A framework and literature review on the economic costs of care

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Abstract

In this project we evaluate the current state of knowledge of the economic costs to family/friend caregivers and to employers of caregivers to adults with long-term health problems or disabilities. A systematic scoping review was used to examine the extent, range and nature of research pertaining to these economic costs and to explore major influences on the magnitude of those costs. A gender lens is used given the assumption that costs will be experienced differentially by women and men.

Three domains of economic costs for caregivers were found with subcategories within each domain: *Employment consequences*, *Out-of-pocket expenses* and *Caregiving labour*. There is evidence that each of the three domains of costs may lead to a different set of economic outcomes. Moderators of the prevalence and magnitude of economic costs for family/friend caregivers varied across domains of economic costs and reflected individual characteristics of the caregiver (gender), care receiver (type and severity of condition), dyad (geographic proximity and relationship) and broader contextual factors (caregiving, community and policy contexts).

In addition, three distinct domains of economic costs for employers of caregivers were found: *Direct costs, Indirect costs* and *Discretionary costs*. The magnitude of direct and indirect costs for employers depends upon the number of employees requiring caregiving-related workplace accommodations. Employers' involvement in providing options for flexible work, paid leave, and information and supports appears to reflect their awareness of employees' concerns, organizational characteristics and workplace culture.

Knowledge and data gaps were identified: definitions and scope; extent of costs in each of the cost domains; interrelationships among domains of costs; public-private cost sharing; the heterogeneity of caregivers; employer costs. Methodological approaches and data sources are suggested to address these gaps. Increased conceptual clarity on the domains of the costs of care to these two stakeholder groups provides a contribution to the discourse on economic costs of care.

Key Words

Costs of care, employed caregivers, family/friend caregivers, care costs to employers, taxonomy of costs of care

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1. Executive Summary

We evaluated the current state of knowledge of the economic costs to family/friend caregivers and to employers of caregivers to adults with long-term health problems and disabilities. A systematic scoping review was used to examine the extent, range and nature of research pertaining to these economic costs and to explore major influences on the magnitude of those costs. We identify knowledge and data gaps on the economic costs of care, proposing methodological approaches and data sources to fill these gaps.

Methods

Two systematic scoping reviews were undertaken to determine the extent, range and nature of research pertaining to the economic costs to family/friend caregivers and to employers of caregivers and to produce a synthesis of the existing literature in each of these bodies of literature. Publications from 2000 to present were reviewed. Key word search terms were used in databases relevant to family/friend caregivers and employers that spanned disciplinary boundaries and emphasized Canadian materials where available. References included in the scoping review were screened by title, abstract and then full text to ensure their relevance.

Two taxonomies of economic costs of care were developed from these reviews. Within each we determined major domains, identified sub-categories of costs within the major domains, and explored major influences on the magnitude of those costs. A gender lens was used given the significant body of literature on the gendered nature of caregiving. Based on these findings, knowledge and data gaps were identified.

Findings on the Economic Costs of Care for Caregivers

The review of the literature on economic costs of care for caregivers showed three cost domains:

- *Employment restrictions*
- *Out-of-pocket expenses*
- *Caregiving labour*

Immediate and longer-term economic outcomes or consequences for caregivers included reduced/foregone income, lost benefits, reduced pension, reduced savings/investments and increased health care costs. There is evidence that each of the three domains of costs may lead to a different set of economic outcomes.

Employment Restrictions reflect accommodations caregivers make in labour force participation, work scheduling, or career progression to meet caregiving demands. There are four main categories of employment restrictions:

- labour force exit/preclusion
- restricted work hours and absences
- decreased productivity
- career limitations

Employment restrictions result in two major types of economic outcomes: reduced current income and foregone future income. There is considerable evidence of short-term reduction in current income, but long-term economic costs of employment restrictions such as those associated with foregone job-related benefits, also are being documented. Women are more likely to accommodate their paid work to meet care demands and their pension entitlements are significantly affected.

Out-of-pocket Expenditures are incurred by caregivers for care provision, purchase of services and supplies for the care recipient. They occur in four main categories

- residential care
- care-related community services
- supplies
- transportation costs

Out-of-pocket costs are a common and significant expense and have greatest implications for low-income caregivers. Medications constitute a large proportion of expenses, particularly in jurisdictions without prescription drug insurance plans. Travel costs can be significant, for accompanying care recipients to specialized treatments or consultations, paying for their accommodations, meals and transportation costs. These expenditures result in extra expenses for the individual, reduced opportunities for saving/investment and significantly affect caregiver economic security.

Caregiving Labour refers to time spent by family and friend caregivers performing tasks and services for the care receiver. Main categories of caregiving labour are

- time spent with the care recipient
- time spent on behalf of the care recipient
- time spent getting to the care recipient
- time spent monitoring the care recipient

Between 2002 and 2007 the proportion of Canadians over the age of 45 providing care increased from 19.5% to 28.9%--a total of 3.8 million caregivers (Fast et al., 2010). Caregiving intensity varies considerably across caregivers and tasks. While some have argued that personal care is the most intense care task, there is evidence that household tasks and care management are time consuming and essential to helping someone remain at home.

Caregiving labour has two main types of economic outcomes. It can reduce the amount of time caregivers spend in the paid labour force, which affects their current and future income; and it can have an effect on caregiver health which in turn requires increased expenditures on health care and other services for the caregiver. The latter category has been little explored and warrants further examination through consideration of the interactions between social, health and economic costs of care.

Factors Influencing the Prevalence and Magnitude of Costs for Caregivers

Key factors in differentiating costs of care are:

- gender
- care recipient characteristics
- geographic proximity
- relationship between caregiver and care recipient

Gender

Women are more likely to accommodate their employment to caregiving, to give up work or quit a job in order to provide care, to incur higher out-of-pocket expenses and to provide more care. There is evidence of women's higher levels of involvement, greater intensity of care and higher likelihood of economic implications of care. Given the fact that in Canada women have lower average incomes than do men, this cost evidence suggests a new double jeopardy of being female and a caregiver.

Care recipient characteristics

Caregivers of those with higher care needs report more changes to their employment. Similarly the care recipient's condition influences the amount of time spent caregiving, with greater hours provided as severity of the condition increases. Both the incidence and magnitude of out-of-pocket expenses vary by type of illness and increase with the severity of the illness.

Geographic proximity

While long distance caregivers are more likely to make accommodations to their work schedule or have more absences to meet the needs of care recipients, caregivers who co-reside with the person they care for spend more time providing care and are more likely to leave the workforce when caregiving demands are onerous. Caregivers who live further away incur extra expenses. Transportation and travel expenses are most sensitive to distance between caregiver and care recipient.

Caregiver-care recipient relationship

Those who care for a close relative (spouse or parent) spend the most time caring, although friends provide assistance with a greater number of tasks and provide more hours of care than do neighbours. Given the importance of non-kin caregivers, research is warranted to better understand their differential care commitments and how these might influence caregiving sustainability.

Findings on the Economic Costs of Care for Employers

The review of the literature on economic costs of care for employers highlighted three cost domains:

- Direct costs
- Indirect costs
- Discretionary costs

The literature on caregiving-related employer costs is very limited. There is a need for more accurate data and for Canadian research on both employer costs and savings that may result from more flexible work arrangements and employer-provided supports for caregivers designed to reduce absenteeism and caregiving burden.

Direct costs

Expenses that can be tracked directly from payroll, benefits and administrative systems. Direct costs include those related to the recruitment, selection and training of new personnel to replace those who leave; wages paid to absent workers; overtime pay and or wages and benefits for temporary replacement workers to cover employee absences; and additional health care claims and benefit costs related to stress, short-term and long-term disability leave.

Indirect costs

Relate to lost productivity deriving from the effects of reduced productivity and performance and from the loss of personnel with training and firm-specific knowledge who may retire or quit their position. Indirect costs can extend beyond individual employees with caregiving responsibilities to their supervisors, co-workers, and ultimately to clients and customers.

Discretionary costs

Associated with the provision of flexibility, support, services or financial assistance to employees with caregiving responsibilities. These benefits and workplace practices are often referred to as "Best Practices" that can help defray avoidable absenteeism and productivity costs and aid in retaining valuable personnel.

Factors Influencing the Prevalence and Magnitude of Costs for Employers

Given the very limited research on caregiving-related costs to employers, specification of the factors that influence the prevalence and magnitude of such costs remains to be done. Related literature would suggest that the prevalence and magnitude of direct and indirect employer costs related to caregiving is likely to depend on:

- a variety of organizational characteristics
- characteristics of an organization's workforce
- public policy and contextual factors

Knowledge and Data Gaps

Given high levels of concern about public costs of care, as well as growing concerns about the availability and sustainability of the family/friend care sector, a more complete view is warranted of the state of the 'private' side of public-private partnerships in caring for adults with long term health problems and disabilities. Our knowledge of these costs is fragmented and uneven. Seven gaps were identified.

Gap 1: Definitions and scope

Definitions of care, of caregivers and of care tasks differ widely making it difficult to evaluate relative costs or build a coherent body of knowledge about them. A further constraint to knowledge of the scope of caregiving responsibilities stems from an emphasis on care provided to a care receiver by an individual (often called primary) caregiver, although caregivers may be caring concurrently for more than one person and care to a particular care recipient often is shared.

Gap 2: Extent of costs in each of the cost domains

There have been few systematic attempts to build knowledge within caregiver cost domains. The extent of employment restrictions is perhaps best understood. However, there are relatively few studies that estimate the monetary value of lost wages and benefits. A notable gap is in information about cumulative losses of people who have foregone employment or left the labour force early because of long-term care responsibilities. Costs of caregiving labour are most poorly documented despite the availability of good time use methodologies.

Gap 3: Interrelationships among domains of costs

Given the uneven nature of knowledge of family/friend costs within the three domains of employment consequences, out-of-pocket expenses and care labour, it is not surprising that little is known about the interrelationships among these costs. Evaluation of lifecourse issues that influence caregiving costs could move forward our understanding of the balance of employment, out-of-pocket and care labour costs at different lifecycle stages.

Gap 4: The prevalence of high costs for specific groups

A key concern for policy makers and service providers is identifying which caregivers are at highest risk for adverse economic and health outcomes. Our analyses of the literature indicate that a mix of caregiver, care receiver and caregiving context factors affect the magnitude and prevalence of economic costs for individual caregivers. Additional data and more systematic analysis would be helpful in this regard.

Gap 5: Private-public cost sharing

In recent years there has been considerable interest in tracking the apportioning of costs across public and private stakeholders. The templates provided here for the assessment of family/friend costs and employer costs set the basis for a more inclusive evaluation of the types of costs incurred by these different stakeholders and for evaluation of how public policy, private policy and population aging might influence this apportioning.

Gap 6: The heterogeneity of caregivers

There has been long-term awareness of the diversity among caregivers and among the persons to whom they provide care. Young carers (i.e. under the age of 18) is an emerging area of special interest. There is little information on economic costs for certain minority groups of caregivers such as LGBT caregivers, low income caregivers, those in immigrant or ethnic minority families or transnational caregivers. An understanding of the unique features of caregiving in Aboriginal families and communities is also required.

Gap 7: Employers' Costs

There are major gaps in our knowledge of employers' costs. Currently there are no estimates available of caregiving-related costs to employers in Canada. Any such estimates require Canadian data that are informed by the various policy factors that affect employers and employees and by the distribution of employees in organizations that vary by sector, industry, firm size and unionization status.

Data Sources and Needs

Clear, concrete information about the potential to fill knowledge gaps with existing data sets and strategic methodological approaches, are essential to creation of knowledge on which to base policy and practice decisions. Through consultations with colleagues from Statistics Canada and other researchers, we scanned the data environment for the best extant Canadian data sets to provide evidence of economic costs of care, and propose methodological approaches and data sources to address remaining gaps.

