact that she does not understand why she and her son have not been able to access the same types of supports and opportunities as some other people with disabilities and their caregivers whose situations are known to her.

Desire to Share Experience to Benefit Other Caregivers

In addition to expecting government and others to take action to provide more support to caregivers, the women also had an interest in and seemed to feel some personal responsibility to share their experiences and knowledge in order to benefit other caregivers. All of the women interviewed indicated either during the interview or in their initial telephone contact with the researcher that this was why they were motivated to participate in this research study. One woman said that "if it might benefit somebody or it can be a blessing for somebody, then I will do it. I cannot say no". A few weeks prior to the interview and for the same reason, this woman had also accepted an invitation to share her life story with a group of women within her faith community. Another woman described how, due to the lack of support she had experienced since the onset of her husband's illness and disability, she was motivated to make sure others did not have the same type of experience. In her words:

> But that's why when I read your note, I thought, well there's something that I could perhaps make a difference and this is probably what I would

> like to do is do something that would make a difference too. And yet you can't really give anybody any advice or, because you're not qualified to do that. But just to be there on the other end of the phone, answering the phone and just saying, have compassion or lead them in a direction that maybe they would like to take or told that there are options. And not only tell that there are options but give them their options because there's no point in telling them what the, that there are options because they don't know what they are. It's when they're upset and upside down like that, they, they can't even begin to ask the right questions because they don't even know what the right questions are. If it's a young family or. That's what I would like to do.

Beyond her participation in the research interview, this woman talked about looking for other opportunities to provide support to other caregivers either through volunteer work or simply reaching out to others in her community if she learns that they are facing a similar situation. Another woman indicated that she has helped others by sharing information that she has gained from her caregiving experience and offering practical support, particularly in the area of income tax deductions and financial supports. Another woman had volunteered as a presenter at a support group that she had previously attended in order to share her experiences with 'new parents' learning to support their child with a disability. Another woman had taken a role in supporting other caregivers in an even more formal manner by working in a voluntary organization where she is in direct contact with families including other caregivers in similar situations to her own. In this role, she shares information about available resources and how to access them. She is also able to advocate on behalf of other caregivers and families or advise them on how to advocate on their own behalf.

A few of the women also expressed their hope that the research would be shared with government decision makers so that they can understand the need for changes to better support families and caregivers. Three of the women indicated that they had already attempted some action on their own by making telephone calls or writing letters to provincial politicians, government staff and others regarding particular concerns and issues as well as about the general need for more support for caregivers and families. One woman had even taken her interest in improving the experiences of caregivers and families to another level by becoming an elected official in order to have more direct influence on changes in the systems that she has encountered as a caregiver.

Theoretical Connections

The women's experience is reiterated in one community organization's description of the current context as one in which:

> Unsupported parents, spouses, siblings and adult children who provide assistance, are required to act as more than just a caring family member. Their role is expanded to provide often unsustainable levels of support beyond those of a typical family. (Canadian Association for Community Living, 2005, p. 6)

According to the Canadian Association for Community Living (2005), "when disability supports are unavailable and when social networks and community systems fail, or remain undeveloped, inaccessible, or unaffordable, then unmet needs can turn a "'caring relationship in a family into one defined primarily, or even exclusively, by 'caregiving'" (p. 5). It is evident from the women's descriptions of their efforts to normalize relationships within their family in spite of their caregiving role that this is exactly the type of situation that they want to avoid. The need for additional government and community support is particularly critical for the women in this study because "for families supporting a family member with a long-term disability, the levels of support required are dramatically increased and extended for a longer period of time" (p. 6).

Through their actions and recommendations for change, these women were essentially challenging the assumption that caregiving for family members living with a chronic illness or disability is a private responsibility. Although they indicated that they willingly accepted the caregiving role they also felt that there should be more support available from government and/or the community to offset the negative consequences that they experience as a result. Their view also seems to be consistent with a theoretical framework that suggests that both unpaid caregivers and formal service providers should be involved in providing care to people in need. In their ecological policy paradigm for elder care, Keating et al. (1997) suggest that the client's caring environment should be seen as one involving a complementary interface between unpaid caregivers and formal care providers rather than one being a substitute for the other.

For the most part, the women in this study appear to be seeking a shift towards a "social model for community care" or "social responsibility for care" (Baines et al., 1998; Guberman, 2004) in which they could still choose to play a role in providing caregiving support to their family member while sharing this responsibility with the broader community. This contrasts with their current situations where they are largely responsible for the care of their family members with relatively minimal supports in most cases. Baines et al. (1998) also similarly advocate for the need to recognize caring as a collective rather than an individual responsibility. According to Guberman (2004), the central principle of this model is that caregiving is a social responsibility that involves "the development of a partnership between all concerned stakeholders: people with disabilities, family caregivers, the public sector, the private sector, the voluntary sector and the community, a partnership orchestrated by the state and organized around a strong public presence" (p. 82). In this model, caregivers would also not be "penalized" or disadvantaged for taking on the caregiving role. In recent discussion on the ethics of caregiving and caregiver support, Hirschfeld & Wikler (2003) also challenge the assumption that caregiving is a private family responsibility. They advocate for a balance between public responsibility and resources and family responsibility and resources.

The women in this study were generally expressing support for this type of shared responsibility that would yield additional supports for themselves and their family members living with chronic illness and/or disabilities.

Caregivers' Costs Are Exacerbated by Barriers to Identifying and Accessing Supports

A consistent aspect of all of the women's caregiving experience was the fact that information about relevant resources is not readily accessible or fully disclosed to all caregivers and families who could potentially benefit. It was their perception that they regularly encountered barriers in identifying and accessing external supports to meet the care receivers and/or their own needs. For these women, this has meant that they have spent a tremendous amount of time as well as mental and emotional energy in seeking out resources and information. They have also had to advocate for access to necessary supports. All but one caregiver described this as a costly or negative aspect of their caregiving experience. Even the individual who felt that her strategy to reach out and build a network of formal support had been an effective coping strategy, acknowledged that many people do not know about available resources or how to find out about them.

The women's stories highlight the significant amount of time and energy required to address this aspect of their reality. One woman summarized her overall experience with accessing resources as “very difficult” particularly in the early years when she was on “a learning curve”. She described how she learned to be the “squeaky wheel” in order to have her own and her daughter’s needs adequately met. Advocacy was a central aspect of her caregiving role and she emphasized the amount of time and energy that this has required.

> There’s the physical caregiver and then there’s a whole other piece where you, you are the advocate. Or you are putting a lot of your emotional time and energy into writing letters to the minister, contacting program directors with the government to make them aware of your situation or just saying, you know, can we work together on changing what’s happening. And just going through your whole chain of command… You know you have to just be, you start with your, your worker when you don’t get a response. There’s that appeal process.

Another woman described in detail a particularly frustrating situation where she consistently spent time making telephone calls, writing letters and meeting with service providers over the course of a number of months just to access funding for a single piece of equipment for her son. From her description, it was evident that she had literally spent dozens of hours on this task. Another caregiver summarized her similar experiences:

> We had a hard time getting calls back or being directed to the right experienced people or the right departments. Um. It’s… weren’t able to direct us to somebody to speak to about any of that. Um. They couldn’t sort of say, oh here’s the person in charge of that, how about you talk to them. They just weren’t able to or they, oh we’ll phone back and we never got called back. And I’ll get really frustrated getting the runaround.

The same caregiver also indicated that this work does not necessarily stop once a particular resource or service is in place. Even with home care services in place, she reports that “I spend a lot of my time trying to organize and coordinate it and get them a little bit, a little bit better for us”.

Another woman shared how she often learned about resources by accident or coincidence through her informal network. This occurred despite her ongoing contacts with social workers and other professionals who were familiar with her family's needs and circumstances. She describes one such situation:

> Things that we learned from neighbours and things that we heard… I learned that from somebody from BC that there was loans that you could get to help out… she says, you know, you could probably add an addition to the house because there's a loan that you could have because you are keeping, taking care of a handicapped son or daughter, whatever. And nobody, there was no social worker, there's no, nobody ever told us about this. If I wouldn't have talked to her and she wouldn't have, like it was just a coincidence back then because her brother was in construction and they were doing repairs to a home to where a young adult was living. So, I grabbed the phone and I called. Oh yea, yea, yea… I said most parents and families don't know about these things. Why is it not told. Like why are we not informed.

It is important to recognize that the time spent in researching available resources and advocating for access significantly increased the amount of time that the women spent in caregiving-related activity. By extension, this has further limited the time they have available for other things such as paid employment and/or for addressing their own needs. In other words, there are both economic and psychosocial costs incurred by caregivers due to the fact that information about relevant resources is not readily accessible to everyone and that caregivers often experience barriers to accessing these resources.

Economic Costs Associated With Barriers

In many instances, if the time the women spent in trying to find and access resources was valued in monetary terms, the costs would be ridiculous in comparison to the monetary value of the equipment or services they are trying to access.

Additionally, some of the caregivers also described how they incurred additional and potentially unnecessary out-of-pocket expenses as a result of being unaware of financial assistance resources. One woman gave the example of not being advised that incontinence soaker pads for her son's bed could be provided free of charge. As a result, she spent many years washing his bedding everyday and incurring extra unpaid labour time and laundry costs on a daily basis until she met another parent caring for a child with similar incontinence difficulties who advised her how she had been able to access these supplies. In another example, the caregiver chose to proceed with home renovations at her family's own expense and with the assistance of extended family members after unsuccessful and frustrating efforts to get information on potential financial assistance resources.

Psychosocial Costs Associated With Barriers

The women's psychosocial costs resulting from barriers to accessing supports are also very significant. Caregivers experienced frustration and other negative emotions as well as associated stress due to the intense and ongoing effort required on their part to get their families needs met.

For example, one woman talked about how hard she worked to find information and resources via a combination of internet research, telephone calls and discussions with health care providers. She emphasized how this was especially difficult to do when she was grieving the loss of her husband's abilities and their relationship as it was prior to the sudden onset of his illness.

Another woman has advocated for her son over the years with politicians and organizational representatives but her efforts had not yet resulted in any significant changes in her son's situation. Consequently, she has become very frustrated and angry:

> And I've sort of been his advocate and I'm sort of like a, but for me Mrs. Milgaard. She got her son. And I've done everything, everything and he... Well I mean I've, you know, I've marked down everything that he's gone through, like you know. And whenever, um, like he's been interviewed or whatever, like you know, or when there's been some problem or that, you know, I would phone. And gone to MLAs and everything. But the victims are left, you know. They're OK when it's time to vote you know, they'll promise you the world and that and so he's just in the, you know. And the thing is that makes me angry is like, you know, I'm retired and like I'm on a fixed income.

Another woman's frustration was also evident when she asked the question, "Why do we have to fight all the time for things that are, that's right, you know, actually?"

Barriers Resulting From Service Providers' Attitudes and Behaviour

Some of the women also talked about how their caregiving experience had been both positively and negatively affected by the attitudes and behaviours of social workers and other professionals as well as paraprofessional service providers. As with so many other aspects of their experience, the women generally reported having a mixed experience in this regard. They indicated that some staff that they encountered were helpful while others were not or were helpful in some areas but not in others. In providing feedback for the member validity check, one of the women particularly emphasized that her main frustration is not with the systems, agencies or the programs themselves but rather with the social workers and other people in the system.