Employment consequences

Surveys from the Statistics Canada General Social Survey (GSS) series Cycles 21 (Family, Social Support and Retirement, 2007) and 26 (Caregiving, forthcoming, 2012) both have information on domains of costs of care to family/friend caregivers. Cycle 26 will include more comprehensive information on employment consequences, in particular on care-related work interruption history, and a more detailed set of out-of-pocket expense categories allowing for a more nuanced understanding of these caregiver costs in particular.

Caregiving labour

Across Statistics Canada surveys, information on care labour is not structured to allow for detailed analyses of consequences. While some data on time spent on care tasks is available in the time use cycle of the General Social Survey, the data are limited and not sufficiently detailed. For example, only medical and personal care tasks are captured for receivers living in the respondent's household. In addition, the time use diary is collected for a single day. Since care tasks are not always performed on a daily basis, it is likely that care time is under-estimated, despite attempts to sample days of the week and year in a representative manner.

Out-of-pocket expenses

The GSS Cycle 21 (2007) has some global questions on out-of-pocket expenses, but the categories are very broad with no breakdown by type of cost. There are plans for Cycle 26 (2012) to include more detailed data on out-of-pocket expenses though these are not yet confirmed. Overall data from these Statistics Canada sources still have only broad categories.

Other methodological approaches

Case study and small scale surveys of caregivers can be employed to evaluate the relevance of the subcategories within each consequences domain and to develop methods for more systematic assessment of their magnitude. Narrative methods could be used to better understand the relative importance of domains of costs and the relevance of particular items within them.

Employer costs

Obtaining reliable data on employer costs is particularly challenging as there is no national survey of employers that can be used for this purpose. Data on compensation and benefits trends typically are based on non-representative samples that under-represent small business. Many organizations do not compile administrative data on costs associated with absenteeism or benefit claims. Members of our larger team (Lero, Spinks and Fast) are currently conducting research on the availability of workplace programs and practices for employees with caregiving responsibilities, which includes some information on employers' experiences. Further discussion with experts in the field would be needed to develop a strategy to use data collected in new Statistics Canada surveys that might be useful for approximations of employer costs.

Conclusion

Increased conceptual clarity on the domains of the costs of care is an important outcome of this project and will frame the other projects in this program of research, provide a basis for our synthesis report, and contribute to the discourse on economic costs of care.

1. Introduction

Families are a central feature in the debate about how societies will face the challenges of population ageing (Keating, 2009a; Keating, 2009b; van Tilburg and van der Pas, 2008). In much of the contemporary discourse, families are viewed as largely responsible for the care and support of their members with a chronic illness/disability (Carmichael, Connel, Hulme and Sheppard, 2008). Yet increasingly researchers and policy makers have expressed concern about threats to the caring capacity of families given structural changes such as divorce, geographic mobility, and high labour force participation rates of women and men (Fast, Keating and Yacyshyn, 2008; Légaré, Gaymu, Busque, Vezina, Decarie and Keefe, 2008).

Structural changes to families, in combination with a sustained global economic recession, have led to escalating economic and time constraints on caregivers and a spillover of costs into the employment domain. Recent surveys confirm that the majority of caregivers to adults and seniors are, or were at some point, employed while caregiving (Fast et. al, 2010; National Alliance for Caregiving (NAC), AARP and MetLife Foundation, 2004, 2009). Caregivers report modifications to their work situations in order to enable caregiving (Keating, Fast, Frederick, Cranswick, and Perrier, 1999; NAC, AARP and MetLife Foundation, 2004; 2009). These modifications may include missing whole or part days of paid work, reducing paid work hours, taking extended leaves of absence, quitting a job, and retiring early (Allegri, et al., 2007; Austen and Ong, 2010; Berecki-Gisolf, Lucke, Hockey, and Dobson, 2008; Fast, Keating and Yacyshyn, 2008; Evandrou and Glaser, 2003; Fast et. al, 2010; Lilly, Laporte and Coyte, 2007, 2010; Mennemeyer, Taub, Uswatte and Pearson, 2006; Muller and Volkov, 2009; Pyper, 2006).

Employer challenges include ensuring workplace efficiency in the face of an increased likelihood of employee turnover, absenteeism and reduced productivity among those with caregiving responsibilities, and increasing demands on employee benefit programs (Evandrou and Glaser, 2003; Fast, Keating, and Yacyshyn, 2008; Henz, 2004; MetLife Mature Market Institute (MMMI) and NAC, 2006, 2010). Additional costs to employers may result from paid leave, increased supervisory time, and secondary impacts on co-workers (MMMI and NAC, 2006). Such changes, in turn, have the potential to slow economic recovery and place caregivers at further economic risk.

In combination, these challenges make it imperative that we better understand the economic costs of care both to caregivers and to their employers, and increase the precision of our current models of costs of care.

2.1 Project Objectives

The purpose of this project is to document the current state of knowledge of the economic costs of care to adults with chronic health problems/disabilities. Two stakeholder groups are featured: family/friend caregivers and employers of caregivers. For each of these groups we have four objectives:

Objective 1:	Review recent Canadian and international literature on care-related costs in order to develop a taxonomy of the costs of care
Objective 2:	Use the resulting taxonomy as a framework to conduct a comprehensive evaluation of the determinants of these costs
Objective 3:	Determine knowledge and data gaps
Objective 4:	Propose methodological approaches and data sources to fill these gaps

2.2 Framework and Approach

Research on the economic costs of care has important conceptual and knowledge gaps which this project addresses. In earlier work (Fast, Williamson and Keating, 1999), we laid out a broad set of stakeholders affected when Canadians provide care to adult family members and friends with long term health problems/disabilities including governments, families, caregivers and care recipients. This project is the first of a set in which we further conceptualize and provide empirical data on costs of care. The conceptualization of domains of economic costs to family/friend caregivers which forms part of this report, builds on previous conceptual work by team members (Lero, Keating, Fast, Joseph, and Cook, 2007). No such foundational work has been done to conceptualize domains of costs of employers of individuals who provide care. Yet employers are important stakeholders in caregiving since increasing proportions of those providing care are in the labour force.

A goal of this project was to develop two taxonomies of the economic costs of care, determining major domains, identifying sub-categories of costs within the domains, and exploring some of the major influences on the magnitude of those costs. A taxonomy is a classification arranged in a hierarchical structure and, in this case, is used to conceptualize the categories of costs of care.

2.3 Gender Lens

There is a significant body of literature on the gendered nature of caregiving, including gender differences in the likelihood and extent of involvement in caregiving tasks, caregiver burden, and employment consequences (Berecki-Gisolf, et al., 2008; Carmichael and Charles, 2003). Since costs will be experienced differentially by women and men, use of a gender lens is imperative in this conceptual work. Members of the project team have conducted gender-based analyses in their caregiving research (see for example Fast, Forbes and Keating, 1999; Fast, Niehaus, Eales and Keating, 2002; Keating, Fast, Frederick, Cranswick, and Perrier, 1999) and have continued in this tradition for this project.

Increased conceptual clarity on the domains of the costs of care (Objective 1) is an important outcome of this project that frame the other projects in the program of research of which it is a part, provides a basis for our synthesis reports, and contributes to the discourse on economic costs of care. The identification of other factors that may affect the magnitude and impacts of costs (Objective 2) and the articulation of knowledge and data gaps and approaches to filling those gaps (Objectives 3 and 4) provide a way forward for researchers and policy makers.

2.4 Methods

The systematic reviews conducted in this project provide syntheses of the literature on the key economic costs of care for caregivers and employers of caregivers. The goal of a systematic review is to find research relevant to the particular research question and use an explicit process to identify what can be concluded on the basis of these studies. A systematic review provides a rigorous protocol, exhaustive searching and thorough examination of existing literature. It requires clarity of what is included in the review, what is excluded and thus, the resulting body of knowledge. A strength of the systematic review is its ability to draw together knowledge across a topic area (Grant and Booth, 2009). One type of systematic review is the scoping review. A scoping review aims to map the key concepts underpinning a research area and the main sources and types of evidence available (Arskey, and O'Malley, 2005). It is generally conducted to examine the extent, range and nature of research in a particular field and produce a profile of the existing literature (Brien, Lorenzetti, Lewis, Kennedy, and Ghali, 2010). Through synthesis and analysis a scoping review can provide conceptual clarity for constructs of interest (Davis, Drey, and Gould, 2009).

A scoping review is an appropriate method for addressing research on the economic costs for family/friend caregivers and for employers of caregivers. The literature in this area is diverse and includes research studies and grey literature, which fits with a scoping type of systematic review. A priority of the scoping review is to compile as much relevant literature as possible in order to obtain a broad view of the research topic. Arskey and O'Malley (2005, p.30) indicate that one of the strengths of the scoping review is that "it can provide a rigorous and transparent method for mapping areas of research", which makes it especially appropriate for the topic at hand. The "York framework" used in this project includes five stages (Arskey and O'Malley, 2005; Brien et al., 2010).

2.4.1 Identification of the research question:

This step involved drawing on the expertise of the project team as well as previous research on the costs of care. The background and rationale are detailed in the introduction (Section 2), while the framework and approach considered for addressing the research question are outlined in Section 2.2.

2.4.2 Identification of relevant studies:

The York framework recommends searching several literature sources in order to conduct a comprehensive search. Sources of information on economic costs are detailed later in the report as part of the reference retrieval procedure for caregivers (Section 3.1.1) and for employers (Section 4.1.1).

2.4.3. Selection of studies to include:

The use of broad search terms in the electronic databases generated a large number of abstracts. To manage these results, inclusion and exclusion criteria were identified based on the focus area detailed by the research question and the full screening process for references described separately for caregivers (Section 3.1.2) and for employers (Section 4.1.2).

2.4.4. Extraction of information and data within included studies:

A multi-stage process was employed for the development of each taxonomy, as per the York framework, which involved extraction of information from individual articles in a parallel process for each of the two stakeholder groups. A list of specific characteristics of information that was extracted from the references is described later in the report for caregivers (Section 3.1.3) and for employers (Section 4.1.3). Details about the quality assessment conducted in this phase are provided separately for caregivers (Section 3.1.4) and employers (Section 4.1.4).

2.4.5. Summation, collation and synthesis:

The purpose of the final stage of the scoping review is to provide a structure to the literature to be included in the synthesis. Due to the broad scope of the research question, a narrative synthesis was developed to organize the findings into specific categories for each stakeholder group, caregivers (Section 3.1.5) and employers (Section 4.1.5).

1. A Systematic Review of the Literature on the Costs of Care for Caregivers

3.1 Method

3.1.1 Reference Retrieval Procedure and Search Strategy

Inclusion criteria addressed the research focus of this project: family and friend care to adults and the experience of economic costs arising from care responsibilities. Keywords that captured the caregiving relationship and costs were used in a variety of databases and disciplines including gerontology, psychology and business. Although the preferred term in this project for the type of caregiver included is family/friend caregiver, an often-used term in the literature is informal caregiver, so it was applied in some of the larger databases. The term 'income' was in a preliminary search but was not used in subsequent stages as it generated articles that dealt with low-income individuals rather than the impact of caregiving on income. An exploratory search using the terms 'caregiver expenses' resulted in a small number of results that were not focused on the topic of interest. Terms were adapted based on what generated the most appropriate results.