Another woman summarized her experience with social work staff in the various programs that she came into contact with as being generally helpful yet still contributing to her caregiving-related costs because relevant information about potentially helpful resources was not shared. In her words:

> I never had difficulty, um, working with them. They've always been very helpful and stuff. It just, things that we could have had through the years. I don't know why they don't tell families. I can't pinpoint it. I don't know why and, but anyways, we were not told.

She also talked about some program administrators who by their attitude and behaviour made it even more difficult for her to jump through the necessary hoops to access needed resources. She described how she was not given any explanation for delays related to a funding request. However, she ultimately concluded that she had been asked to do additional background work with respect to additional estimates so that staff could defer a decision on her request until the next fiscal year when new funding would be available. As a result of this and other experiences, she believes that not telling families about all potentially available services and sources of financial assistance is a way of rationing services and managing budgets without acknowledging that this is what is happening:

> And I says, why were we not told about this? It seems as though, and I can't understand and I'm wondering if that's the way it works. Like the social worker and/or that department works on a fixed budget that I know… So to meet that budget, I think they tell certain families about certain things. And the others are just next year and the next year and the next, you know, because my budget only carries this. And I can't tell'em that this is available, that's available or that's available because I'll blow my budget to kingdom come… And it gives us that feeling, families. I've talked to other families and we feel the same way. Like just, is it, is it facts, is that the way it's, it is run. Is that the way it functions or is that the way it. And so you try, I know they have to keep in their budget. I've been on so many committees and dealing with so many things, I know how it works... But then the families need these things and they're not given information on how to get it and where and, and what's possible and what's not possible.

Through their stories, the women shared some examples of the specific types of service provider attitudes that they encountered that increased their financial and/or psychosocial caregiving-related costs.

Firstly, some of the women encountered situations where the service providers' rigid application of assessment and other criteria reinforced an assumption of care. In other words, they assumed that these women should be the primary caregivers and that available supports should be available on as limited a basis as possible. One woman described this as "the attitude you should be thankful for what you're getting". She stated that "I always felt like they were really doing me a favour and I should be really thankful that I'm getting any help at all". Another woman felt that the same type of attitude was involved when home care services related to providing her son with lunch were eliminated when home care staff discovered that the caregiver often came home for lunch herself. The assumption appeared to be that if she was physically there she should be providing any necessary care and support to her son regardless of the fact that this was her "break" from paid employment. Yet another woman talked about the assumption of care behind the changes to her partner's home care service after they moved in together:

> Home Care assumes because I live with him that the Home Care workers no longer need to prepare meals and make sure he takes his pills. Make sure he has clean clothes cause before, if he was living on his own or in a co-op group or something like that, that would be completely up to Home Care. He'd have to have a worker come in and clean for him and, uh, cook for him and everything. But because I live with him.

A couple of the women also expressed concerns regarding attitudes among service providers that did not respect and value people with disabilities or their caregivers. One woman described how this surfaced for her with direct home care service providers who would provide personal care to the care receiver without closing doors so that care was provided in a manner that she felt did not respect her family member's right to privacy when others were in the home. A few of the women also described their concerns related to staff in various aspects of the health, education and social service systems who appeared to minimize their family member's abilities. The women suggested that some staff did not appear to recognize and respond to the care receiver's potential to make meaningful progress and contributions.

On a different but related matter, another woman suggested the fact that people not recognize people with disabilities as sexual beings capable of having a family of their own has created barriers to service providers recognizing, understanding and responding to her family's needs.

Beyond this, three of the women specifically referred to service providers' and societal attitudes related to the employability of people with disabilities as contributing to their financial costs and/or making the mental and emotional aspects of their caregiving role more difficult.

For the most part, the women talked about these problematic attitudes at the individual service provider level. The implication was that these attitudes made things more difficult for the caregivers by increasing their worry as well as the need for advocacy to ensure that the care receiver has access to appropriate supports. However, one woman suggested that the provincial government's overall attitude and approach to supporting people with disabilities was also relevant. She highlighted what she saw as signs that Manitoba's provincial government was beginning to take a more respectful approach with recent initiatives such as new inclusive education legislation and a new income assistance program for people with disabilities.

Some of the women also encountered situations where they felt that their caregiving role and "hands on" expertise regarding the care receivers' abilities and needs were not respected or listened to by physicians, educators or other service providers. For example, in her member validity check feedback, one caregiver emphasized the difficulties that arose for her as a caregiver when health care staff limited her access to information regarding the care receiver's condition and treatment. In another instance, one woman provided several examples of her experience with the school system where teachers and others would not acknowledge her expertise and listen to her regarding her son's care needs in the school environment. In her son's school division, a particular policy prevented teaching assistants from communicating with parents about their children. According to her, the intent of the policy was to prevent paraprofessionals from commenting on the students' academic progress since only teachers are deemed qualified to do this. However, in her experience this policy was being applied rigidly to all communication between the teaching assistant and the parents. She felt that she needed to be able to communicate with the staff who provided direct care and supervision to her son for most of the school day. She wanted to know how he was managing in the school environment from a non-academic perspective and if there were any difficulties related to his physical and personal care needs and related matters. She also wanted to be able to convey information about how she was experiencing and managing his changing needs at home. She described the difficulties and safety concerns that her son encountered when this communication was not in place. She also contrasted this with her experience when one teaching assistant took it upon herself to break the rule and risk her job security in order to regularly communicate with her. She said that this person's willingness to work outside the policy made a significant difference to her as she was able to have less stress and worry regarding her son's safety and well-being at school.

Another woman described a similar contrast between her experience with two different physicians. She described how she felt supported when a new physician explicitly acknowledged and valued the fact that, as a mother and primary caregiver, she had some knowledge of her daughter's needs and care. By contrast, a previous physician had labeled her as having difficulties with adjustment and denial when she did not fully accept his negative prognosis for her daughter's development.

Potential solutions

In addition to sharing their experience with these barriers to identifying and accessing supports, some of the women also shared their perspective on potential solutions to address this significant issue. Although their specific suggestions somewhat varied, the women were all generally proposing that there is a need for a mechanism(s) within the formal health, education and social service delivery systems that provides for automatic, equitable and complete provision of information regarding all relevant organizations, programs and services to all families affected by chronic illness and/or disability.

In their discussions, the women were suggesting that all families affected by chronic illness and/or disability should automatically be advised of the existence of such a mechanism once it is in place. This way they will know where to turn as they begin to search out information and resources. Furthermore, some of the women talked about the need for complete information-sharing that would not be dependent upon caregivers' requests or inquiries. Based on their experience, they were looking for a way to address the fact that caregivers, particularly in the early stages of their experience, do not even know about the types of services and support that they should inquire about.

In general terms, these women were recommending a centralized resource for accessing information on all available sources of financial and other assistance. A few emphasized the importance of having a central contact point identifiable as "the place" to phone or visit for information. Websites, telephone lines and designated offices were all suggested as potential options.

In their experiences, the women often had to contact a number of individual organizations whenever they were trying to get information on resources or help with a particular issue. One woman summarizes the current situation from her perspective:

> You have to talk to the Health Care people and then they have to make the inquiries so things get lost and the interpretation of what you're wanting or what you're needing. And because there's that time span and you could have to wait for someone to get the inquiries for you, there's no, there's no direct place where you can go.

Overall, it seemed that the women were looking for a central contact that could more quickly direct them to the appropriate organization or resource. In this way, the time and energy required would be minimized.

One woman suggested that the development and maintenance of a comprehensive manual that would be automatically given to all families is necessary to ensure that the information is available to all relevant people across the province. She recommended that this type of manual be developed for families with a child with a disability since this was the basis of her caregiving experience. She feels that this type of mechanism is necessary to ensure that all families coping with a child with a disability have equitable access to the same information on the potentially broad range of services, equipment and funding options that could be beneficial to them over time. Given her experiences, she felt that this was preferable to any situation where professionals are in a position to play a gatekeeping role by sharing certain information about resources with only select families. She felt so strongly about the need for this type of mechanism that she indicated that she had even contemplated writing this type of resource herself.

Another woman suggested that a support group focused on resource information for caregivers might be an appropriate mechanism for sharing information particularly about the financial resources that other caregivers have found in "nooks and crannies". Although this woman had successfully accessed the resources that she required, she acknowledged that there are others who would be less knowledgeable about where to start and/or skilled in taking on this type of search for resources. From her perspective, the support group would provide opportunities for those who are less experienced or have less knowledge to benefit from the knowledge and experience of others.

Finally, another woman suggested that a publicly funded course for caregivers could also be a mechanism by which this type of information was shared with caregivers and potentially their other family members as well. From her description, she appeared to be recommending a psycheducational program where caregivers could be provided with both information on particular topics and resources and support in developing their coping strategies.

Although their specific recommendations varied, there seemed to be consensus that no adequate mechanism currently exists and that government should play a role in ensuring that some publicly funded mechanism is developed to address this significant and costly aspect of caregivers' reality.

Theoretical Connections

Feminist theory on caring is useful in examining the women's experience with the barriers they encountered in identifying and accessing supports.

Firstly, there appear to be assumptions being made at both the service provision and policy design level regarding the women's willingness and availability to provide this unpaid caregiving support. This reality is consistent with Baines et al.'s (1998) contention that caring work such as unpaid caregiving for family members with chronic illness or disability has been defined as women's "natural responsibility". They further suggest that "this orientation underlies policies that lodge responsibility for others with women and limit programs to supporting women rather than redistributing responsibility for caring" (p. 9). This was clearly evident in the policies and practices that the women encountered whereby they and their care receiver were provided with the least amount of support possible based on the assumption that the care receivers' care is primarily their responsibility. Hooyman and Gonyea (1995) propose that the ideology of familialism is behind the assumption that women will be available to provide free caregiving labour in the home (pp. 111-112). This ideology defines caregiving as an individual responsibility. The expectation that home care supports should be cut back because a caregiver comes home during her lunch break from paid employment is just one piece of striking evidence of this type of ideology at work in the lives of these women. In other cases, the women were clearly not offered additional supports until they inquired about them and often not until after they expended considerable time and energy in repeatedly presenting their case with respect to why particular resources or supports were needed.

There also appears to be a lack of regard within the health, education and social service systems as well as by some individual service providers for the cost implications of the time involved in accessing relevant external supports. This lack of concern can be linked to the fact that unpaid caregiving work is not valued because it takes place in the private sphere of the home. Feminist theorists and authors have noted the devaluation of caring in the private sphere and the related lack of support and its negative implications for women in unpaid caregiving roles (Baines et al., 1998; Hooyman & Gonyea, 1995). Consequently, the women's experiences would suggest that the current system of supports lacks continuity and coordination to facilitate easy access and encourages an adversarial, advocacy-oriented approach to securing services because no one is concerned about the fact that this costs caregivers additional time. This is due to the fact that women's time in unpaid caregiving-related activities is not valued. Given that women provide most of the unpaid caregiving, they experience most of the related economic and non-economic costs associated with this reality. It would be interesting to see if a sample of male unpaid caregivers would identify the same degree of disregard for their unpaid caregiving time as they attempt to access services.

Furthermore, at least one woman identified the barriers that she encountered in accessing services as being connected to the fact that there are limited resources to deliver services within the health and social service system. She felt that barriers were erected and information withheld in an attempt to ration services in a context where there are insufficient resources available to meet all of the need. The devaluation of unpaid caregiving is recognized as contributing to the current situation where there is a lack of support for caregivers (Cancian & Oliker, 2000). Baine et al. (1998) suggest that this situation has been exacerbated by the Canadian government's focus on deficit reduction and the subsequent reduction of the welfare state. They conclude that the "downsizing that occurs as services are shed, relocated into the commercial or non-profit sectors, or moved by default, back into the family, all have sharp and particular impacts on women" (p. 4).

Need for Improvements in Available Supports to Adequately Address Caregivers' Psychosocial and Economic Costs

The women identified inadequacies in the current system of supports with respect to their ability to have a positive and meaningful impact on both their psychosocial and economic caregiving consequences. They also shared their thoughts on how things could be improved.

Supports for Psychosocial Needs and Costs

While many of the women talked about the important role their informal support networks played in meeting their caregiving-related psychosocial support needs, most of them also talked about their experience with formal supports intended to address these needs. Overall, the individual women's experiences combined highlight a very varied situation with respect to formal psychosocial supports for caregivers. The women also differed somewhat in terms of the types of support that they felt would be most beneficial.

Some of the women had had experience with self help or support groups or events offered by umbrella disability or disease-specific organizations in the voluntary sector.

Some of these women spoke positively of the opportunity to connect with other caregivers. Two of the women were particularly articulate in describing the importance of the psychosocial support that they received from their connections with other caregivers in similar situations who provided both emotional support and practical advice. According to one woman:

> But it surely helped understand that we're not the only ones that are going through this. Some have already been through this and they're doing OK and the parents are doing OK and the kids are doing OK. So OK, let's think this, not, battle this challenge and let's run with it, you know. And it helped us quite a bit joining this group.

Another woman described a similar positive experience:

> And I had an opportunity to help with other people who take care of people as well and relate our stories and our difficulties and, you know. Learn a little bit about our situations and constantly see the, you know, my situation, there are other people in similar situations. I'm not alone.

However, some of the women who had participated in support groups did not feel that they provided support that reduced their negative psychosocial consequences. One woman even suggested that she stopped participating not just because of scheduling and time demands but also because participating made her more emotionally distressed:

> But they kind of didn't help me. They kind of got me more upset, talking about other people and talking, seeing how much, how much pain, how much sickness and how much troubles is around. I would come home and I couldn't fall asleep and plus when I come home from work I'm usually tired.

Similarly, another woman was frustrated to discover that the psychosocial support services that were available for her as the caregiver did not meet her needs. She talked about two different experiences where she sought out support for herself in order to emotionally come to terms with her situation and obtain information about her husband's condition and available resources. In each case, she did not feel that she received any help or support. Firstly, she was not able to relate to the other caregiver participants in the support group because they were caring for family members other than a spouse who were significantly older than her husband. Consequently, she felt that their caregiving situations and their needs were very different from her own. She also met with a psychologist once but found it "more stressful to go than not" because she was frustrated by the professional's body and verbal language which indicated to her that she was not really interested or did not understand her needs as a caregiver. She felt that a more appropriately organized and facilitated support group might be beneficial. However, this woman was also suggesting that the government should fund professional counselling services for caregivers and/or their whole family as well as training and information programs to help caregivers' learn about their role and coping skills and strategies.

Although aware of available support groups, one woman said that she had chosen not to participate because it was currently more important and beneficial to her to foster non-caregiving related activities and interests within her informal network. However, she acknowledged that she may want to move from these informal supports to more formal supports if her situation changes. For example, she suggested that if her husband started to exhibit changes in his cognitive functioning that this might be a point at which she could benefit from more formal psychosocial support such as a support group.

The women also talked about regular opportunities for caregivers to have a break as another important type of psychosocial support for caregivers. In fact, only one of the caregivers did not address the issue of the need for access to replacement care for such respite opportunities. Four of the women talked about their actual experience in accessing replacement care or respite services. The remaining two women felt that they could potentially benefit from this type of support. However, one of them believed that she would not be eligible due to the nature of her son's disabilities. The other woman was aware of human resource shortages within the home care program in her local rural area so had not pursued accessing this service. Two of the women who had used this type of service felt that they had received very limited benefit. In addition to having concerns about the service providers' ability to adequately care for the care receiver, these women also had difficulties in accessing services within a time frame that worked for them. On the other hand, two of the women described how they have incorporated regular respite opportunities into their caregiving reality and what this has meant for them in terms of providing opportunities to rejuvenate and focus on their own needs.

> The respite. The getting away and finding myself. Totally not having to think, OK, I have to be, uh, I can only be away for half an hour because he needs this. When I walk out the door in the morning, I don't think about that.

The woman describes the essential nature of this service for her:

> I mean you have to because you just burn out... And I'm not sure how or why I came to that realization. It just seemed to me that if I knew that it got to a point in time where if I didn't do that, I would be of no use to [the care receiver] or myself.

She went on to recommend that "if anything comes out of this research, it's that, don't take away family's respite".

The women's experiences highlight the fact that different caregivers may need different types of psychosocial support. Furthermore, the same caregiver may want different types of support at different points in their caregiving experience. Consequently, it is evident that there needs to be a range of options available so that caregivers can choose what will best meet their needs.

Supports for Economic Needs and Costs

Given the economic caregiving-related costs experienced by the women in this study, it is evident that the sources of financial support and assistance that are currently available are inadequate to address the full extent and range of their caregiving-related costs. Most of the caregivers talked about the fact that there is currently some government funding for some types of equipment for the care receivers as well as some income tax deductions for some medical expenses. However, they described the resulting compensation as often quite limited in comparison to the true nature of the overall expenses incurred. Additionally, as with other types of supports, the women gave many examples of how it can be quite difficult to get information on what is available in terms of financial assistance and how to access it. Furthermore, one woman also described in detail the labour intensive record-keeping required to claim income tax deductions for travel to medical appointments. She described receiving a net benefit of approximately $10 one year for hours of record-keeping work on her part. This is yet another example of not valuing the time caregivers have to spend in accessing available benefits.

Most of the women articulated a belief that governments have a responsibility to assist to a greater extent with caregivers' caregiving-related financial costs. Most of the women suggested that government should provide additional financial supports to caregivers by reimbursing them for all of their caregiving and disability- or illness-related out-of-pocket expenses either through direct payment or deductions or tax credits through the income tax system. Some of the women did not specifically indicate whether they preferred the direct payment or indirect compensation through the income tax system. On the other hand, some women identified the limitations of the income tax system and emphasized direct payments to families and caregivers. However, there was not consensus among the study participants because one of the women stressed the importance of income tax deductions for all related expenses to offset income. Based on the information shared during the interviews, it seems probable that the preference for indirect compensation through the income tax system might be influenced by the family's current income bracket. For instance, the woman who stressed this option indicated that she was still paying income tax despite the significant caregiving-related financial costs that she was identifying. Overall, the women were looking for improvements to the current situation where only certain types and proportions of costs are publicly funded or reimbursed.

After having the opportunity for further reflection, one of the women suggested in her member validity check feedback that in addition to disability-related expenses, she now also wonders about the possibility of being able to claim expenses as a business manager for herself and her husband for income tax purposes. She summarizes her question and experience as follows:

> Can one claim being a business manager over the affairs of her husband and herself in connection with all the researching, meeting and decision making pertaining to health, safety, rights, applicable taxes, proper medication. Life making decisions becomes a business.

In other words, she is looking for some form of compensation for her time and other costs related to the care coordination and advocacy activities of her caregiving role. It is important to note that she still feels that these aspects of her caregiving role are very time consuming even though her husband now resides in a personal care home.

Beyond compensating out-of-pocket expenses, three of the women also recommended that there should be options for financial compensation or payment to currently unpaid family caregivers for the time they spend in their caregiving role. Despite recognizing some of the complexities involved and the potential impact on her relationship with her partner, one woman still felt that it was an option that should be available for caregivers. She indicated that since others are already being paid to provide the same care that she provides for free simply because she is in a conjugal relationship with a person with a disability. In her words:

> Some days it feels like, you know, that I should [be paid] for the amount that I'm doing. Um. Because a lot of people who come in other days being paid, you know, pretty decently to come in and do, you know, 20 minutes worth of work. And then I'm even doing everything on their list.

Additionally, another woman recognized the fact that there may be financial resources available to caregivers but they simply are not aware that they exist. Consequently, she suggested that another way of addressing caregivers' caregiving-related financial costs would be to provide a support group focused on sharing financial information because "sometimes the financial issue is a matter of finding the resources. Like this isn't going to apply to everybody but there are a lot of little nooks and crannies out there that will, uh, make things easier".

Some of the women talked about financial caregiving-related costs from the perspective of ensuring that both the care receiver and caregiver have access to adequate sources of income. Two of the women suggested that one of the most important ways this could be addressed would be for government and employers to ensure that people with disabilities have access to more and better employment opportunities.

As with supports to address psychosocial needs, the caregivers' range of suggestions for addressing economic costs indicates that there is a need to make a variety of supports available so that caregivers can select the options that work best for their particular situation.

Financial Issues are Considered in Some Caregiving-Related Decisions

In addition to these suggestions for improving financial reimbursement and compensation options for currently unpaid caregivers, it is important to note that some of the women described how financial considerations had played a role in some of their caregiving-related decision-making. The fact that economic considerations have factored into some important life decisions further compels the need for action to better address economic, caregiving-related costs.

The women did not identify financial considerations as having been involved in their decisions related to assuming or continuing their caregiving role. In fact, many of the women emphasized that their caregiving role was something that they would continue regardless of the financial and other costs involved. However, some of the women did describe how they had taken financial issues into consideration when they made other, subsequent caregiving-related decisions with respect to their paid employment status and long-term care placement.

Firstly, a few of the women described situations where they found themselves in the position of considering financial issues when making decisions related to their paid employment status as a result of their caregiving role. For three of the women, their decision-making centred around the possibility of taking early retirement. In one case, the woman felt that she had to work to pay the bills regardless of the amount of her caregiving responsibilities. From her perspective, she did not feel that there were any other sources of replacement income for her throughout her caregiving experience. This consideration also extended to her decision related to early retirement. Although she would have liked to consider early retirement for personal health and other reasons, she had decided that she could not take early retirement because her income would be too low. Consequently, she planned to work until age 65. At the time of the onset of her husband's disability and health difficulties, another woman had been in the process of transitioning to early retirement with her husband after having been self-employed in their own business. Due to the financial stress related to her caregiving-related costs and other expenses, she wanted to consider a return to paid employment. However, as she understood home care services at the time, she thought that she would have to purchase private care in order to be able to go out to work because her husband needed constant supervision. Consequently, she decided that she could not pursue employment because the care costs would essentially eliminate any income gained. Another woman also decided in favour of early retirement in order to focus on her caregiving responsibilities. However, she considers herself fortunate because both she and her husband had adequate disability and retirement pensions so that the decision to take early retirement could be made without significant negative financial consequences.

Financial issues were also a consideration for two women when making decisions regarding the type and amount of care that could be provided at home versus the necessity of long-term care placement. When her son required 24 hour care that exceeded both the level of service the Home Care program would offer and her ability to provide additional care around her work schedule, one woman felt that long-term care placement was the only option that she had left. Another woman also felt that she had no choice when it came to the personal care home placement of her husband since home care refused to provide service in the home any longer. She indicated that the only way she would have had a choice at this point is if she had sufficient income to pay for a substantial amount of private care. If she had had that option, she said that she may have taken it. However, since this was not financially feasible, she had no choice but to go along with placement. She summarizes the situation as "he didn't want to go into a personal care home but, uh, financially it was unaffordable to keep him at home because that meant 24 hour care at, you know, 15 dollars an hour…"

One woman describes the general impact of the consideration of financial issues in caregiving-related decision-making:

> So you have to be careful how much money you had to pay somebody to, to do the job that you know you could do yourself. To come and give him his pills or, or Home Care is paid.