- *Inclusion criteria*
  - ◊ Family members or friends who provide care to an adult with a long-term health problem or disability (primary and other caregivers). Criterion based on chronic condition lasting for 6 months or more
  - ◊ Family members or friends caring for receivers living at home or in care facilities such as nursing homes
  - ◊ Focus on one or more economic costs of caregiving
  - ◊ Definitions
    - ⇒ *Family /Friend caregiver* refers to an individual who provides care on an ongoing basis that is based on a personal, often longstanding relationship (Lero et al., 2007).
    - ⇒ *Care is defined as a set of tasks and services provided by a family member/ friend because of the recipient's long-term health need or disability (Keating, et al., 1999) that is provided on an ongoing basis.*
    - ⇒ *Care recipient is an individual who receives care from a family member or friend due to a long-term health problem or disability.*
- *Exclusion criteria*
  - ◊ Research related to acute illnesses and crisis care which is short term and time limited.
  - ◊ Research on the formal sector of paid caregivers and on volunteers
  - ◊ Care provided to children (those under age 18)

- *Search strategy*
  - ◊ Keywords: caregiving, caregiver outcomes, family caregivers, informal care, caregiver risks, employed caregivers, caregiving and work, working caregivers, economic costs, elder care.
  - ◊ Date: Material published or produced since 2000 was reviewed in order to capture new literature that was not reviewed and analysed in the development of the

taxonomy on costs of care (Fast, Williamson and Keating, 1999). A limited number of the most frequently cited articles and reviews that were published in the late 1990s were included.

- ◊ Particular attention was paid to finding Canadian materials, although studies from other countries were not excluded.

- *Sources of information*
  - ◊ Databases: Abstracts in Social Gerontology, Academic Search Complete, Ageline, Business Source Complete, Business Source Elite, EconLit with Full Text, Family and Society Studies Worldwide, Family Studies Abstracts, Human Resources Abstracts, MEDLINE, PsycEXTRA, PsycINFO, Psychology and Behavioural Sciences Collection, Social Work Abstracts, SocINDEX with Full Text, Sociological Collection.
  - ◊ Electronic reports and studies were obtained from research centres, policy institutes, government agencies and departments, and websites of relevant organizations and associations.
  - ◊ Other Sources: Manual searching of reference lists, personal recommendations, existing bibliographic database, previous search results.
  - ◊ Disciplines and fields: Literature for this topic was found across a variety of academic disciplines and included book chapters, academic journals, government reports, and grey literature (reports produced via research centres, non-profit organizations, etc.). The major disciplines/fields drawn upon include gerontology, family studies, sociology, psychology, work-family, health, management and business. Both quantitative and qualitative studies were included.

3.1.2 Screening Process for References

A description of the screening process to reach the final set of articles is presented below.

Title review

References were either included or excluded based on the pre-determined criteria for article titles (Section 3.1.1). At this point two reviewers screened a sample of titles, consulting to ensure consistent screening and discuss any discrepancies or clarify inclusion criteria as needed. Using two reviewers helped to reduced selection bias during this phase of the review. During this stage a total of 289 of 2524 titles were chosen for the next stage of abstract review. The majority of references that were excluded (around 80%) did not address the focal topic of family/friend caregivers and economic costs. Examples included those dealing with rural ageing, social isolation, healthy aging, or services for caregivers. Many articles were excluded because they focused on non-economic costs such as caregiver burden or health and well-being consequences. The majority of literature on caregiving is focused on these non-economic costs.

Abstract review

The next phase was to screen the abstracts of the remaining references for relevance. When information contained in the title and abstract was not sufficient to determine inclusion, the full text was reviewed. At this stage, 118 references were chosen for the next stage of full text review.

Full text review

After full text review a total of 104 references were selected for inclusion in the study. At these final two stages of review, articles were excluded because they failed to report at the level of the caregiver, because the focus was on the cost measurement tool or instrument, because the care recipient was under the age of 18, because the article focus was on policy implications or recommendations; or because the reference could not be found either in hard copy or electronically. After completion of the full literature search, twelve additional references were included. These references were identified by experts in the field, including team members. Thus the total number of articles included for data extraction was 116. Throughout the process researchers used EndNote software to track all references. This program allows information on the reference to be entered such as abstracts, keywords and source as well as it allows for online sharing between researchers.

3.1.3 Extraction of Data from References

According to the York scoping review method, the data extraction process is multi-staged, involving extraction of information from individual articles. Information was collected on sample characteristics and key findings from included studies to create a detailed spreadsheet database. The extraction form used was developed and tailored to the review question by the project team.

The main categories of the data extraction table for costs to caregivers include:

- *Reference source*: author, title, year, source, country
- *Employment consequences: job loss/early retirement; restricted work hours/options; unpaid absences or leave; reduced income and pensions; lost benefits; other.*
- *Out-of-pocket expenses: residential care; community care services; supplies; transportation/travel; other.*
- *Caregiving labour: time spent with the care recipient; time spent on behalf of the care recipient; time spent getting to the care recipient; time spent monitoring the care recipient; replacement costs or opportunity costs; other*
- *Additional details: sample characteristics; details on measurement; magnitude (including frequency, duration); gender differences; and other group differences.*

Data were extracted from the primary sources to simplify, abstract, focus and organize the data into a manageable framework as proposed by Whittemore and Knafl (2005). The initial process included extraction of information on methods, sample, and definitions. Data extraction for each of the main domains of costs to family/ friend caregivers was conducted separately in order to focus exclusively on one domain at a time. Domains and categories in which caregivers incur costs or consequences were noted. The data extraction table was double checked to ensure that reporting was accurate and that all relevant information was captured.

3.1.4 Quality Assessment

All potential publications were evaluated for topic relevance and methodological quality. Topic relevance was determined through evaluation of the appropriateness of each publication to our research question. The final set of relevant articles was arrived at the screening process described in the methods section. The methods used in each publication were noted during the data extraction process and standards used to evaluate the main elements of qualitative and quantitative methodologies were applied (Merriam, 2002; Smith-Sebasto, 2001). (See Appendix 7-1 for a summary of these standards).

3.1.5 Narrative Synthesis

The purpose of the narrative synthesis was to identify sub-categories of costs within the domains and themes of economic costs of caregiving for caregivers. A narrative synthesis is appropriate when studies are too diverse (either substantively or methodologically) to combine in a meta-analysis (Centre for Reviews and Dissemination, 2009).

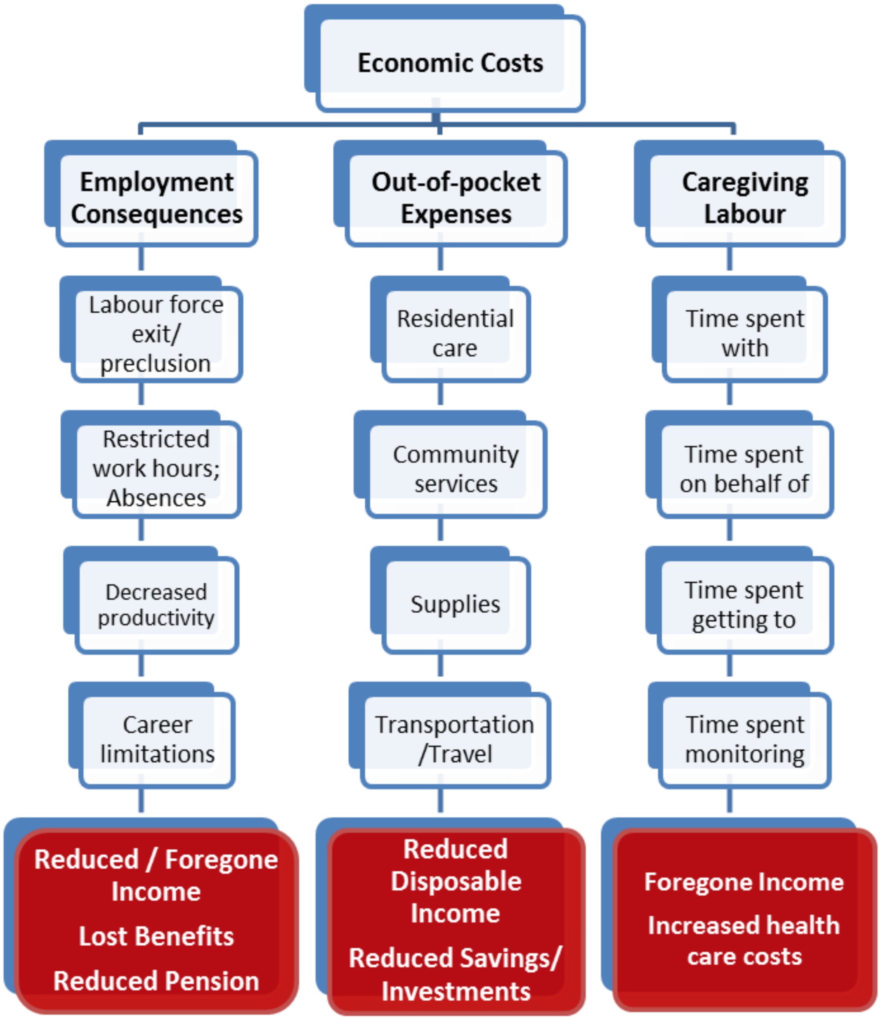
3.2 Findings

The review of the literature on economic costs of care for caregivers highlighted three cost domains: employment consequences; out-of-pocket expenses; and caregiving labour. *Employment consequences* include changes made in the extent of caregivers' labour force participation (job loss or labour force exit, reduced paid work hours) and work schedule (rescheduling paid work time to accommodate caregiving needs, including coming in late or leaving early). Employment consequences also include employee absences (both planned, such as leaves or to accommodate appointments known in advance and unplanned absences that occur in response to caregiving crises) and impacts on employees' productivity and engagement. Finally, caregiving responsibilities may affect employed caregivers' capacity or willingness to participate in workplace or off-site training and in opportunities intended to lead to career advancement.

Out-of-pocket expenses are extra expenditures made by the caregiver that they would not have made in the absence of their care responsibilities, including paying for services and supplies, and other extra costs related to the provision of care. *Caregiving labour* refers to the time spent by family members and friends on caregiving and related activities.

The following figure represents the taxonomy of economic costs of care to caregivers based on the results of this review.

Figure 3.1 Taxonomy of the Economic Costs of Care for Family/Friend Caregivers



3.2.1 Employment Consequences

Within the domain of employment consequences, four sub-domains were identified: labour force exit/preclusion; restricted work hours; absences (full and/or partial days as well as periods of leave taken to provide care); decreased productivity as a result of fatigue role strain distractions; and career limitations. The literature that was reviewed on employment consequences includes analyses based on data collected by national statistical agencies and research on less representative populations conducted by individual researchers and organizations. There are some inconsistencies that result from differences in sampling and some findings that may be country or workforce-specific, in part reflecting differences in public policies and workplace norms. In this section, we provide an overview of the most common findings in the literature.

Making some accommodation to one's work is fairly typical among employed caregivers (Fast, Eales and Keating, 2001), with variations in the frequency and extent of accommodations noted, especially based on the intensity of caregiving involvement. The most recent national study of caregivers in the U.S. reported that 69% of employed caregivers to adults made one or more changes to their work in order to accommodate caregiving (NAC, AARP and MetLife Foundation, 2009). The most frequently reported accommodation (self-reported by 65% of U.S. caregivers) involved going to work late, leaving early or taking time off during the day to provide care. Next most common was taking a leave of absence (20%), followed by reducing work hours or taking a less demanding job (12%). Quitting one's job or leaving the workforce is less common (9%), but is likely to have the most serious immediate and longer-term economic outcomes.

Labour force exit/preclusion

Labour force exit/preclusion includes withdrawing from the labour force due to job loss, quitting a job or taking early retirement. Those who did not enter the labour force because of caregiving responsibilities assumed in early adulthood are considered to be precluded. Studies across a variety of countries provide evidence of a modest, negative association between providing care and labour force participation (Bolin, Lindgren and Lundborg, 2008: Carmichael and Charles, 2003; Crespo, 2006; Decima Research, 2002; Evandrou and Glaser, 2003; Henz, 2004; Lilly, Laporte and Coyte, 2007, 2010; Masuy, 2009; Schulz and Martire, 2009; Van Houtven, Coe and Skira, 2010). Lilly et al., (2007) reviewed more than 35 studies, conducted primarily in the U.S. and the UK, and concluded that caregivers, in general, are not less likely to be in the labour force, but that a number of studies showed the relationship between labour force participation/continuation and caregiving to be strongly conditioned by the intensity of caregiving involvement. For example a study in Australia found that, "all carers are less likely to be working full-time than the Australian average (42.0%). In particular, the rate of full-time employment among primary carers is just 19.2%, less than half that of the general population" (Access Economics Pty Limited, 2005, p23).

In Canada between 1% and 2% of employed caregivers age 45+ in both the 2002 and the 2007 Statistics Canada General Social Survey (GSS) reported they had quit or lost a job to provide care (Cranswick, 2003; Statistics Canada, 2009). Research indicates that decisions about the timing of retirement are determined by a range of factors, with finances and job-related issues predominating. Pyper (2006) reported that one in five caregiving women needed to provide care to a family member as a reason for their retirement, twice the rate of those not providing care when surveyed in 2002. Caregiving was not as significant a factor in men's retirement decisions as it is in women's retirement (Humble, 2009; Uriarte-Landa and Hébert, 2011).

Other findings from the literature include the following: The 2006 MetLife Mature Market Institute/National Alliance for Caregiving study of employed caregivers to seniors in the U.S. estimated that 9% of full-time employed caregivers left the workforce (either leaving work entirely or taking early retirement) due to caregiving responsibilities. In a small Canadian qualitative study, three out of seven caregivers for a family member with a chronic disease or long-term physical disability stated that pursuing a full-time paid employment position had not been an option for them due to their caregiving responsibilities (Gibbens, 2005). A national Canadian survey of family caregivers over the age of 18 found that 20% of caregivers who were not employed at the time of the survey had quit due to caregiving responsibilities (Decima Research, 2002). In a recent U.S. study, 47% of caregivers of veterans reported quitting work entirely or taking early retirement due to care responsibilities (NAC and United Health Foundation, 2010). In another U.S. study 27% of female caregivers for elderly male veterans with dementia who had retired reported doing so due to care responsibilities (Moore, Zhu and Clipp, 2001).

These results are supported by other findings that caregivers are less likely than non caregivers to participate in the labour force. A Canadian study by Latif (2006) found that caregiving negatively impacts the number of work hours for men and women caregivers. Another Canadian study of caregivers for adults with disabilities found that almost one third of veteran's supporters quit a job as a result of support demands (Fast et al., 2008). An international review also reported that caregivers are less likely to participate in the

labour force and that caregivers are more likely than non-caregivers to reduce their work hours and stop working all together (Schulz and Martire, 2009).
Lilly, Laporte and Coyte's (2007) review suggested that it is difficult to determine the extent to which the preclusion hypothesis can be supported (i.e., those who provide care are less likely to enter the labour force) since other factors including one's education and employment skills may be key determinants of labour force participation.

Caregiving from an early age (young carers and parents of children with significant disabilities) can limit one's participation in education and work, affecting the development of job skills and future earnings (Lero et al., 2007). Using the European Community Household Panel, Casado-Marin, Garcia-Gomez and Lopez-Nicolas (2008) found among women aged 30 to 60 who were not working prior to becoming a caregiver, had a lower likelihood of ever entering employment.

Another employment restriction caregivers may face is difficulty returning to work after caregiving ends. Heitmueller and colleagues reported that caregivers identified in the British Household Panel Study (1991-2002) have a reduced probability of being in the labour force post-caregiving (Heitmueller, 2007; Heitmueller and Inglis, 2007; Heitmueller, Inglis and Institute for the Study of Labour, 2004).

Restricted work hours and absences

Restricted work hours/options are care-related changes such as working fewer hours, missing days of work, working part time, rearranging schedules, or changing jobs or positions in order to reduce pressures or increase flexibility in paid work hours. Taking a leave of absence (paid or unpaid) is also included in this category. These employment adaptations may follow a period of time in which employed caregivers rearrange schedules on an occasional basis or miss a few hours of work (coming in late or leaving early). Occasional changes may still be needed to accommodate caregiving needs.

A review of the international literature provides many examples of employed caregivers making a variety of adaptations to their work hours or work options. Some researchers confirm the prevalence of caregivers making changes such as working fewer hours, for example by moving from full-time to part-time work or turning down overtime in order to be able to combine work and care (Bereki-Gisolf et al., 2008; Bolin et al., 2008; Carmichael and Charles, 2003; Carmichael et al., 2008; Covinsky et al., 2001; Dautzenberg, Diederiks, Phillipsen, Stevens, Tan and Vernooij-Dassen, 2000; Evandrou and Glaser, 2003; Gillen and Chung, 2005; Henz, 2004; Rossi et al., 2007; Schulz and Martire, 2009; Spiess and Schneider, 2003; Viitanen, 2005; Wakabayashi and Donato, 2005). Estimates of the proportion of caregivers reporting these consequences range from 11% to 44% (Evandrou and Glaser, 2003; Henz, 2004; Pyper, 2006; Spiess and Schneider, 2003; Wilson, Van Houtven, Stearns and Clipp, 2007). In contrast, others have reported that caregiving has no statistically significant impact on paid work hours (Bittman, Hill, and Thomson, 2007).

Other strategies for accommodating paid work to caregiving demands include changing work schedules (Dautzenberg, et al, 2000; Ellenbogen, Mead, Jackson and Barrett, 2006; Fast et al., 2008; Habtu and Popovic, 2006; Henz, 2004), missing whole or part days of work (Dautzenberg et al., 2000; Duxbury and Higgins, 2001, 2005; Fast et al., 2008; Gibson and Houser, 2007; Gillen and Chung, 2005; Gray, Edwards and Zmijewski, 2008; Lai and Leonenko, 2007; Moore et al., 2001; Reid, Stajduhar and Chappell, 2010; Smith, 2006), using holidays or sick days to meet care responsibilities (often used as a way to avoid a loss in pay) (Dautzenberg et al., 2000; Gillen and Chung, 2005), declining promotions (Dautzenberg et al., 2000; Gillen and Chung, 2005), changing jobs (Lai and Leonenko, 2007; Rossi et al., 2007) and taking unpaid leaves (Lai and Leonenko, 2007).

Recent analyses of 2007 GSS data for employed caregivers confirm that women and men incur a variety of employment consequences, and that women are more likely to make adaptations to their work demands (Fast et al., 2011). Specifically 30% of women and 21% of men aged 45+ who provided care had missed at least one full day of work to provide care in the previous year. Women and men were almost equally likely to report reducing their paid work hours because of caregiving responsibilities (16.8% of women, 15.3% of men).

Burton and colleagues (2004) report that more than half of caregivers (52%) took up to 4 hours away from work, while a further 20% missed 8 hours during the two week survey period. The MMMI and NAC (2006) study found 16% of employed caregivers providing 12 or more hours of personal care per week reduced their work hours from full-time to part-time. Fully 58% were required to leave work early or come in late to attend to caregiving responsibilities, with an estimated 22% of that group likely unable to make up the time lost. Recently, the National Alliance for Caregivers found that 6 in 10 caregivers of a veteran cut back the number of hours in their regular employment schedule due to care responsibilities (NAC and UFH, 2010). A recent Canadian study reported that almost 30% of caregivers decreased their work hours (Reid et al., 2010). The number of caregivers who report reducing their hours ranged from 5% (Lai and Leonenko, 2007) to 60% (Moore et al., 2001), depending on mean weekly hours of paid work and the intensity of caregiving. For example 60% of caregivers to stroke patients gave up 25 hours or more of employment per week (Mennemeyer et al., 2006). In the national US study by Metlife on long distance caring, 44% of carers rearranged their work schedule for caregiving (NAC, MMMI and Zogby International, 2004).

A particular concern for employers and caregivers is the prevalence of missing full days of work and of taking a period of leave. Absences may be considered both an example of a work restriction and/or a factor that impacts on productivity for individual employees and their coworkers. Absences among caregivers are common. Recent analyses of 2007 GSS data indicate that 21% of men and 30% of women missed at least one full day of work to provide care within the previous 12 months (Fast et al., 2011). Similarly, in its report on productivity losses to U.S. businesses, the Metlife Mature Market Institute estimated that among those employed full time, men who provided care missed an average of 9 days per year and women missed an average of 24.7 days per year (MMMI and NAC, 2006). Thirty-six percent of U. S. caregivers who lived more than one hour away from the care recipient reported missing days of work (NAC, MMMI and Zogby International, 2004).

Accurate data on the number of employees who take a leave of absence for caregiving reasons is lacking. The recent U.S study of caregivers conducted by NAC and AARP reported that “one in five caregivers took a leave of absence at some point while they were caregiving” (NAC, AARP and MetLife Foundation, 2009, p.9). MMMI estimates for business costs used several sources to estimate an average of 10 days leave taken by more than 2.5 million employed caregivers (16% of men and 16% or women). The most recent

Canadian report available on EI benefit claims for the period April 2009-March 2010 revealed that there were 5,978 claims established for The Compassionate Care Benefit, a 2.4% increase over 2008/09 (Canada Employment and Insurance Commission, 2011). Given the strict eligibility criteria for this benefit, this number likely represents only a small portion of the number of leaves taken to meet caregiving needs.

Decreased productivity

Decreased productivity may occur as a result of absences as noted above, and as a result of mental preoccupation (Rosenthal, Martin-Matthews and Keefe, 2007), taking or making phone calls (Ellenbogen et al., 2006; Reid et al., 2010), low morale (Duxbury and Higgins, 2001), interruptions at work, stress, and caregiver strain, which can reduce job performance, potentially affecting job security. Loss of clients or customers may be a significant risk to those who are self-employed whose absence or failure to provide goods or services on time can directly affect their current and future income. Giovannetti and colleagues found that providing care to a disabled older adult was associated with a 20% decrease in work productivity (Giovannetti, Wolff, Frick and Boult, 2009). In this study, work productivity loss was measured as the number of days absent from work (absenteeism) and the degree to which caregiving affected productivity while at work (presenteeism) using the Work Productivity and Activity Impairment questionnaire (Giovannetti et al., 2009). The MMMI report on productivity losses (MMMI and NAC, 2006) estimated productivity loss of one hour/week for each of 50 weeks for 34% of men and 52% of women employed caregivers. They further estimated that an additional 60% of employed caregivers would experience a work disruption due to a crisis in caregiving for an average of 3 days per year. As Duxbury et al. have noted, employees with eldercare responsibilities experience higher levels of work-life conflict, including role overload and work-family interference which, in turn, are correlated with higher levels of job stress, lower job satisfaction, absenteeism and fatigue. Employees with high levels of financial, physical, and especially emotional caregiving strain are particularly vulnerable to experiencing high levels of stress, burnout, and depressed mood which can affect their physical and mental health as well as their productivity at work (Duxbury, Higgins and Schroeder, 2009).

Career limitations

Career limitations are opportunity costs that caregivers may experience due to their care responsibilities. Fast and colleagues (2011) report that among those aged 45 and older less than 5% of employed women caregivers and 3% of their male counterparts turned down a job offer or promotion because of caregiving responsibilities. As many as 40% of employed caregivers in one U. S. study indicated that caregiving had an impact on their ability to advance in a job as a result of their having to pass up promotions, turn down training or decline relocation (Koerin, Harrigan and Secret, 2008). Career-limiting consequences, such as declining a promotion have long-term economic implications for caregivers, such as foregone income and/or reduced pension benefits (Fast et al., 2008). Similarly, caregivers report turning down training opportunities at their place of employment due to caregiving (Bernard and Phillips, 2007; Keck, Saraceno and Hessel, 2009).