Overall, she concluded that "you end up doing more yourself because you need to save money". Her comments illustrate the potential for caregivers to experience increased economic and psychosocial caregiving-related costs when they are forced to take financial issues into account when making caregiving-related decisions. It is evident that there are currently not adequate supports available to ensure that caregivers can exercise free choice.

Theoretical Connections

The fact that current supports are inadequate to address caregivers' economic and non-economic caregiving-related costs is further evidence of the fact that unpaid caregiving is not valued in our society. Cancian and Oliker (2000) suggest that the lack of support for family caregivers is directly related to the fact that their role and work are not valued. Additionally, Hooyman and Gonyea (1995) suggest that the dominant ideology of separate spheres and familialism also maintain the status quo by reinforcing care as a private, family responsibility. Alternatively, Guberman (2004) suggests that in the context of a social model of care, individuals who choose caregiving roles would not be disadvantaged by caregiving-related costs. She proposes that:

> To promote empowerment and genuine choice, a social model must assure that the measures, programs and services offered by the public sector and other stakeholders are characterized by flexibility, adaptability, variety, continuity, coordination and the organized input of people with disabilities and caregivers. Another aspect of the model is that it promotes a global and holistic vision of care. (p. 83)

These characteristics of a social model of care resonate very closely with the recommendations that the women in this study made in identifying current inadequacies and stating their case for further supports.

Neysmith (1998) proposes that moving towards a vision of collective or social responsibility for care requires that "the policy-making model would not be one of competing interests gathered around a table, but rather one of putting processes in place that can turn up the volume on the voices of those who belong to segments of society seen as vulnerable to the impact of a given policy" (p. 243). If this study is any indication, there are definitely caregivers who are ready, willing and able to engage in these types of policy discussions. Furthermore, the recommendations and suggestions made by the women in this study provide some insight into the direction of some of the changes that need to be made in order to meaningfully impact women's caregiving-related costs.

It is interesting to note that other recent work on other aspects of caregiving policy and practice have highlighted the need for an approach that provides a range of service options with sufficient flexibility to address individual needs. Based on earlier and ongoing work in the voluntary sector and in consultation with key government, academic and voluntary sector stakeholders, VON Canada (2005) has recently developed a policy lens that is "intended to provide an analytical and developmental framework by which policy recommendations related to respite can be analyzed and evaluated" (p. 1). The framework is based on the assumption that caregiver respite policy should have a holistic focus on the caregivers' health and well-being and be based on the rationale of facilitating opportunities for relief or renewal for caregivers. The framework poses questions related to the extent to which a policy recognizes "the individual nature of caregiving and the resulting need for access to an array of services" (p. 4). The inclusion of an "assessment framework to assure that caregivers' expressed needs and preferences are an integral part of ongoing development of respite service plans" is also recommended (p. 4). This framework appears to be consistent with the type of approach the women in this study were identifying as necessary in order to better address their economic and non-economic caregiving-related costs.

Factors Affecting Caregivers' Service Utilization

The women's descriptions of their experiences revealed several factors that affect caregivers' utilization of available services. These factors are involved in caregivers' decision-making related to whether they will seek out formal supports for themselves and/or the care receiver. They also play a role in determining whether the caregiver will initiate or continue to utilize available services once they have been identified. The relevant factors identified in this study include: awareness of available supports, caregivers' assessment of the relative costs and benefits associated with accessing services, reluctance to use caregiver-specific supports when the care receiver has unmet needs and caregivers' help-seeking attitudes. These factors are connected to some of the previously identified themes but the important implications for service utilization warrant a separate discussion.

Awareness of Available Supports

The women's stories about their difficult experiences with attempting to identify and access formal supports drew attention to two related factors that affected their use of formal support services: awareness of available supports and caregivers' assessment of the relative costs and benefits associated with accessing services.

Firstly, the caregivers' emphasized that they need to be aware of potential supports and services before they can decide whether or not to use them. The women reported that there were times when they did not access services or sources of financial support that they could have benefited from because they were unaware of their existence. One caregiver described the situation as "of course there's nobody telling us what we're entitled to at the same time or which ones he can have". According to these women, they did not even know that supports such as publicly funded home care services to enable the caregiver to seek or maintain paid employment or specific equipment or renovation funding were available. Consequently, they did not know enough to even ask about these types of supports. At the same time, they were not informed by their contacts within the health and social service system that there were other resources that might potentially benefit them or their family. The women's experiences included examples of situations where, when they eventually found out about potential resources, they or their care receiver no longer met the eligibility criteria or their caregiving situation had changed so that the resource was no longer relevant.

Caregivers' Assessment of Relative Costs and Benefits Associated With Accessing Services

In a context where these women were encountering significant difficulties in identifying and accessing potential supports, they appeared to sometimes undertake a rudimentary cost-benefit analysis. The caregivers essentially made an assessment and subsequent decisions based on their perceptions of the caregiving-related costs associated with accessing services relative to the potential benefits. These perceptions seemed to be largely based on their previous experiences and the information that they had immediately available to them about both the costs and benefits.

In these assessments, the women were considering both economic and non-economic costs. One of the primary costs that the women appeared to take into consideration was the amount of their time and energy that was required to access a particular resource or support. For example, some of the women talked about the degree of difficulty and amount of time involved in determining and subsequently proving their compliance with eligibility criteria. One of the women described two situations where she had tried to obtain information regarding accessible housings options followed by information on sources of financial assistance for home renovations to increase accessibility. In both cases, she became frustrated when she encountered both confusing eligibility criteria and inappropriate or inadequate information provided by voluntary and government sector organizations. As a result, she eventually gave up and used her own financial resources combined with support from her informal network. In these two related situations, family members helped them find and purchase an appropriate home and then undertook the necessary renovations themselves in order to reduce their costs. A different situation resulted in a similar decision for another caregiver. After maintaining the necessary records to claim medical expense deductions related to travel for medical appointments for income tax purposes one year, a caregiver decided not to expend the time and effort in subsequent years after she saw a net benefit of approximately $10 on her income tax return. She felt that the miniscule benefit was not worth the cost of her time and energy involved in claiming it.

When deciding whether to apply for or request a particular service or program, the women appeared to assess the potential benefits based on their perception of whether the available support would adequately address their needs and/or the care receiver's needs.

Based on her past experience with employment programs that did not meet her son's needs, one woman had become skeptical that any voluntary sector or government program and service would offer anything that could result in a meaningful benefit or positive outcome for either her or son. Consequently, she had not attempted to access respite and home care services because she believed that they would not be eligible for the types of services that would benefit them.

Another woman had also chosen not to request home care services even though this could have relieved some of her demands as a caregiver. In her case, she was aware of human resource shortages within the home care program in her area so she was uncertain if the program would be able to respond to her request. Additionally, she said that she felt guilty about asking for assistance when she knew that there is so much demand with such limited resources.

Another cost-benefit assessment was evident in one caregiver's consideration of the family-managed or self-managed care option available through the public home care program. She was interested in the potential for increased control and flexibility regarding scheduling and service provision with this program. However, she had so far chosen not to pursue this option because she was concerned about the associated increase in responsibility and the decreased support for emergency situations that she felt might minimize the positive benefits. In other words, the increased costs in terms of her time and effort may negate the potential lifestyle benefits for her family. This was the same woman who emphasized the importance of maintaining a couple relationship with her partner outside their 'working' or caregiving relationship. It was evident that she would also take into account any potential negative impact on their couple relationship as well.

Caregivers' Reluctance to Use Caregiver Supports When Care Receiver Has Unmet Needs

Caregivers' service utilization also appears to be affected by their belief that adequate care-related supports for care receivers also benefit caregivers and their commitment to finding these supports. Some of the women acknowledged that they were reluctant to access supports for themselves as caregivers when they felt that the care receiver still had significant unmet needs that they needed to address and/or spend time advocating to have addressed. For instance, one woman described her caregiving-related financial costs but then stated "that really doesn't bother me, you know, I can, I can manage with nothing" in order to refocus the discussion back to how her care receiver's needs needed to be better addressed. In another example, one woman talked about how she had spent a significant time away from a church group that was an important source of support for her in order to be able to focus on her son's needs. However, once he was settled into a personal care home placement that adequately met his needs, she returned to the group.

Caregivers' Help-Seeking Attitudes

For some caregivers, their attitudes towards help-seeking also appear to play a role in their decisions regarding whether to seek out supports and services. For example, while acknowledging that some additional supports would be helpful, one of the women emphatically stated "I don't want any handouts". She described herself as a very independent and private person who is reluctant to ask for help from either informal or formal sources. According to her account, in recent years, her efforts to access formal supports have essentially been exclusively focused on employment training and placement for her son while she has not sought out support of any kind for herself. At the other end of the help-seeking spectrum, another woman described how she has proactively sought out and utilized all sources of potential help. However, she made the observation that she has noticed that some other care receivers and caregivers that she is aware of seem to be reluctant to do the same. She expressed the opinion that her willingness to seek external help had made an important difference to her quality of life and ability to cope and hoped that others would come to see it that way.

Theoretical Connections

These findings are consistent with Guberman's (2004) contention that:

> Choices in terms of caregiving arrangements are always dependent on one's social conditions, economic status, knowledge of available resources, capacity to analyze the costs/benefits of different options and capacity to make a decision. To truly have the possibility of choice, there has to be a balance between a person's individual values, conditions, capacities and skill at making choices, and concrete viable options from which to choose. (p. 83)

Additionally, in its recent work on the development of an analytical framework for caregiver respite policy, VON Canada (2005) recommends that any such policy or service include a communications and education strategy to ensure that caregivers are aware of its existence and to encourage its utilization. The framework also highlights the need for a range of service options with the capacity to respond to individualized needs.

Previous research has also suggested the need to take caregiver attitudes, beliefs and perceptions regarding service utilization into account in planning services to meet their needs (Smyth & Pedlar, 1999). This study sheds some light on some of the relevant attitudes, beliefs and perceptions that appear to affect service utilization by women who are caregivers for younger adults living with chronic illness and/or disabilities. Furthermore, these findings suggest that caregivers' underutilization of existing services cannot be explained away solely as a function of women's socialization in North American culture which has made them reluctant to use services because they have been taught to value self-reliance and understand caregiving as their private responsibility. Generally, the women in this study were actively seeking services to address their needs but encountered barriers and inadequacies in the available system of supports. In their study of the health of caregivers in Manitoba, Hawranik and Strain (2000) found, with respect to home care service utilization, that "there was a general consensus that resources were limited in availability, were difficult to discover and obtain and frequently excluded the caregiver" (p. iv).

These factors affecting caregivers' service utilization are particularly important to understand and acknowledge given the fact that a persistent concern related to some policies, programs and services for caregivers is that they are underutilized even when caregivers' needs are so apparent and significant (Parris Stephens, 1993, Zarit et al., 1999). Policies, programs and services that ignore these factors in their development and implementation run the risk of providing decreased benefits to caregivers and being underutilized.

The Women Are Committed to Their Caregiving Role Despite the Associated Costs

After talking candidly about the caregiving-related costs they experienced, the women often reiterated the fact that these costs did not prevent them from wanting to continue to be their family member's caregiver. A few of the woman minimized their concern over some of the negative consequences that they had described in order to emphasize their willingness to provide the necessary care and support. For example, after describing a variety of negative consequences for her own physical health, one woman stated that "I don't know that I'm all that distressed about it. Kind of luck of the draw, you know" and then went on to say that "she's [care receiver] just giving so much to me every day and she just reminds me of what's important in life you know". Two other women emphasized that although there had been a negative impact on their financial situation they would not change what they had done because caring for their family member was more important than their finances. In her member validity check feedback, one caregiver also suggested that the reason she did not mind the economic costs that she incurred is because there is in fact more reciprocity than is immediately apparent from her description of her caregiving role. By way of explanation, she described some household maintenance and repair tasks that the care receiver is able to do so that she did not have to hire outside help for this work.