Postponing job-related or other education also is reported by caregivers (Pyper, 2006). Additional work-related opportunities such as work travel and relocation are turned down by caregivers who are unable to leave their care responsibilities (Fast, Eales and Keating, 2001). Researchers have reported long-term consequences to a caregiver's career including interrupted career trajectories due to care (Dunham and Dietz, 2003) and foregone opportunities (Ellenbogen et al., 2006).

3.2.2 Out-of-pocket Expenses

Out-of-pocket expenses are expenditures made by the caregiver that s/he would not have made in the absence of their care responsibilities. These are typically expenditures on care, services and supplies for the care recipient, but may also include services that allow the caregiver to provide hands-on care (such as child care our housekeeping services for the caregiver that frees up the caregiver's time that can then be spent on care-related tasks).

In studies based on two different nationally representative Canadian surveys, both conducted in 2002, it was estimated that between 38% (Habtu and Popovic, 2006) and 44% (Decima Research, 2002) of caregivers incurred extra expenses associated with caregiving. In a more recent Canadian study of persons caring for non-senior adults with high levels of disability between 63% and 80% of caregivers reported incurring care-related out-of-pocket expenses (Fast, Keating & Yacyshyn 2008). In a report out of the United Kingdom the majority (58%) of caregivers reported incurring out-of-pocket expenses associated with caring for someone with a disability or illness (Carers UK, 2007). Out-of-pocket expenditures can be substantial for caregivers. In a study of caregivers of adults in the community and in residential care, Hollander et al (2002) found an annual average of $2080 in out of pocket expenses with those providing care to older adults living in the community reporting the highest expenses (up to $6783) for.

Findings from a national survey in the United States indicated that expenses for groceries, medicines, or other kinds of cash support ranged between $2400 and $324 USD per year (Gibson and Houser, 2007). In a more in-depth U.S. study that had caregivers record their out-of-pocket expenses in a diary for a period of 30 days it was estimated the annual expenditures (on items that included medical expenses, long distance travel, care attendants, etc.) to be $12,348 USD (Evercare and NAC, 2007). Half of the caregivers in a Hong Kong study reported spending $128 USD per month on caregiving expenses, which represented 10% of their median monthly income (You, Ho and Sham, 2008). In the Canadian study of caregivers to non-senior adults with high levels of disability cited above, out-of-pocket expenditures were modest for most, but for about ⅓ expenses exceeded $5,000 in the past year (Fast, Keating & Yacyshyn, 2008).

Caregivers also may transfer money to the care recipient. For example, 15% of U. S. women caregivers reported transfer an average of $696 USD to their parents in the last 12 months (Johnson and Lo Sasso, 2004). A more recent U. S. study of individuals aged 50 and over with one living parent found that one-quarter of respondents provided financial assistance in the amount of $500 USD or more to a parent in the last two years (MMMI, NAC, and Centre for Long Term Care Research and Policy (CLTCRP), 2011).

These extra out-of-pocket expenditures can threaten the economic security of some caregivers. Fifteen percent of caregivers of adult recipients in the AARP Caregiving in the US study report a high degree of financial hardship (4-5 on a 5 point scale) (NAC, AARP, and MetLife Foundation, 2009). The figure exceeded 40% for Canadians caring for non-senior adults with high levels of disability (Fast, Keating & Yacashyn, 2008). In a recent Australian study about twice as many caregivers as non-caregivers reported that they were unable to pay utility bills or their mortgage/rent on time, had had to pawn or sell something, or had had to ask friends or family for financial assistance (Edwards, Higgins, Gray, Zmijewski & Kingston, 2008).

Out-of-pocket expenses were found to occur in the following four sub-domains, with variations reflecting different policy contexts in the country/jurisdiction in which the study was conducted.

Residential care

Residential care includes costs associated with a variety of settings from nursing homes to lodges. When a care recipient co-resides with their caregiver there are additional costs for utilities and other regular household expenses (Carers UK, 2007; Dosman, Keating and Factor, 1998; Duxbury et al., 2009; Fast et al., 2001; Fast et al., 2008). Only 5% of the sample in the Evercare study reported nursing home or assisted living facility expenses; however the average cost for those who did report out-of-pocket expenditures in this category was very high at $980 USD per month (Evercare and NAC, 2007).

Care-related community services

Care-related community services includes fees or other costs related to accessing services provided by specialized health care providers and professionals on either an ongoing or occasional basis (physiotherapist, geriatric assessment, lawyer, etc.), as well as for acute care situations (ambulance fees, hospital stays or emergency room visits). Home care services, respite services, day support, and household help are other services that caregivers may pay for. Such services are used primarily to address the care recipient's needs; however some services are ones that caregivers may purchase in order to give themselves more time to provide care to the dependent adult such as child care, or house cleaning services or to get respite from intense caregiving demands (Keating et al., 1999).

In a recent Canadian study of palliative care patients and their families, home care accounted for 4.4% of costs to the families ($216 over 6 months) (Dumont, Jacobs, Fassbender, Anderson, Turcotte and Harel, 2009). Another Canadian study of caregivers reported that 19% of caregivers who had out-of-pocket expenses paid for respite services and 20% paid for professional services such as physiotherapy for the care recipient (Decima Research, 2002). Fifty-three percent of caregivers in the US National Longitudinal Caregiver Study report paying for some kind of formal care (Moore et al., 2001).

In a six-month period, U.S. caregivers of non-institutionalized people with Alzheimer's Disease paid out-of-pocket for hospitalization (averaging $2578 USD for 2.3 days) and emergency room visits ($166 USD for .5 visits on average per caregiver) (Small, McDonnell, Brooks and Papadopoulos, 2002). A survey of 1000 caregivers in the United States reported costs for community services such as day services or home care in the amount of $547 USD annually. Other services, including respite, counseling and care management, cost $343 USD annually and professional legal fees cost caregivers an average of $78 USD annually. All of these services combined accounted for 17.5% of total annual caregiver expenses (Evercare and NAC, 2007). All but two of the studies referenced in this section are from the United States where health care costs differ from those in Canada. Parallel Canadian studies are needed to determine the magnitude of community service costs to Canadian caregivers. These contextual differences are addressed further in Section 3.2.5 on factors influencing costs.

Supplies

Supplies includes food, clothing and personal items for the care recipient, as well as health and medical supplies such as medication (including supplements and vitamins), equipment (walkers, wheelchairs, etc.), health supplies (incontinence products, wound care, pressure stockings, etc.), and home adaptations (ramps, lifts, grab bars, etc.). Medications constitute a large proportion of out-of-pocket expenses in the supplies category, particularly in jurisdictions without prescription drug insurance plans. In the United States, for example, 21% of total annual out-of-pocket expenses for caregivers were medication costs (Evercare and NAC, 2007). In a sample of Canadian caregivers, 71% reported paying for non-prescription medications, and 43% for prescription medications (Decima Research, 2002). Medications also were among the most common expenditure categories reported by Fast et al. (2008). Personal items purchased for the care recipient are a component of supplies. These items include food, clothing, household goods and bedding. This category accounted for 15.7% of expenses or $868 USD per year for caregivers (Evercare and NAC, 2007).

Transportation/travel

Transportation/travel consists of expenses for taxis, parking, gas, airfare, accommodation and meals that caregivers incur in travelling to, with or for the care receiver. Lauzier and colleagues (Lauzier, Maunsell, Drolet, Coyle and Hebert-Croteau, 2010), who conducted focus groups with Canadian caregivers of breast cancer patients, found travel to be a substantial cost category among caregivers who paid for accommodations, meals and transportation to travel for the care recipient's treatment or consultations. Overall 81% of Canadian family caregivers in the Decima Research study reported transportation costs associated with caregiving (Decima Research, 2002). A U.S. study found that caregivers spent 10% of their total out-of-pocket expenses or $551 USD annually on travel (Evercare and NAC, 2007).

3.2.3 Caregiving Labour

Caregiving labour refers to time spent by family and friend caregivers performing tasks and providing services to the care receiver because of that person's long term disability or chronic illness. Caregiving labour involves time, energy and engagement on the part of the caregiver.

Estimates of the prevalence and intensity of care differ considerably based on methodological issues such as tasks included, as well as definitions of care and caregivers. For example, in a nationally representative Canadian survey, caregivers aged 45 and over reported spending between 7.9 and 10.4 hours per week on care tasks on average (Hollander, Liu and Chappell, 2009). However, these estimates do not represent a full accounting of direct care labour costs because, while they included a subset of care tasks (personal care, house maintenance and household work such as meal preparation, and shopping), they excluded tasks such as care management, travel to provide care and emotional support, all of which can take substantial amounts of time. Differences in accounting for hours of care may be the basis for UK results showing that 1.8 million carers provide over 20 hours of care per week (Carers UK, 2007), and U.S. studies reporting that 34 million caregivers provided an average of 21 hours of care per week (Houser and Gibson, 2008; NAC, AARP and MetLife Foundation, 2009). Mean hours of care are similar in Australia where less than one quarter of Australian caregivers provided 40 or more hours of care per week, while nearly one-quarter of caregivers performed between 20-39 hours of care per week (Bittman, Fisher, Hill and Thomson, 2005) and almost half of U.S. caregivers provided no more than eight hours per week while 13% provide more than 40 hours of care per week (NAC, AARP and MetLife Foundation, 2009).

In Canada, there has been a longstanding assumption that 70 to 80% of care for older adults living at home is provided by caregivers (Hébert et al., 2001). Recent research has provided increased specificity about Canadians involved in care. Based on data from the 2007 and 2002 General Social Surveys, Fast et al. (2010) reported an increasing prevalence in caregiving. Between 2002 and 2007 the proportion of Canadian caregivers over the age of 45 increased by 10%, from 19.5% to 28.9%. This amounts to 3.8 million caregivers, an increase of nearly 1.5M caregivers in just 5 years.

The amount of time spent on care, varies considerably across caregivers and tasks. Thresholds for high-intensity care have not been established, although estimates in previous studies range between 10 and 20 hours per week (Carmichael & Charles, 2003; Feinberg, Reinhard, Houser and Choula, 2011; Heitmeueller, 2007). Some have argued that personal care is the most intense care task (Van Houtven et al., 2010), although there is evidence that household tasks and care management comprise large proportions of hours of care and are essential to helping someone remain at home. Of Canadian caregivers for adults aged 19-64 with disabilities, 50.2% reported providing personal care, while 62.9% provided care management, and 74.7% provided help with everyday housework (Fast et al., 2008).

Four main sub-domains of caregiving labour were identified: time spent with the care recipient, time spent on behalf of the care recipient, time spent getting to the care recipient and time spent monitoring the care recipient.

Time spent with the care recipient

Time spent with the care recipient involves face-to-face activities that are important to the quality of life, or even the survival, of the care recipient. They include: providing personal care (feeding, dressing, bathing and toileting), household help, transportation, and/or attending medical appointments with the care recipient. Help with personal care is time intensive and physically and emotional demanding. One study estimated time spent on personal care tasks at 649 hours annually, compared to 345 hours spent on help with chores and errands (Johnson and Lo Sasso, 2004). In 2002 Decima Research (2002) estimated that one in four Canadian caregivers provided daily assistance with basic hygiene to a family member. In a Canadian study of caregivers for adults aged 19-64 with high levels of disability living at home, more than one-quarter of caregivers (26%) provided almost around the clock assistance for someone with cerebral palsy (Fast et al., 2008). Time spent with the care recipient often includes time spent being a companion, facilitating social interactions and reducing social isolation. Other tasks include providing transportation for shopping, recreation and/or medical appointments, performing household chores such as basic housekeeping and meal preparation, doing home and yard maintenance work, and monitoring the care receiver to ensure their health safety. Fast and colleagues (2008) reported the proportion of caregivers who provided different types of support: 91% of caregivers for a veteran reported providing help with appointments and running errands, 87% of those caring for a paraplegic or someone with cerebral palsy, and 67% of caregivers for people with Schizophrenia provided support with travel to appointments or running errands.

Time spent on behalf of the care recipient

Time spent on behalf of the care recipient includes activities done by the caregiver for the care receiver but which the caregiver may or may not be present to observe. These include tasks such as managing finances, coordinating care and services, shopping for the care recipient and crisis management. Rosenthal and colleagues (2007) identify care management as a type of caregiving that includes management of formal services as well as negotiations with other family members and the care recipient, dealing with financial matters, paperwork and seeking information. In a Canadian study of employed caregivers to older adults, Rosenthal et al. (2007) found that 84% had provided managerial care in the past 6 months. For caregivers who live an hour or more away from the care recipient, almost half (46%) spent an average 3.4 hours per week arranging services for the care recipient (NAC, MMMI and Zogby International, 2004). The majority of caregivers of adults aged 19-64 with cerebral palsy reported managing care for the care recipient (Fast et al., 2008). In addition, 64.9% of caregivers for a veteran, 56.7% of caregivers for someone with Schizophrenia, and 45.9% of caregivers for a paraplegic also report providing support with care management (Fast et al., 2008).

Time spent getting to the care recipient

Time spent getting to the care recipient is the travel time involved in providing care. This category has only recently been recognized as having potential for significant amounts of expenditures of time and likely will become increasingly important with high rates of geographic mobility in Canada. The majority of employed caregivers in an interview study conducted by Duxbury and colleagues (2009) worked the equivalent of two full-time jobs: they spent an average of 36.5 hours per week in paid employment and 34.4 hours per week in caregiving of which 4.1 hours per week was spent commuting. Other research has shown that caregivers who live within a half-day commuting distance of the care receiver are under particular time duress (Keating et al., 1999).

Time spent monitoring

Time spent monitoring involves checking in with the care recipient and problem solving with or for them. In a national study of U.S. caregivers who lived an hour or more away from the care recipient, 49% spent an average of 4 hours per week checking on the care recipient (NAC, MMMI and Zogby International, 2004). A study of caregivers for individuals with Alzheimer's disease found that caregivers spent an average of 100 hours per month on behaviour management and supervision (Beeri, Werner, Adar, Davidson and Noy, 2002), an indication of the need for greater vigilance when caring for those with cognitive impairments. Some of the monitoring tasks are transferred to formal caregivers when the care recipient resides in an institution, although proportions differ depending upon the type of residential care. For example, family and friend caregivers of elderly care recipients living in a nursing home spent less time monitoring the recipient's medical status and well-being than caregivers of those living in a assisted living or residential care settings (Port, Zimmerman, Williams, Dobbs, Preisser and Williams, 2005). In addition, even when the recipient is in residential care family members and friends must continue to monitor them to ensure that facility staff are providing needed services in an appropriate manner.

3.2.4 Outcomes

A new component of the taxonomy that came from this literature review is the identification of immediate and longer-term economic outcomes or consequences for caregivers. Evidence is emerging that each of the three domains of costs may lead to a different set of economic outcomes.

Employment consequences

Employment consequences may lead to two major types of economic outcomes: reduced current income and foregone future income resulting from lower wages and pension entitlements. Because of differences in methodology and operational definitions findings cannot be compared across the studies referenced, they indicate the need for increased investigation of both short and long-term losses incurred by the increasing proportion of caregivers that are in the labour force.

There is evidence of short-term reduction in current income from a number of countries. In a report on Australian caregivers, Bittman et al. (2007) reported that the average annual incomes of those who had had caring responsibilities for 1 to 2 years is 30% lower than for non-caregivers. Women caregivers in the U.S. who coresided with a sick and elderly parent experienced an income loss of over $4,000 per year (Leger, 2000).

Long-term economic impacts of Employment consequences also are being documented. Analysis of findings from four British surveys found that women's pension entitlements are significantly affected by having a caregiving role (Evandrou and Glaser, 2003, 2004). Caregivers may also lose employment-related benefits if they leave employment to provide care (Fast et al., 2001). The loss of these benefits may, in turn, lead to extra expenses for caregivers, such as paying for health services and medications for themselves and other family members that would otherwise have been covered by employer benefit programs. Houser and Gibson (2008) reported that 15% of U.S. caregivers reported losing job benefits. While the situation may be different for Canadian caregivers who benefit from affordable basic health insurance, employer-provided extended health and dental benefits may still be lost when hours of paid work are reduced significantly or jobs lost entirely. Evidence about whether such losses are experienced is not generally available, however.

A study recently released by MMMI, NAC and CLTCRP (2011) found that the total impact on income of caring for a parent is $324,044 for women in the U.S. Of this total amount, $142,693 comes from lost wages; an estimated $50,000 is attributed to impact on pension benefits, and $131,351 to reduced social security benefits. Men were estimated to lose a total of $283,716 with $89,107 from lost wages, an estimated $50,000 impact on pension benefits and $144,609 lost in social security benefits. This study estimated lost earnings on the basis of the median wage of the sample, the reduced hours of paid employment due to care, and estimates of early labour force exit by a typical caregiver (MMMI, NAC, and CLTCRP, 2011; all costs in USD).

Out-of-pocket expenses

Out-of-pocket expenses can be significant for caregivers, affecting not only their ability to cover their own current expenses but also their ability to save and invest for the future thus threatening their economic security in later life. Caregivers with the lowest income (less than $25,000 USD) in the Evercare study reported average annual care-related expenditures of more than 20% of their annual income (Evercare and NAC, 2007). Reduced savings was an issue for 44% of carers in a survey by Carers UK who reported having spent down any previous savings (Carers UK, 2007). Increased out-of-pocket expenses may have greatest implications for low income caregivers.

Caregiving labour

Caregiving labour has two main types of economic outcomes. It can reduce the amount of time caregivers spend in the paid labour force, which affects their current and future income; and it can have an effect on caregiver health which in turn requires increased expenditures on health care and other services for the caregiver. The latter category has been little explored and warrants further examination by considering the interactions between social, health and economic costs of care.

Men and women caregivers forego significant earnings because they are less likely to be in paid employment than are non-carers (Carmichael and Charles, 2003). Research has shown that caregivers make other sacrifices in their jobs (passing up promotions, training, job transfer or relocation, or assignments in order to care for family and friends) that affect not only current earnings and benefits but also future earnings as by limiting the caregivers' ability to advance in their jobs (MMMI, NAC and National Centre on Women and Aging (NCWA), 1999). Further, there is little opportunity for caregivers to recover these lost wages. While the incidence of these employment consequences is increasingly well-documented, their monetary impact is not. In one notable exception, Carers Australia used an opportunity cost approach in which the value of time spent on care is estimated at what the caregiver could have earned had they spent that time on paid work instead, to estimate Australians' foregone earnings to be approximately $4.9 billion (Access Economics Pty Limited, 2005).

Perhaps more importantly, the care labour is of significant economic value in its own right. The value of this labour has been estimated for several countries, typically using some variation of a replacement cost method in which the time spent on care tasks is valued as "if all hours of informal care were replaced with services purchased from formal care providers and provided in the home" (Access Economics Pty Limited, 2005, p.9). Carers Australia estimated the replacement value of all care work performed by Australian caregivers in a year to be $30.5 billion (equivalent to 3.5% of GDP and 62.2% of the cost other formal health care). Hollander, Liu & Chappel (2009) used similar methods to impute the dollar value of care provided in a single year by all Canadian caregivers to be "a reasonably conservative" $25 to $26 billion. Several U. S. studies have estimated the replacement cost of unpaid care work in specific states, and for the country as a whole. The most recent study conducted for the American Association of Retired Persons places the value of unpaid care work for the whole of the U.S. at $375 billion in 2007, up from an estimated $350 billion in 2006 (Houser & Gibson, 2008), A recent report published by Carers UK estimates the economic value of UK carers' work to be £119 billion per year, which they note is more than the annual cost of all aspects **of** the National Health Service and 37% higher than the 2007 estimate.

Overall, while there is agreement that caregiving labour represents a significant contribution to the Canadian (and other) economies, there has been little documentation of the costs to individuals who provide that care. There may be a lingering assumption here that, while caregiving labour is valuable, it is 'freely' provided by caregivers whose rewards lie in their fulfillment of family obligations and reciprocity to spouses or parents. This report goes a long way to debunking this assumption and documenting the economic costs family/friend caregivers incur.

3.2.5 Factors Influencing Costs of Care for Caregivers

Another goal of this project was to better understand factors influencing the economic costs of care. In our analysis for this report we found several factors which can be categorized as caregiver characteristics; care recipient characteristics; dyad characteristics; and broader contextual factors such as the caregiving context, community context and the policy context.

In this section of the report we discuss the current state of knowledge about factors that influence the prevalence and magnitude of costs to caregivers (Objective 2) in each of three caregiver cost domains: Employment consequences, out-of-pocket expenses and caregiving labour. Within each domain we discuss the individual characteristics of the caregiver, care recipient, caregiver-care receiver dyad, caregiving context and the broader context, including community and policy milieu. We also acknowledge that there are complex interactions within and across these categories that can affect economic costs in one or more areas, and have noted specific examples in this section. Knowledge gaps, methodological inconsistencies and differences in relevance of these factors across cost domains are also discussed.

Table 3.1 summarizes the moderators of the prevalence and magnitude of economic costs for family/friend caregivers across domains of economic costs incurred by caregivers. Details about these factors are elaborated below.

Table 3.1 Factors that moderate the economic costs of care for family/friend caregivers by cost domain

	Employment consequences	**Out-of-pocket Expenses**	**Caregiving Labour**
Caregiver characteristics	· Gender · Age/Life stage · Health · Education · Employment status	· Gender · Income	· Gender · Age · Employment Status · Income
Care recipient characteristics	· Disease/disability type · Severity of condition	· Disease/disability type · Severity of condition	· Disease/disability type · Severity of condition
Characteristics of the caregiver-care recipient dyad	· Geographic proximity · Relationship	· Geographic proximity · Relationship	· Geographic proximity · Relationship
Caregiving context	· Intensity of care provided		· Intensity of care provided
Community context		· Home or residential care	· Home or residential care · Social context of care
Policy context		· Health care system	· Availability and affordability of formal services

Factors influencing caregivers' employment consequences

In this section, we review evidence from research studies on factors that influence caregivers' economic costs related to Employment consequences, including labour force exit/preclusion, restricted work hours/options and work absences, decreased productivity, and career limitations. Moderating factors are organized according to whether they are individual characteristics of the caregiver, characteristics of the care receiver, characteristics of the caregiver-care receiver dyad, or broader contextual factors.

Caregiver characteristics

Gender is a predominant predictive factor in studies of the costs of caregiving. Women are both more likely to be caregivers and to experience employment consequences when they are (Decima Research, 2002; Dunham and Dietz, 2003; Fast et al., 2001; Lilly et al., 2010; NAC, AARP and MetLife Foundation, 2009; MMMI, NAC and CLTCRP, 2011). For example, analyses of 2007 Canadian GSS data revealed that, among employed caregivers, women were not only more likely than their male counterparts to miss at least one full day of work to provide care in the previous 12 months, but they also were more likely to miss more days per month when they were absent (3.1 days per month on average among the 30% of employed women caregivers who were absent compared to 2.4 days per month among the 21% of men who missed any work time)(Fast et al, 2011). In the same study, although roughly equal proportions of women and men reported reducing their paid work hours because of caregiving responsibilities, women cut back their work hours more. It appears, however, that gender interacts with the number of hours care provided, since a variety of research studies confirm that women caregivers, on average, provide more hours of care and more hours of personal or direct care (Carmichael and Charles, 2003; Decima Research, 2002; MMMI and LifePlans Inc., 2006; NAC, AARP and MetLife Foundation, 2009). Lilly and colleagues (2010) reported that women were also more likely to self-identify as primary caregivers (caregivers with primary or major responsibility for care). They revealed that being the primary caregiver was more common among women (31% compared to 20% of men) and that primary caregiving women provided on average 16 hours of care per week compared to the 11 hours provided by men. They also reported that primary caregiving women were more likely to report having a lack of caregiving substitutes, adding to their responsibilities.