Some of the women also spoke eloquently about their love for the care receiver and their positive, caring relationship with that person. Some of them indicated that this love was behind their commitment to their caregiving role. In one woman's emotion-filled words, "it's been difficult but has been blessed too… Like our love, our love is just, just, it doesn't break…" Another woman describes a similar emotional commitment;

> Just basically that being a caregiver doesn't, isn't just taking care of physical needs. I mean because I'm also his partner, there for him emotionally and mentally as well, so not just somebody to do the physical work but to rely on to do for that. And that I'm not just there to take care of him. I'm also his, you know, like I said, I'm his partner and we're a family as well.

Despite the costs involved for these women, their caregiving is important to them and none of them were looking for solutions or supports that would completely remove them from their caregiving role. In three cases, the women had faced or could face in the near future the possibility of long-term care placement for the care receiver. In two other cases, the women might reconsider the amount of physical care they are providing if there were more alternate care services available that responded to the individualized nature of their circumstances. In another situation, the care receiver was being transitioned to a group living situation with 24 hour supports but the caregiver still expected to be very much involved in her family member's life and care. Two other women would not consider other alternatives for their sons or daughters with disabilities even though the possibility of institutional or other placements exist and/or had been suggested to them. One of the women explained her commitment to care for her son at home:

> I would have done with much less if, you know, if I knew definitely that we had to place him. There's no way that I, never even crossed our minds. Like he belonged with the family.

Theoretical Connections

The women's commitment to their caregiving role supports Armstrong and Kits (2004) conclusion that "the risk is not that families will not provide care but rather that they will not be able to provide care without risking their health and their relationships if formal services fail to support them" (p. 67). Recent Canadian data would also suggest that Canadians are showing a continued willingness to provide care for their friends and family members (Cranswick, 1997, 2003). This evidence combined with similar findings from other research negates policy debates "centered on the concern that the development of programs providing greater assistance to caregivers through respite and more flexible home care services could trigger greater usage of formal services and erode family caregiver support" (Montgomery & Feinberg, 2003, p. 1). At the same time, it is imperative not to lose sight of the fact that the negative consequences for many caregivers can be quite significant and require further attention.

In describing what she calls "the primacy of caring", Benner and Wrubel (1989) recognize that "because caring sets up what matters to a person, it also sets up what counts as stressful, and what options are available for coping" (p. 4). She further describes how caregivers come to understand that caregiving for their family member is the only thing that they can do. In her words:

> There is no other option compatible with being who this person is, that is, a person who cares for a loved one. When people are praised for their courage or devotion in caring for a seriously ill loved one, they typically respond, 'I just did what I had to do'. Walking away or not caring simply does not occur to the person. (p. 4)

Gilligan also identified women's "innate disposition towards connectedness or 'relational' rather than 'rational' thinking" and suggested that "female 'identity is defined in the context of relationship and judged by a standard of responsibility and care'" (as cited in Baines et al., 1998, p. 9). However, Baines et al. (1998) challenge this assumption and propose that "to equate 'caring' with selfless, never-ending, and uncomplaining 'giving' virtually obliterates the constraints, costs and consequences that fall so heavily on women" (p. 9).

The contradiction identified by Baines et al. (1998) is apparent in the caregiving stories of the women in this study. For the most part, they wanted their negative consequences or caregiving-related costs recognized and addressed but at the same time emphatically stated their commitment to their caregiving role regardless of the costs. In some cases, the women tried to reiterate their commitment by retroactively downplaying the costs they described or essentially apologizing for "complaining" or "whining" when providing descriptions of their caregiving-related costs.

The contradiction between their commitment to caring and its negative consequences has made these women vulnerable to being taken advantage of by a society that devalues their caregiving work and romanticizes their self-sacrifice in caring for a family member. Governments are also slow to respond to their caregiving-related needs because they assume that they should and will continue to provide care. In this context, policies and programs are developed on the premise that only minimal levels of support are necessary to keep caregivers propped up in their caregiving role.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Unpaid, family caregivers, mostly women, provide the bulk of caregiving to younger adults living with chronic illness and/or disabilities. This research study was initiated in the hope of developing a more in depth understanding of the caregiving-related costs experienced by these women from their own perspective and examining the implications for current policy and practice discussions related to addressing caregivers' economic and non-economic caregiving-related costs. In this final chapter, the findings are summarized, relevant implications and recommendations are discussed and future research directions are proposed.

Summary and Discussion of Research Questions and Findings

Four of the women in this study were mothers caring for their son or daughter with a chronic illness or disability and three of the women were providing caregiving support to their husband or male partner. All of the women had a multifaceted caregiving role that involved a range of physical, instrumental, mental and emotional caregiving tasks. They indicated that there were both positive and negative aspects to their caregiving experience with the primary positive aspect being their emotionally close relationship with the care receiver.

There was considerable variation in certain aspects of the women's caregiving experience with several factors identified by the women as having either a significant positive or negative effect on their experience. The factors related to the care receivers' condition and the caregiving situation included the chronic, long-term nature of their caregiving situation, the type of onset of the care receivers' disabling condition, the care receiver's and caregiver's age at onset and the nature of the illness and disability. The women also discussed how their use of personal coping strategies and informal and formal supports had affected their caregiving experience, in some cases, positively and in other situations, negatively.

This research study was guided by the following questions: How do female unpaid caregivers of younger adults living with chronic illness and/or long-term physical disabilities describe the caregiving-related costs they experience? What do these costs mean to these caregivers?

With respect to the women's description of caregiving-related costs, they all identified both economic costs and a range of non-economic, primarily psychosocial costs.

With regards to economic costs, all but one of the women described themselves as being in a difficult financial situation with limited income relative to their expenses. They indicated that their caregiving situation had contributed to their current financial situation due to out-of-pocket expenses resulting from the care receivers' care and disability needs and opportunity costs that decreased their current and/or future incomes.

In terms of non-economic costs, negative effects on the caregivers' own physical health and psychosocial consequences including emotional loss and pain and decreased opportunities to address their own needs were identified.

The interview questions used to explore the research question of what these caregiving-related costs mean for these women, yielded several themes relevant to understanding the meaning and impact that these costs have in the women's daily caregiving reality. These themes are summarized below within the framework of feminist theory and analysis of women's caring.

Recent statistics indicate that 1.9 million people with disabilities get at least some of the help they need from a family member and 2.8 million people provide support to family members and friends who need assistance due to a long-term health condition or disability (as cited in Canadian Association for Community Living, 2005). In recent years, there has been increased research and policy dialogue directed towards identifying the needs of unpaid caregivers and assessing alternatives to meet those needs. In August, 2004, the federal government under the leadership of Prime Minister Paul Martin, appointed Hon. Tony Ianno as the Minister of State (Families and Caregivers) under the broader portfolio of Social Development Canada. This marks the first time in Canadian history that there has been a designated cabinet minister with the clear mandate to develop a policy response to the needs of unpaid caregivers. The new minister has been conducting consultations across the country in an effort to develop some type of initial national policy or program to address the needs of unpaid caregivers with the relatively limited and short-term funding that has been allocated to this initiative. At first glance, this appears to be a promising step forward. However, when the related funding commitment of $1 billion over five years is broken down, this is actually a very limited amount of money to develop a national policy response to address the needs of the 2.8 million Canadians who have been identified as unpaid caregivers.

Beyond this, within the last two years, there have only been a couple of limited federal policy responses including the increased income tax deduction for caregivers announced in 2005 federal budget and a Compassionate Care Benefit program offered through the Employment Insurance program for short-term leaves for caregivers in palliative caregiving situations. At the provincial level, there has been no significant policy development in support of unpaid caregivers other than amendments to provincial labour legislation to provide job protection to complement the federal Compassionate Care Benefit.

Given this current policy context and responses to date, it seems that governments' interest in supporting unpaid caregivers is not motivated by an increased appreciation of the value of this unpaid work. It would appear that government's interest in minimally improving support to caregivers is motivated by their awareness of the need to keep these women in their place as unpaid caregivers in order to avert a further health care crisis. According to the Canadian Caregiver Coalition (2002), "if caregivers did not provide this level of care, the health care system, as we know it, could not function and would collapse" (p. 2).

Feminist theorists and researchers have emphasized how the increasing shift to community-based care has been supported by the mainstream ideology of separate spheres that relegates the responsibility of caring for others primarily to women as if it is their "natural responsibility" (Baines et al., 1998; Hooyman and Gonyea, 1995). Women are further mandated into their unpaid caregiving role by neoconservative ideologies and values that reinforce care as a private, family responsibility that is best provided by family members in the home (Guberman, 2004; Hooyman and Gonyea, 1995).

The caregiving stories of the women in this study confirm that care has been relegated to them with very little choice or options for support and that they are experiencing both negative economic and non-economic consequences as a result. The women in this study were all in situations where they were primarily responsible for providing a comprehensive range of care and support to their family member living with a chronic illness or disability. Only one of the seven women indicated that she had some regular support and assistance from a man (i.e., her husband) in providing care for her son but she was still clearly the primary caregiver. The women varied in terms of the formal, publicly funded support that they were receiving, ranging from no formal support to a relatively high level and comprehensive range of services from various sources. Most importantly, all but one of the women indicated that they needed more economic and non-economic support than they were currently able to receive.

The themes related to the meaning that these costs had for them further support the feminist critique's contention that women's unpaid caregiving work is devalued. As a result, women are negatively affected by the current social conditions and context under which their caregiving takes place. The themes that highlight the common elements and concerns in these women's caregiving experience are:

- These women experience both economic and non-economic (primarily psychosocial) caregiving related costs and these costs are interconnected in their experience.
- These women feel that their caregiving costs are also addressed when adequate care and disability-related supports are provided to the care receivers.
- These women recognize that their caregiving role exceeds what is generally considered a 'normal' or typical family role. Further to this, they feel that they are deserving of support to assist with the required care and the associated caregiving-related costs.

- These women regularly encounter what they perceive to be barriers to identifying and accessing external supports and caregivers' economic and non-economic costs are exacerbated by these barriers.
- The women generally feel that the supports that are currently available to them do not adequately address the nature and extent of their psychosocial and economic caregiving-related costs.
- The women also identified several important factors that can limit or otherwise affect their service utilization. These factors include awareness of available supports, their assessment of the relative costs (including non-economic and economic costs) and benefits associated with accessing a particular resource, reluctance to use caregiver-specific supports when the care receiver has unmet needs and finally, caregivers' attitudes towards help-seeking.
- These women are committed to their caregiving role despite the associated costs.

Implications and Recommendations

The findings of this study have implications for public policy, social work practice, social service administration, caregivers' service utilization and social work education.