While the prevalence of leaving a job due to caregiving responsibilities is not as common as other work restrictions, there is ample evidence that it is more often a consequence that women bear. Analyses of 2002 Canadian *General Social Survey* (GSS) data by Pyper (2006) confirmed that caregiving is a reason for retirement, contributing to decisions by one in five women caregivers who retired, compared to 8% of male caregivers who retired. Several studies across multiple countries found that women are more likely to give up work or quit a job due to care responsibilities. The National Alliance for Caregiving (NAC) and the United Health Foundation (UHF) found that women caregivers of U.S. veterans were more likely than men to report giving up work or quitting a job in order to provide care (NAC and UHF, 2010). Decima Research found that women were twice as likely as men to have quit or retired to provide care (Decima Research, 2002). Similarly, in a smaller scale U.S. interview, 15% of the women caregivers reported quitting a job to care for their family member with dementia (Dunham and Dietz, 2003).

In addition to quitting a job in order to provide care, women are also more likely not to return to the labour force post-caregiving. Findings from the *Great Britain Family and Working Lives Survey* showed that half of the women who reported leaving the labour market to provide care did not return to employment (Henz, 2004).

Other individual caregiver characteristics that have been identified in the literature include: life stage, caregiver's health, caregiver's education, and employment status (full or part-time). Based on analyses of data from eleven countries in the European Community Household Panel, Masuy (2009) concluded that life stage is an important determinant of women's likelihood of ceasing work. Although each of the variables referred to above were contributors, assuming heavier caregiving demands was most likely to lead to ceasing work among women aged 50 or more years. Similarly, Johnson and Lo Sasso (2004) found that women caregivers aged 53-63 who provide personal care to parents cut back their work hours by about 70%. Women, in particular, were found to be more likely to retire if they have worked longer over their lifecourse, according to data from the *Cornell Retirement and Well-being Study* (Dentinger and Clarkberg, 2002). Caregiver health also has been found to be a factor that influences employment costs. The poorer the caregiver's health, the more likely they are to experience employment consequences (Bullock, Crawford, and Tennstedt 2003; Lilly et al., 2007). Employment consequences often are experienced by caregivers with less education (Lilly et al., 2007, 2010), although one study suggested the opposite, possibly indicating that better-educated people enjoy greater job flexibility (Keating et al.,1999).

Care receiver characteristics
The number of work days missed is affected by care recipient characteristics such as *disease or disability type* and *severity of impairment*. Canadian caregivers to family members and friends with higher care needs, such as adults with cerebral palsy, report more changes to their employment (Fast et al., 2008). Decima Research also found that employed family caregivers of someone with a mental disability are more likely to report a change in their employment situation compared to those who care for someone who is physically disabled or has both mental and physical disabilities (Decima Research, 2002). In U.S. study persons caring for a spouse with Alzheimer's disease were almost 2 ½ times more likely than other caregiving spouses to have quit a job to provide care (MMMI and LifePlans Inc, 2006). Family/friend caregivers of non-institutionalised elderly with Alzheimer's disease in the U.S. reported missing an average 5 days per month over a 6 month period because of caregiving (Small et al., 2002). The number is similar in a Canadian study of caregivers to family members and friend with cancer, which reported that caregivers are absent from their jobs an average of 7 days per month (Longo, Fitch, Deber and Williams, 2006). The majority (65%) of employed caregivers of stroke survivors in the U.S. missed an average of 27 work days per year (Ko, Ayock and Clark, 2007). Family caregivers of veterans with service-related illnesses or injuries were more likely to stop working or take early retirement (47%) than employed caregivers of adults nationally (9%) (NAC and UHF, 2010).

Dyad characteristics
A contributing factor to Employment consequences is the *geographic proximity of* care recipient and caregiver. Data from the 2007 GSS on employed caregivers age 45+ indicated that 40% of caregivers who lived more than half a day's journey from their chronically ill parent reported missing full days of work in order to provide care while only 36% who lived within closer commuting distance (between 1 hour and a half a day's drive) and 28% who lived in the same neighbourhood reported absenteeism (Vezina and Turcotte, 2010). Distance also affects other paid work accommodations because of the time needed to

travel to provide ongoing, crisis or respite care. A large national study conducted in the U.S. found that up to 25% of long distance caregivers (living an hour away or more) reported reporting to work late or leaving early at least once during the past year due to care (NAC, MMMI and Zogby International, 2004). This study by the NAC also found that long distance caregivers were less likely to change from full time to part time work (only 3%) but more likely to make other changes in their work arrangements such as reorganizing work schedules (44%) (NAC, MMMI and Zogby International, 2004). Vezina and Turcotte (2010) similarly reported that Canadians caring for a parent reported that the number of days of work missed increases with the distance they lived from their parent.

In contrast to the circumstances of long-distance caregivers, who most often make work schedule accommodations and have more absences to meet the needs of care recipients, there is substantial evidence that caregivers who co-reside with the person they care for are more likely to leave the workforce when caregiving demands are onerous, (20 or more hours per week) (Heitmueller, 2007).

The *nature of the relationship* between a caregiver and care recipient is a factor as well. Dentinger and Clarkberg (2002) found in the *Cornell Retirement and Well-Being Study* that adults aged 50-72 who cared for spouses were more likely to retire. In this study of caregivers, women who were providing care to their husbands had odds of retirement more than 5 times as high as women who were not providing care to their spouse. This impact held true for men as well, but not at such a high rate. Uriarte-Landa and Hébert (2011) similarly reported that the risk of retirement was higher for Canadians caring for family members than those caring for non-kin.

Context characteristics

Lero and colleagues identified the caregiving context as including the nature and duration of care, the amount and types of care provided, whether care is shared with other family members and other health/service providers, the nature of other roles and circumstances of the caregiver, and geographic contexts (Lero et al., 2007) which could also include the health care system of that region. The variable most often investigated in this category is the *amount of care provided* (i.e., what is often used as an indicator of the intensity of care). Although care intensity is not operationalized consistently across studies, there is general consensus that simply being a caregiver (providing any number of hours of care) has little explanatory effect. In their review of 35 studies from the US and UK, Lilly et al. (2007) concluded that caregivers "who co-reside with care recipients or who report heavy caregiving commitments appear much less likely to be in the labour force" (p.664), to work fewer hours in the labour market and/or to make more work accommodations. Other indicators of care intensity included being the primary caregiver, being closely related to the care recipient, and the care recipient's increasing health limitations. Other studies, such as Masuy's (2009) 11-country study of eldercare and women's lifetime participation in paid work refer to the extent to which women assume "heavy" care responsibilities. Pyper's (2006) analysis of 2002 GSS data suggested that caregiving involvement among employed caregivers is largely bimodal both in hours and effects on caregivers' employment. Low-intensity caregivers typically provided one hour or less of elder care per week compared to high intensity caregivers (4 or more hours per week). Gender, number of work hours and caregiving intensity interacted to produce stronger employment consequences for women. Lilly and colleagues (2010) specifically analyzed the effects of caregiving intensity on labour force participation and found that, after controlling for intensity of care (being the self-identified primary caregiver), both primary caregiving men and women were less likely to be employed than either secondary caregivers or non-caregivers. Their results are consistent with those reported by Bittman, Hill and Thompson (2007), Heitmueller (2007), Crespo (2006) and Carmichael and Charles (2003) among others.

Other studies suggest that the intensity of caregiving affects other workplace accommodations. Thirty seven percent of U.S. caregivers with intense caregiving responsibilities (operationalized in their study as providing constant care and help with at least four activities of daily living) report changing from working full time to working part-time (Gibson and Houser, 2007). Similarly, Canadians who spent more hours caring for non-senior family members with high levels of disability were more likely to report giving up work or quitting a job in order to provide care (Fast et al., 2008).

Factors influencing caregivers' out-of-pocket expenses

Out-of-pocket expenses are experienced by a significant proportion of family and friend caregivers. A wide range of estimates of the proportion of caregivers who experience these costs has been documented. For example, approximately 30% of caregivers in the same neighborhood as a care recipient living at home declared out-of-pocket expenses (Vezina and Turcotte, 2010) while 95% of those caring for relatives/friends in an assisted dementia care facility did so (Dosman et al., 1998). In other countries just over 50% of caregivers reported extra expenses: 53% in the United States (Moore et al., 2001) and 58% in the United Kingdom (Carers UK, 2007). For some, these expenses are particularly burdensome. Twenty percent of participants in a Canadian quantitative study of adult cancer patients and their families, reported that the financial burden of care was significant or unmanageable (Longo et al., 2006). There is also a range in the estimated dollar amounts of out-of-pocket expenses, from $200 USD on average per month for non-spousal caregivers 18 years of age and older providing help to someone also 18 years of age or older (NAC, AARP and MetLife Foundation, 2004) to over $5000 per year for Canadian caregivers of people with high levels of disability (cerebral palsy, spinal cord injury of schizophrenia) (Fast et al., 2008).

Variation in the proportion of caregivers experiencing out-of-pocket expenses and in the value of their expenditures can be explained in part by individual characteristics of the caregiver and of the care recipient. Gender is the key caregiver characteristic, and the nature and severity of the recipient's chronic condition or illness the most important care recipient characteristic influencing out-of-pocket expenses.

Individual characteristics of the caregiver

Gender of caregivers is often used as an explanatory variable in analyzing the nature and magnitude of costs to caregivers. There is evidence that more women than men caregivers incur extra expenses. In a secondary analysis of the 2002 General Social Survey on working caregivers aged 45-64, Habtu and Popovic (2006) found that 41% of employed female caregivers who were caring for an older adult reported extra expenses compared to 35% of employed male caregivers. There is also evidence that in addition to women being more likely to incur out-of-pocket expenses, their costs also are higher than those of men. A study of long distance caregivers to adults 55 years of age and older who had a chronic physical, cognitive or mental health problem, found of those who reported paying for services (10%), women caregivers spent an average of $751 USD per month on services while men spent $490 USD (NAC, MMMI and Zogby International, 2004). While there is longstanding evidence of women's higher levels of involvement in and greater intensity of care, these data indicate that they also assume greater proportions of economic implications of care. Given the fact that in Canada women have lower average incomes than do men, this cost evidence suggests a new double jeopardy of being female and a caregiver.

Income of the caregiver affects the amount of out-of-pocket expenses for caregivers over the age of 18 in a national U. S. survey. Forty-nine percent of caregivers making $100,000 USD or more have paid for modifications to the care recipient's home compared to 35% of those earning less than $30,000 USD (NAC, AARP and MetLife Foundation, 2004).

Care recipient characteristics

A number of links have been found between out-of-pocket expenses and the *nature and severity of the chronic illness or disability* of the care recipient. An overall finding is that both the incidence and magnitude of costs increase with the severity of the illness. In a study of primary female caregivers of elderly male veterans with dementia, Moore et al. (2001) found that 42% of caregivers for people with no limitations in performing activities of daily living (ADLs such as bathing, toileting, and dressing) purchased supplies and services at an average weekly cost of $53 USD. In contrast, 63% of caregivers whose care recipient was impaired on all ADL tasks spent an average of $99 USD per week on community services. There has been interest in the trajectory of the cost of medication over the course of dementia. Research in Argentina showed that individuals and families with severe dementia spent $828.90 USD over the previous three months on medications, while those with mild dementia spent approximately half that amount ($471.00 USD) (Allegri et al., 2007).