Policy

This research was initiated with an interest in identifying implications for the development of public policies to address caregivers' negative economic consequences arising from their caregiving role. However, the study findings highlight the fact that economic and psychosocial caregiving-related costs are intertwined in caregivers' day-to-day reality and that adequate care and disability-related supports provided to care receivers also have the potential to address caregivers' caregiving-related costs. This would suggest that policies intended to address caregivers' negative economic consequences cannot be considered in isolation from other relevant caregiving, health care and social policy. The women in the study brought forward suggestions for addressing their economic caregiving-related costs including better coverage or reimbursement for caregiving-related out-of-pocket expenses and introducing options for financial compensation or payment for their caregiving time. However, they also addressed the need to improve and expand upon the psychosocial supports for caregivers and placed even greater emphasis on the need for adequate care and disability supports for their family members. This raises questions about how these women would respond if a policy was developed and implemented to address their economic costs in the absence of simultaneous and coordinated efforts to address some of the other issues and needs they identified.

Keefe (2004) is currently conducting research on international models of financial compensation for caregivers with the intent to assess their potential applicability in the Canadian context and recommend related policy actions. However, it will be important that other efforts to frame public policy responses to address caregivers needs in the context of a broader public policy framework or agenda also proceed so that any public policy related to caregivers' economic security is situated within a broader context and an agenda that also seeks to address the full range of both care receivers and caregivers' needs. The Canadian Association for Community Living (2005) has similarly cautioned against addressing economic security issues in isolation from other types of supports:

> A strategy that focuses exclusively on family economic security as though families should be the only source of disability-related support and that

> leaves unaddressed community provision of disability supports will render people with disabilities vulnerable. A strategy that addressed the economic security of families without addressing the isolation and exclusion of families in communities will not effectively address the totality of family vulnerability. (p. 13)

This position appears to be supported by the women who were interviewed for this study. They highlighted the need for improvements in a wide range of supports rather than just those focused on addressing their economic consequences.

Currently, the Canadian Caregiver Coalition (2004b) is advocating for the development of a "Canadian Caregiver Strategy" that would provide a comprehensive public policy framework for the federal and provincial/territorial governments to address the full range of caregivers' needs. Similarly, the Canadian Coalition for Family Supportive policy proposes that the "caregiver agenda" be advanced in the context of a broader family supportive policy and disability supports agenda so that the needs of both the caregiver and care receiver are addressed in policy recommendations (Canadian Association for Community Living, 2005). Riggs (2003) also recommends a comprehensive approach by suggesting that "the goal of family caregiver policy must be to meet the needs of the person needing care and to address the physical, emotional and financial needs of the caregiver that arise as a result of the caregiving role" (p. 69).

Additionally, as caregiving policy evolves, it is important to remember that the women's stories also highlighted the need for a range of options within supports intended to address the care receivers' needs and caregivers' caregiving-related costs. This would enable both caregivers and care receivers to exercise greater choice in selecting supports that are best suited to their needs and circumstances. This choice is essential because some caregivers are not eligible for some forms of support and/or certain types of support provide them with absolutely no benefit depending upon their circumstances. Women are particularly likely to find that they do not benefit from some financial compensation measures. For example, caregiving leave benefits such as the current Compassionate Care Benefit provided through the federal Employment Insurance (EI) program are only relevant for those who qualify for EI thereby excluding many women (Morris, 2004, p. 108). Similarly, income tax deductions are only effective for individuals with a sufficiently high level of income to be able to benefit and "provide little economic benefit to informal caregivers" (Fast et al., 2001, p. 44).

Although this approach to addressing unpaid caregiving policy may seem more daunting, it is very necessary in order to meaningfully address the complex interconnection of economic and non-economic costs that the women in this study have described as their caregiving reality. It is encouraging to note that based on their review of public policies in support of caregiver in six countries, Montgomery and Feinberg (2003) conclude that "recent policy initiatives have taken a broad view of community care by establishing multi-pronged programs for national, state, provincial, and/or private responsibility for long-term care of older persons and, in some instances, their caregivers" (p. 1). They further suggest that there has been some positive movement forward from earlier policy discussions that "have sometimes been restricted by assertions that it is not necessary for government to pay for care that families provide for 'free'" (p. 1).

It should also be noted that a commitment to this type of approach requires recognition of the value of unpaid caregiving beyond that which is evident in current 'stop gap' measures in terms of caregiver support. It also moves us closer to the type of social responsibility for care that Guberman (2004) and Baines et al. (1998) propose is necessary to decrease the negative consequences currently incurred largely by women.

While this broader policy agenda is advanced, action can also be taken on another key recommendation made by the women themselves. These women were looking for the creation of a centralized mechanism for ensuring that all caregivers have an easily identifiable source for user-friendly access to information regarding all relevant organizations and programs and services with the potential to address both the care receivers' needs and their own economic and non-economic caregiving-related costs. Additional investigation and problem-solving are needed to determine what type of mechanism(s) will best address the concerns identified by the women in this study. In determining the best direction to take, it will be important to include the voice and experience of caregivers at all stages and through a variety of means such as focus groups and steering committees. If this study is any indication, there are likely many caregivers who would be interested in contributing their expertise to this process in order to ensure that the end result is something that they will utilize and that adequately addresses their caregiving realities.

Social Work Practice and Social Service Administration

The women's experiences also revealed some implications for social work practice and social service administration.

Firstly, there are a few potential actions that social workers working within the health, education and social service systems could take to decrease the barriers that the women had to surmount in order to access external supports. As a starting point, front-line social workers who work with caregivers can ensure that their own attitudes and behaviour do not exacerbate the situation as was the case in some of the women's experience.

With respect to social service administration, programs and services should be designed and delivered with sufficient flexibility to be able to respond to the unique nature of each family's situation. As practitioners, social and health service administrators and policy analysts, many social workers are in a position to ensure that maximum flexibility is exercised in the application and delivery of current policies and services in order to be responsive to families' needs. Additionally, social workers can make contributions to program design and policy development processes through consideration of these findings and by ensuring that caregivers' voices are directly represented in those processes.

Obviously, some of the suggestions made by the women in these studies go beyond what individual social work practitioners can accomplish within the scope of their current positions. However, both front-line social worker practitioners and social workers in administrative positions within relevant government departments, regional health authorities and voluntary sector organizations are in a position to identify what can be accomplished through changes in practice and administration and what requires a more comprehensive policy change approach. They can subsequently share this information with or become involved with groups such as the Canadian Caregiver Coalition and Manitoba Caregiver Network who are interested in providing advocacy leadership to encourage the policy development process.

In keeping with the feminist "action orientation" that informed this study, I am personally interested in making connections between this research and the ongoing policy and practice discourse concerning response to unpaid caregivers' negative consequences. As a social worker and a citizen engaged in volunteer and paid work in this area, I intend to disseminate the findings from this study to key stakeholders who are in a position to influence change or take action on the recommendations and implications identified in this chapter. To this end, I intend to pursue publication of the study findings in professional journals and newsletters. I will also be looking for other opportunities to exchange this knowledge with social workers and other relevant professionals as well as voluntary sector organizations and coalitions engaged in policy development and advocacy in this area. Additionally, I will seek to share the key messages arising from the findings with relevant policymakers and politicians. The women who participated in this study have encouraged me to disseminate the findings from their voices in this way in order to positively change the context and supports within which they and other caregivers must provide care on a daily basis.

Factors Affecting Caregivers' Service Utilization

These recommendations for social and health policy, social work practice and social service administration also take into consideration this study's findings regarding factors that affected the women's service utilization.

Firstly, some of the factors are positively addressed by improving access to information about available supports and decreasing caregivers costs associated with accessing services, particularly in terms of their time and energy.

Additionally, the factor of the women's reluctance to use supports for themselves when the care receiver has unmet needs can be addressed with policy development and practice approaches that simultaneously address the needs of both the care receiver and caregiver. Based on her work with caregivers of spouse with stroke and other chronic neurological conditions, Ellis-Hill (2001) suggests that supportive interventions should not be focused on the caregiver and care receiver in isolation from one another. Instead, professionals should focus on both and seek to enhance the quality of life for both. This is similar to the approach recommended by the Canadian Association for Community Living (2005) for change at the policy level. Furthermore, a holistic and integrated approach to care receiver and caregiver support at both the policy and practice level is supported by the argument that the caregiving role only becomes difficult or unsustainable when there are not adequate supports from government and community. It is suggested that "the need to support a person because of disability signals a change in a typical family relationship, only because families, typically, have not been sufficiently supported to play this role" (p. 5). This closely aligns with the contention of the women in this study who wanted to maintain their caregiving role but wanted additional supports to decrease their caregiving-related costs and enable them to maintain 'normal' family relationships.

As we consider the way forward for caregiver supports in the Canadian context, it is critical to identify and address factors affecting caregivers' service utilization in order to ensure that policies and programs are effective in achieving their intended objectives for caregivers. This has recently become even more imperative given the surprising and significant underutilization of the federal Compassionate Care Benefit for short-term caregiving leave for family members providing caregiving support in palliative care situations (Galloway, 2005).

Social Work Education

Some of the study participants identified individual social workers' attitudes and behaviours as contributing to the barriers they encountered in trying to access external supports for themselves and the family members for whom they provide care. This finding has important implications for social work education. It is apparent that social workers need to have a greater understanding of the complex realities faced by caregivers such as these women. Furthermore, social workers need to understand how policies, practices, attitudes and behaviours devalue the unpaid caregiving role and are based on an assumption that women will and should be available to provide this care with minimal support regardless of the short and long term consequences for their own health, well-being and economic security. Consequently, it is apparent that social work education needs to include opportunities for students to gain knowledge and insight regarding the assumptions related to women's caring that underlie many of the barriers that these women encounter in seeking to have their families' needs addressed.

There is a need for social work students to understand these issues at both a theoretical (i.e., feminist theory of women's caring) and practical level (i.e., how social work practice and health and social policy can either positively or negatively affect female caregivers experience). Firstly, all social work students should be introduced to feminist theory on women's caring. This introduction should include an examination of how caring work continues to be devalued in our society. It is imperative that social workers understand how current Canadian health and social policies are based on assumptions and expectations related to women's availability to provide unpaid care to family members including those living with chronic illness and disability. Students need to understand how this fact means that Canadian caregivers continue to experience significant economic consequences or costs as a result of their experience. Beyond this, students should be compelled to examine their own experiences, preconceptions and attitudes regarding women's caring in our society. This self awareness is necessary to ensure that individual social workers do not contribute to caregivers' negative consequences as a result of their personal attitudes and beliefs related to women's caregiving roles.

Future Research Directions

This qualitative study provided an opportunity for an in-depth exploration of female caregivers' experiences and perceptions with respect to their caregiving situations and caregiving-related costs. The women's descriptions of their experiences are consistent with previous research literature that has highlighted the gendered nature of care and caregiving-related costs and consequences. Additionally, the women's description of their caregiving role and contextual factors affecting their caregiving experiences is consistent with previous research findings.

The most significant contribution of this study is that the qualitative approach illuminated the complexity of the women's experiences and identifies important implications for policy and practice derived from the key findings related to the meaning of caregiving-related costs in the women's lives. In particular, the women's narratives highlight the interconnection of the caregiver and care receivers' experience and the related implications for caregivers' service utilization. This finding draws attention to the need for supports for the care receiver-caregiver dyad or family as a whole rather than either in isolation. Similarly, the complex interconnection of monetized and nonmonetized caregiving-related costs experienced by the women identifies potential problems with a public policy approach that might try to compartmentalize and independently address these different but interrelated types of costs for caregivers.

Furthermore, this study has identified some important issues and themes that should be addressed in future research.

Firstly, a follow-up study with a larger sample with more diversity in terms of representation of visible minority groups would be useful to confirm the identified themes and obtain further input from female caregivers on the related implications for policy and practice. A follow-up study could also include caregivers of people with multiple sclerosis who had to be excluded from this study due this researcher's conflict of interest. Further research is also necessary to bring forward the voices of male caregivers for the caregiver population studied and analyze gender-based similarities and differences.

Secondly, the issue of factors affecting service utilization warrants further study since we have obviously not learned enough in this regard given that the Compassionate Care Benefit, one of the most significant caregiver policy initiatives ever undertaken by the Canadian federal government is being significantly underutilized compared to projections. Original government projections indicated that 270,000 caregivers per year would qualify but the reality is that only 3,175 caregivers applied in the first six months of the 2004-2005 fiscal year with 20% of these applicants being deemed ineligible (Galloway, 2005). This study has highlighted the fact that women consider both economic and non-economic costs in determining whether they will utilize a service. Further research may be able to build upon this finding. The development of a model of cost-benefit analysis for caregivers' service utilization decisions that includes both economic and non-economic costs could be an important contribution from further research. Some leading Canadian caregiving researchers have already developed a policy analysis framework that conceptualizes economic and non-economic costs for caregivers (Fast et al., 2001; Fast et al., 1999). However, this conceptualization has yet to be applied to the service utilization issue.

Thirdly, deLeon (1998) has noted the limited acceptance of qualitative research approaches to policy research among the policy research community and subsequently policy decision-makers. It is generally accepted that policy decision-makers want quantitative data including cost-benefit analysis when making decisions regarding public policies. While this study has yielded some important findings regarding female caregivers' experiences and perceptions of caregiving-related costs, the quantitative knowledge gap with respect to the nature and magnitude of these costs still remains. This study does not provide detailed quantitative findings with respect to the specific type and magnitude of economic consequences experienced by this group of caregivers. Yet policy-makers often require quantitative data on social issues such as caregiving-related costs in order to develop and garner support for an acceptable policy response. Further quantitative research may be required to support the unpaid caregiving policy agenda.

Finally, based on the significant interconnection between the caregivers' and care receivers' experiences highlighted in this study, there are also opportunities for future research to focus on these interrelationships. This is consistent with Berg-Weger and Tebb's (2003) recommendations that there is a need for the development of research designs that include "relationship analysis" and "explore resiliency and reciprocity" (p. 12).

Conclusion

This research study sought to bring forward the voices of women as unpaid caregivers of younger adults with chronic illness or disability in order to better understand the caregiving-related costs that they experience and what these costs mean for them as women and as caregivers.

The women candidly shared their realities and described in detail the interrelated economic and non-economic caregiving-related costs that they experience. At the same time, these women expressed their commitment to continue in their caregiving role despite the associated costs. Most importantly, the women seem to recognize the value of their caregiving role and gave a clear message that they should be better supported in their role. These women also went beyond identifying the current problems and inadequacies to share their visions of potential solutions. They are looking for an approach or strategy within the health and social service systems that is supportive of both the care receivers' and caregivers' needs simultaneously since they are very much interrelated in their experience.

Without progress on the recommendations for policy and social work practice, these women will likely continue to provide caregiving support to their family members but will do so with significant costs to their own health and well-being and, ultimately, further costs to the health and social service system. The time has come for Canadian society and governments to recognize that caring for individuals living with chronic illness and disabilities is a social responsibility that we all must share. Only then will these and other women not be further disadvantaged by the expectation that it is their responsibility to provide this caregiving with little or no support.

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Appendix A

Study Recruitment Materials

Printed on University of Manitoba institutional letterhead for distribution

Letter to Caregivers (i.e. Potential Study Participants)

Dear Caregiver,

I am a graduate student in the Faculty of Social Work currently initiating a research study exploring the experiences of female family/unpaid caregivers. This research study is being conducted as a requirement for the completion of my Masters of Social Work degree.

The focus of the study will be women who are unpaid caregivers to adults aged 21-55 years living with chronic illness and/or long-term disabilities of a primarily physical nature. I have approached several chronic disease, disability and home care provider organizations who have agreed to provide this letter to any female caregivers in contact with their organization whose situation might fit within the scope of my research.

The individuals that I am interested in meeting with in order to hear their caregiving story are those women who see themselves as primarily responsible for the care and support of their adult family member or friend living with a chronic illness and/or long-term physical disabilities. I am interested in hearing about the realities of your situation from your perspective including the personal and financial costs you have experienced as well as the types of supports you have used or that you think would make a difference for you.

It is my intention to arrange for confidential, one-on-one, in-person interviews or conversations with women who wish to participate. I anticipate that the interviews will last approximately 1 ½ to 2 hours. The interview would be arranged at a time and location that is most convenient for you. If possible, interviews will be scheduled during January and February 2004.

If you are interested in participating or obtaining additional information, please contact me by phone at or by e-mail at

Thank you for your time and consideration of participating in this study.

Sincerely,

Michelle Gibbens, B.S.W.

Printed on University of Manitoba institutional letterhead for distribution

Letter to Chronic Disease/Disability/Home Care Provider Organizations

Dear Executive Director or appropriate alternate,

Thank you for your time during our recent phone conversation. As I explained, I am a graduate student in the Faculty of Social Work currently initiating a research study exploring the experiences of female family caregivers (i.e. unpaid caregivers) with respect to the caregiving-related costs they experience. This research study is being conducted as a requirement for the completion of my Masters of Social Work degree.

I am currently contacting several organizations for assistance in identifying individuals who are interested in participating in the study and intend to conduct in-person interviews with interested caregivers during the months of January and February 2004.

The focus of the study will be women who are unpaid caregivers to adults aged 21-55 years living with chronic illness and/or long-term disabilities of a primarily physical nature. As I explained during our phone conversation, the purpose of the research is to learn more about these caregivers' personal experiences. This research does not involve an evaluation of the services of your organization. I have contacted your organization for assistance in recruiting study participants because, given the mandate of your organization, it is likely that your staff/volunteers are in contact with many caregivers who would fall within the scope of this study. As a result, I anticipate that they may have the opportunity to share information about this study with several female caregivers.

Thank you for agreeing during our recent conversation to share information about this study with female caregivers who are in contact with your organization. I have enclosed several copies of a letter that I am asking your staff/volunteers to distribute to women who are unpaid caregivers to adults aged 21-55 years living with chronic illness and/or long-term disabilities of a primarily physical nature. Please note that due to my current employment with the Multiple Sclerosis Society of Canada, I will not be able to include caregivers of individuals with multiple sclerosis in this study.

All interested individuals are asked to contact me directly to obtain additional information and/or indicate their interest in participating in the study. In order to preserve confidentiality, I will not be advising you if individuals known to your organization chose to participate in the study.

In addition to the letter for potential study participants, I have also enclosed an announcement about the study that can be published in your newsletter or on your website if this is feasible. I have also enclosed copies of a poster that could be posted in your reception area, meeting rooms etc.

Thank you in advance for your assistance. If you have any questions, please contact me by phone at or by e-mail at

Sincerely,

Michelle Gibbens, B.S.W.

Newsletter/Website Recruitment Announcement for Caregiver Study

The version utilized depended upon space available.

Version #1
Looking for Caregivers Interested in Sharing Their Story and Experiences

Every day, thousands of Canadian citizens act as caregivers by providing ongoing care and assistance, without pay, for family members or friends in need of support due to chronic illnesses or disabilities. Research currently being conducted by a graduate student from the University of Manitoba, Faculty of Social Work is exploring the experiences of some of these caregivers.

Recruitment for the study is underway and there are still opportunities for interested caregivers to participate. The study is focused on women who are primarily responsible for the care and support of an adult family member or friend aged 21-55 years who lives with a chronic illness and/or long-term physical disabilities.

If this sounds like your situation and you would be willing to share your caregiving story and experiences so that the reality of unpaid/family caregivers' experience can be better understood then consider participating in this study. Participation will involve a 1 ½ to 2 hour confidential interview to discuss the realities of your situation from your perspective including the personal and financial costs you have experienced as well as the types of supports that have made or could make a difference. Interviews will be arranged at a time and location convenient to each participant.

For more information or to indicate your interest in participating, please contact:

Michelle Gibbens, BSW, RSW
Phone:
Fax:
E-mail:

Version #2
Share your caregiving story

Would you like your experiences as an unpaid/family caregiver to be better understood and recognized? A research study being conducted by a graduate student at the University of Manitoba could give you a chance to have your voice heard. If you are a woman who provides care and support for an adult (aged 21-55) living with a chronic illness or long-term physical disabilities, contact Michelle Gibbens at Ph: 885-5315 or E-mail: mlagibbens@shaw.ca for more information.

Recruitment Poster/Leaflet

ARE YOU A WOMAN CARING

FOR AN ADULT LIVING WITH A CHRONIC ILLNESS OR DISABILITY?

If you are, I am interested in hearing your story.

As a graduate student in the University of Manitoba, Faculty of Social Work, I am conducting a research study on the experiences of female caregivers of younger adults (aged 21-55 years) living with chronic illness or long-term physical disabilities.

This is a chance to tell your story, have your voice heard and have your experiences as an unpaid/family caregiver better understood.

Contact Michelle Gibbens for more info:
Phone:
E-mail:

Appendix B

Interview Guide

* Note: Close-ended questions regarding sociodemographics have been incorporated into this interview guide. The interviewer will fill in the caregiver's response without asking the question directly if the information is shared during the caregiver's narrative of their experience.

Overall, I am interested in hearing about your experience, your caregiving story in your own words & what it has meant for your life.
I have a few questions to that I'll ask you to guide us to talk about certain aspects of your experience but generally I just want you to share what is meaningful or important to you about your caregiving experience.

Caregiving Experience

1) Start by talking about/telling me about your caregiving situation, your caregiving role & the responsibilities you have taken on in providing care & support to "?"
Please tell me about your caregiving responsibilities and the person you provide care for.
(The following close-ended questions and probes will be used only as necessary to elicit a more complete narrative of the caregiving situation and the caregiver's experience)
   a. What is your relationship to the person you provide caregiving for? I am his/her
      ☐ spouse/partner ☐ daughter ☐ son ☐ mother ☐ father ☐ friend
      ☐ other, please specify ______________________________

   b. What is the gender of the person you provide caregiving for?
      ☐ male ☐ female

   c. What is the primary diagnosis of the person you care for? What aspects of his/her condition makes your current caregiving necessary?

   d. How many years has this person been diagnosed with this condition/disease?
      ☐ less than 1 year ☐ 1-2 years ☐ 3-5 years ☐ 6-10 years ☐ 11-19 years
      ☐ 20 or more years

   e. How long have you been a caregiver?
      ☐ less than 1 year ☐ 1-2 years ☐ 3-5 years ☐ 6-10 years ☐ 11-19 years
      ☐ 20 or more years

   f. On average how much time do you spend doing caregiver related activity?
      ☐ 0-2 hours a day ☐ 3-6 hours a day ☐ 7-10 hours a day
      ☐ 11-15 hours a day ☐ 16-23 hours a day ☐ 24 hours a day

Before & after long-term care placement

g. What kinds of caregiving tasks and responsibilities do you perform in taking care of this person?

h. How do you see the care you provide for "?" as different from the care and support you provide to other family members?
How is the care you provide different than the care and support you provide to other family members? How is it different than your original expectations of the care and support you would be providing for this person at this stage of your relationship and life in general?

i. What are some of your greatest challenges as a caregiver?

j. Can you tell me about some positive aspects of your caregiving experience?

Caregiving-Related Costs

Overall, how do you think your caregiving experiences have affected your life? What has this meant for/to your life?

Can you share/describe some specific examples of these effects?

What does/did that look like or feel like for you?

1. Do you think you have had to give up anything as a result of your caregiving? Please tell me about this and how you feel about having to do this.

2. Tell me about a time when you had what you feel was a costly experience as caregiver? What type of cost did you experience? Were the consequences personal (i.e. social, emotional)? Financial/economic?
    a. Please explain what happened. How did you handle or resolve the situation?
    b. Did you or anyone or anything else do anything that reduced or alleviated the costs you were experiencing?
        i. If not, please talk about what you think might have made a difference?

3. Can you tell me about a time when you felt that the costs you were experiencing were reduced either temporarily or permanently?

4. Do you feel comfortable with your current financial situation?
    a. Do you feel that you have adequate income to address your family's current needs? Do you have any concerns about your ability to have sufficient income to meet these needs into the future? Please explain why you feel this way. If not, does your discomfort/financial concerns relate to the impact of caregiving/illness on your family or something else?

What things/factors do feel have affected/influenced your decisions regarding your caregiving role?
-Economic? Other?

Do you see your personal needs/desires as a caregiver separately or differently from the needs/desires of the family member you are a caregiver for?

Service Utilization and Experience with policies and programs intended to benefit unpaid caregivers

1. Tell me about your experience in accessing services or support for yourself as a caregiver? for the person you care for?
   a. Voluntary, private, public sector (Direct service, tax credits etc.)
   b. Informal (i.e. family/friend)

2. From your perspective, do you think that these services have decreased, increased or had no impact on the costs you have experienced as a caregiver and why you think this is the case.

3. Are there other programs and services that you are aware of but have not accessed? Please explain why you have not accessed these services.

What factors do you feel have affected or influenced your decisions re: accessing services and supports (i.e. either formal or informal)?

Are there other services or support that you would like to have/have had but do not appear to be available? Please describe what would be or would have been helpful? What would make a difference for you?

Anything specific to addressing the costs that you described above (emotional, social financial, health)?

Sociodemographic Information

Asking these questions so we have a general profile of the range of caregivers involved in the study

1. What is your age?
   ☐ under 18 ☐ 18-29 years ☐ 30-39 years ☐ 40-49 years ☐ 50-64 years
   ☐ 65-74 years ☐ 75 and over years

2. What is the age of the person you provide caregiving for?
   ☐ 21-29 years ☐ 30-39 years ☐ 40-49 years ☐ 50-55 years

3. What is your living arrangement?
   ☐ Live alone ☐ Live with spouse/partner ☐ Live with daughter/son
   ☐ Live with other family members ☐ Live with friends
   ☐ Other (Please specify ________________________)

4. What is your marital status?
   ☐ Single ☐ Married ☐ Common-law ☐ Divorced/separated

5. What is your current status with respect to paid employment?
   ☐ Employed full-time ☐ Employed part-time ☐ Self-employed full-time
   ☐ Self-employed part-time ☐ Retired ☐ Unemployed and looking for paid employment ☐ Unemployed and not currently looking for paid employment
   ☐ Other (Please describe ________________________________)

6. Has your employment status changed as a result of your caregiving responsibilities?
   ☐ Yes ☐ No
   If yes, please describe how it has changed.

I want to ask a few questions document the ethnic background of the study participants so that we are aware of the amount of diversity in this regard in the study sample.

7. Where were your parents born?
   ☐ Both were born outside of Canada
   ☐ One was born in Canada
   ☐ Both were born in Canada
   ☐ Don't know

8. To what ethnic group did your father's side of the family belong?

9. To what ethnic group did your mother's side of the family belong?

10. How would you describe your ethnic identity?

11. Do you identify yourself as a member of a visible minority group? If so, which one?

12. Which number comes closest to the total income for this past year before tax and deductions of ALL THE MEMBERS LIVING IN YOUR HOUSEHOLD?
    ☐ less than $14,999 ☐ $15,000- $29,999 ☐ $30,000- $59,999
    ☐ over $60,000 ☐ No income

13. Which number indicates your total individual income for this past year (before tax and deductions)?
    ☐ less than $14,999 ☐ $15,000- $29,999 ☐ $30,000- $59,999
    ☐ over $60,000 ☐ No income

14. What are the current sources of your personal income?

15. What are the current sources of your household income?

Request for participation in cross-check for validity and accuracy of findings

Would you be interested in reviewing the findings before they are finalized in order to provide feedback regarding your perception of the accuracy of the written document based on your experience and your recollection of our conversation?

Request for snowball sample suggestions?
Give poster & letter if seems appropriate, ask her to pass my phone number on to others

Appendix C

Consent Form

Printed on University of Manitoba institutional letterhead for distribution to study participants

Caregiver Research Project Consent Form

Research Project Title: A Study of Female Unpaid Caregivers of

Younger Adults with Chronic Illness and Physical Disabilities

Researcher: Michelle Gibbens

Advisor: Lyn Ferguson
Faculty of Social Work
University of Manitoba
Winnipeg, MB
Phone: 474-8273

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I have been invited to participate in a study that will look at the experiences of unpaid caregivers of adults living with chronic illness and/or long-term physical disabilities. I understand that I have been asked to share my experiences as they relate to my role as an unpaid caregiver. It is hoped that this research will be used to inform ongoing discussions regarding public policies to address the needs of unpaid caregivers.

I also understand that the researcher, Michelle Gibbens, is a graduate student in the Faculty of Social Work and is conducting this study as thesis research that is a requirement for completion of her Masters of Social Work degree.

I understand that Michelle Gibbens will be interviewing me once for approximately one to two hours and making an audiotaped recording of our conversation. I understand that I have the freedom not to answer any of the questions that I am asked.

I understand that I may terminate the interview or withdraw from this research project at any time without penalty or negative consequences from the researcher or the organization through which I was invited to participate in the study.

I understand that the benefits of this study include documenting the realities of caregivers' lives so that they can be better understood. I further understand that there is a possible risk that this process could be emotionally upsetting for me. If this should happen, I understand that Michelle Gibbens has a list of support resources that I can contact.

I agree to participate in this study knowing that the taped conversations will be kept confidential and that both the tapes and written transcripts from these tapes will be destroyed after this research study has been completed. Only Michelle Gibbens and her faculty advisory, Lyn Ferguson will have access to information that identifies the study participants.

I understand that the information from the interview and the results of the study will be used for research purposes only, including a research report and publication. I further understand that all reports and publications will not directly identify individual participants and all information will be presented in a non-identifying manner.

I understand that if I disclose or report abuse of a person in care in a personal care home, hospital, or other designated health facility during the course of the interview that Manitoba's "Protection for Persons in Care Act" requires the researcher to forward this report to the Protection for Persons in Care Office.

I further understand that if I request it I may receive a written summary of the results and that a final written thesis will be available to read at the University of Manitoba Library upon completion.

I can contact Michelle Gibbens if I require any additional information. If I have questions concerning the ethical aspects of this study I can communicate with Lyn Ferguson who is the faculty advisor of this research study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. You are free to ask for clarification or new information throughout your participation in this interview.

Researcher: Michelle Gibbens Phone:
Faculty Advisor/Supervisor: Lyn Ferguson Phone: 474-8273

This research has been approved by the University of Manitoba, Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or to the Dean of the Faculty of Social Work (474-9550) for referral to the Joint Faculty Research Ethics Board. A copy of this consent form has been given to you to keep for your records and reference.

______________________________ ____________________________
Participant's Signature Date

My mailing address is: ____
My phone number is: __________________________
The best time to reach me is: _________________________________

______________________________ ____________________________
Researcher's Signature Date

Appendix D

Resource List

Counselling and Other Resources

Crisis Line:

Klinic Crisis Line
Phone: 786-8686

- This is a 24 hour crisis/suicide line.

Free/Low Cost Counselling:

The Family Centre
401-393 Portage Avenue (4th Floor, Portage Place)
Phone: 947-1401

- Provides counselling for individuals, couples and families with fees charged on a sliding scale

Interfaith Marriage and Family Institute
515 Portage Avenue (at the University of Winnipeg)
Phone: 786-9251

- Provides individual, family and couple therapy
- Has sliding fee scale

Klinic Community Health Centre
870 Portage Avenue
Phone: 784-4090
Community Drop-In Counselling Program: 784-4067
Crisis Line: 786-8686/ Outside Winnipeg Toll Free 1-888-322-3019

- Operates 24-hour crisis line.
- Offers free in-person counselling, on a drop-in basis and short-term follow-up counseling to a maximum of 6 sessions on any issue.

Manitoba Farm & Rural Stress Line
Phone: 1-866-367-3276

- Offers confidential support, counseling and information for farm and rural families.
- The website **www.ruralstress.mb.ca** also has a Rural Database that you can search for programs and services in rural Manitoba.

Women's Health Clinic
3rd Floor- 419 Graham Avenue
Phone: 947-1517

- Provides low-cost ($30 per session) and free counselling

Elizabeth Hill Counselling Centre
301-321 McDermot Avenue
Phone: 956-6560

- Provides free therapy and counselling services
- Part of University of Manitoba, Faculty of Social Work
- A training center for social work and psychology students

For Listings of Licensed/Accredited Private Practice Counsellors

Manitoba Institute of Registered Social Workers
4-2015 Portage Avenue
Phone: 888-9477

Psychological Association of Manitoba
162-2025 Corydon Avenue, #253
Phone: 487-0784

Association of Marriage and Family Therapists
www.aamft.org - This website can provide you with a listing of accredited marriage and family therapists in Winnipeg.

Other Resources for Support and/or Information & Referral

Amytrophic Lateral Sclerosis (ALS) Society of Manitoba
Deer Lodge Centre, 2109 Portage Avenue
Phone: 831-1510

- Provides a support group as well as information, education and referral services for people with ALS and their family and friends.

Arthritis Society
105-386 Broadway Avenue
Phone: 942-4892

- Assists those with arthritis and their families to understand and cope with the disease by providing information, education, referrals and the Arthritis Self-Management program.

Canadian Diabetes Association
102-310 Broadway Avenue
Phone: 925-3800

- Sponsors support and self-help groups for people with diabetes
- Provides a Diabetes Information & Support Centre, educational services and personal consultations

Cerebral Palsy Association
1060 Ellice Avenue
Phone: 982-4842

- Provides information and support to individuals with cerebral palsy and their families
- Provides support groups for adults and parents

Huntington Disease Resource Centre
2nd Floor, 825 Sherbrook Street
Phone: 772-4617

- Provides services to persons with Huntington Disease and their families including information, short-term individual or family counselling and referral to other community resources
- Offers family support groups

Kidney Foundation
730 Taylor Avenue
Phone: 989-0800

- Provides support for individuals and their families affected by kidney disease through patient services, peer support, education and income tax preparation assistance.

Manitoba Epilepsy Association
825 Sherbrook Street
Phone: 783-0466

- Provides support, information & self-help groups for people with epilepsy and their families

Muscular Dystrophy Association
1 Morley Avenue
Phone: 233-0022

- Provides information and support for people with muscular dystrophy and their families.

Society for Manitobans with Disabilities
825 Sherbrook Street
Phone: 975-3010

- Provides social, rehabilitative and vocational services for physically disabled and deaf or hard of hearing children and adults
- Houses the Self-help Clearinghouse, a federation of independent self-help, advocacy organizations sharing office accommodation and administration resources and providing information to the public

Stroke Recovery Association
1-333 Vaughn Street
Phone: 942-2880

- Provides direct service programs for those who have experienced stroke and their family members.

Winnipeg Regional Health Authority
Information & Intake Phone: 940-2655

- For information on home care and other health services