The incidence and magnitude of out-of-pocket expenditures also is associated with the type of chronic condition. Fast and her colleagues (2008) found that the highest proportion of caregivers to adults under age 65 who reported out-of-pocket expenses were those caring for people with spinal cord injury and schizophrenia. Approximately 80% of these caregivers experienced costs for supplies such as medications, and for travel or transportation. In comparison, about 68% of caregivers for adults with cerebral palsy and 63% of caregivers for Veterans reported out-of-pocket expenses. Of these caregivers to adults with disabilities, one third reported out-of-pocket expenses greater than $5000 in the past year. For all the groups of non-senior adults with disability, both the incidence and magnitude of out-of-pocket expenditures was greater than noted in general caregiver populations.

The Evercare study of caregivers for family members over the age of 50 who need help with ADLs or IADLs (instrumental activities of daily living), found that reported annual expenses ranged from $533 USD to $12,348 USD based on recall and diary methods respectively (Evercare and NAC, 2007). Direct comparability across studies is not possible in this case due to different characteristics of care recipients, although it is evident that costs can be substantial. Further research is needed to understand the influence of data collection methods on the magnitude of reported out of pocket expenses.

Dyad characteristics

Key dyad characteristics that influence variability in out-of-pocket expenses are *relationship* (family relationship such as spouse, adult child-parent, or friend versus neighbour) and *geographic proximity* between the caregiver and care receiver. In a review of literature Keating and her colleagues (1999) found that family members are more likely to experience out-of-pocket expenses associated with caregiving than are neighbors or friends. There has been little follow-up research to assess the magnitude of the cost differences among these groups of caregivers. However, in a secondary analysis of the 1996 General Social Survey, LaPierre and Keating (in review) used a sub-sample of 324 friend and neighbour caregivers to compare amount of care and care tasks provided by each group. There were no analyses of the monetary value of care provision, although the greater hours of care provided by friends may be associated with higher out-of-pocket expenses related to that care.

Much more is known about the impact of proximity on costs. U. S. caregivers over age 18 who live with the recipient (24%) are more likely to say they experience financial hardship as a result of being a caregiver than those who do not live with the person they care for (8%) (NAC, AARP and MetLife Foundation, 2004). Canadian researchers (Vezina and Turcotte, 2010) have found that caregivers of parents who lived further away were more likely to incur extra expenses. Using a sub-sample of caregivers to parents or parents-in-law from the 2007 General Social Survey, they found that the proportion of caregivers with out-of-pocket expenses was highly correlated with distance. Proportions were 62% of those living more than a half-day drive away, 49% of those living between one hour and a half-day journey by car, 40% of those living less than an hour by car, and 30% of those in the same neighborhood. Among the more distant caregivers, 39% spent more than $500 a month on extra expenses (Vezina and Turcotte, 2010). These findings are to be expected given travel costs within Canada across great distances and dispersed populations, although there have been few such studies in Canada since both travel time and travel costs typically have been excluded from caregiving research. In telephone surveys and focus groups with family and friend caregivers and patients with breast cancer in Canada, Lauzier and colleagues (2010) found that transportation and travel costs were higher for long distance caregivers. Families who lived less than 25km from the treatment site spent on average $54 on travel and transportation per week compared to those living between 25 and 49km ($141), and more than 50km ($240) away.

Similar findings come from the United States. In a national survey, the National Alliance for Caregiving found that caregivers who lived more than three hours away from the care recipient spent on average $674 USD per month, compared to caregivers who lived between one and three hours away ($386 USD on average per month) (NAC, MMMI and Zogby International, 2004).

Context characteristics

In this review, we found that two broader contextual issues, in addition to *caregiving context*, arise as important in understanding variability in out-of-pocket expenses. These are the *policy context* (especially the health care system) and the *community context* (home or residential care setting).

The health care policy context in Canada determines to a great extent whether out-of-pocket expenses are incurred for care to people with long-term health problems and disabilities. Dumont and colleagues (2009) note that costs for services such as inpatient hospital care and home care are covered by the public health care system in Canada, while 97% of ambulatory care (outpatient care, doctor visits, tests and treatments) also is covered. However, home care resources are limited so that hours of care received may not meet care needs. Further, expenses covered in acute care settings such as medications, dressings or equipment such as hospital beds are not covered outside of hospital settings. Thus this research does not address the limitations of home care resources which lead to families requiring private-pay services to fill gaps in care needs at home. In a Canadian study of out of pocket expenses of family friend caregivers of people at end of life, Hollander and Tessaro (2007) included income tested user fees for long-term care facilities, home care services and drugs.

Findings from other countries show that home care costs can be substantial. Families in Israel who care for someone living in the community had more out-of-pocket expenses for paid help (65% of monthly costs) and day support (15%) than those who cared for someone living in an institution (less than 0.1% for both) (Beeri et al., 2002). Beeri and colleagues (2002) studied families whose relative with Alzheimer's disease is institutionalized and found that the cost of institutionalization comprised 94% of the total out-of-pocket expenses.

Regression analysis in the study by Small and colleagues (2002) detailed above on caregivers for people with Alzheimer's disease indicated that, as disease severity increased, so did visits to the hospital which are a source of extra expenses to the individual and their families in the United States. This same study found that with increasing disease severity and reduced physical functioning, patients with Alzheimer's Disease had more doctors' visits which, over the course of 6 months, cost $363.96 USD (Small et al., 2002). In Canada out-of-pocket expenses are not incurred for hospital or physician visits, although there is evidence of health care costs in other areas. For example, expenses may include prescription and non-prescription medication and vitamins or supplements which are not covered by the Canadian health care system. One family in a Canadian focus group study of patients with breast cancer and their families reported spending as much $80 per month for vitamins (Lauzier, Maunsell, De Koninck, Drolet, Hebert-Croteau and Robert, 2005).

The cost of medication also varies widely across countries as well as across care settings. In the Canadian study by Dumont and colleagues (2009), the cost for prescription medication for individuals in acute settings was almost all covered by the public health care system (97%). However medication costs generally are not part of public sector costs for people in residential care or those living at home. Some exceptions exist for people over age 65 who may have prescription medication coverage from their provincial health care system. In comparison, in a study of costs of Alzheimer's type dementia in Argentina, Allegri et al., (2007) found that institutionalized patients with Alzheimer's dementia and their families incurred higher costs for medications than community-dwelling participants ($979.40 USD vs. $450.00 USD for three months) in part because of the higher levels of illness severity among those in institutions. In Israel community dwelling people with Alzheimer's disease and their families spent 13% of their total out-of-pocket expenses on medication compared to 4% for institutionalized individuals (Beeri et al., 2002). Clearly health care costs are complex and dependent on residential care setting, regional or country context and type of cost. Caregivers and recipients who live in rural areas and are at a distance from acute care and physician care, experience higher transportation and travel costs (Lauzier et al., 2005).

Type of residential care setting also can influence magnitude of out of pocket expenses. Family or friend caregivers of recipients over the age of 65 who resided in a residential care/assisted living setting spent $500 USD per month on out-of-pocket expenses, while caregivers for a recipient in a nursing home setting spent $400 USD (Port et al., 2005). In this study, out-of-pocket expenses for the caregiver included facility rates, medical care costs, extras, transportation costs, and any additional services paid for by the caregiver.

Factors Influencing Caregiving Labour

Caregiving labour represents the time that caregivers spend in care tasks. The value of caregiving labour has been well-established. For example, using data from the 2002 GSS, Hollander and colleagues found that a reasonably conservative estimate of the imputed economic contribution of unpaid caregivers in Canada is $25-26 billion (Hollander et al., 2009). These researchers used unit cost data from a Canadian national survey including market rates for type of provider and hourly wages for home support workers. The average hours of care per week found in this study ranged from 7.9 to 10.4. Further, for caregivers of labour force age, time spent on caregiving labour reduces time available for the paid labour force, although our knowledge of this relationship is limited.

The next section provides evidence of the factors influencing hours that family and friends spend in caregiving labour. Research findings indicate that key caregiver characteristics are gender, age, employment status and income. Care receiver characteristics include type and severity of disease or chronic condition, and living arrangement. The main dyad characteristic is family or friend relationship. There is some evidence of importance of policy and community contexts of the care recipient.

Caregiver characteristics

Gender of the caregiver is a predominant factor influencing hours of care. Studies across countries find consistently that women provide greater hours of care. A U.S. study involving interviews with family caregivers to care receivers aged 65 and over with

Alzheimer's disease and those caring for someone with a physical disability found that regardless of care recipient disability, women provided 17% more care hours each week than men (MMMI and LifePlans Inc., 2006). Using data from the UK *General Household Survey* on respondents between the ages of 18 and 64, Carmichael and Charles (2003) found that male caregivers reported significantly fewer care hours than female caregivers. In fact, less than 60% of female caregivers spent fewer than 10 hours a week caring, while over 70% of male caregivers reported caring for fewer than 10 hours a week (Carmichael and Charles, 2003). Men and women caregivers aged 45 to 64 in a Canadian sample provided similar hours of transportation per month (men at 2.8 hours; women at 2.3 hours) (Habtu and Popovic, 2006).
Canadian data were obtained from the 2002 *General Social Survey* (GSS) to examine the prevalence and impact of elder caregiving among middle-aged Canadians (aged 45-64). This study found that the median number of hours spent caregiving was significantly higher for women than for men (3.0 vs. 1.6 hours per week respectively) (Pyper, 2006). Using the same national survey data (2002 GSS) Habtu and Popovic (2006) found much higher weekly hours of care for men and women who were employed; women provided an average of 26 hours of care per month, employed men provided 15 hours of care.

In addition to the total number of care hours, there are gendered differences in patterns of time spent in different care tasks. Of total care hours, women spent the most time providing personal care and housekeeping tasks such as meal preparation and household chores. In contrast, men spent the most time helping the recipient maintain their home by doing outdoor maintenance and yard work as well as providing transportation to necessary appointments such as physician visits. These differences in patterns of task provision are not surprising given that the personal and housework tasks are more likely to be done by women for family members throughout the life course, while men traditionally have had outdoor maintenance tasks as part of their set of normative behaviours. The difference in hours may be accounted for by the fact that tasks more likely done by women require daily, regular contact with the recipient, while men's care tasks do not have such daily obligations (Habtu and Popovic, 2006).

Research findings from outside Canada show similar patterns. Using a nationally representative sample of U.S. female caregivers aged 53-63 for an elderly parent; Johnson and Lo Sasso (2004) found that the mean time spent on personal care was 649 hours annually compared to 345 hours for help with chores and errands. Another U. S. study of long distance caregivers (more than one hour travel time from the care recipient) to those 55 years of age and over, using an online survey, found that women provide more hours of care for both personal care and helping around the home. These long distance women caregivers reported an average 23.5 hours per month helping around the home and 14.5 hours per month spent on personal care, while men reported 21 hours per month on helping around the home and 11 hours on personal care (NAC, MMMI and Zogby International, 2004).

Age of the caregiver can be an important factor as well. Bittman and colleagues (2005) found that, among Australian co-resident female primary caregivers, the proportion of caregivers reporting 40 hours or more of care increased with age. For Canadian caregivers aged 45-64 the most common activity to be provided on a daily basis was personal care (25.3%), while for older caregivers aged 65 and over 60.7% of caregivers provided personal care on a daily basis (Hollander et al., 2009).

Employment status is another caregiver characteristic that influences caregiving labour. There is evidence that full time employed caregivers provide higher hours of care than those who are not employed or employed part-time. In a study of women aged 25-64 from the 1996 *General Social Survey* who reported providing care to a person aged 65+ because of a long term physical disability, Kemp and Rosenthal (2001) found that full-time employed caregivers reported substantially more caregiving hours (34 hours per month) compared to 29 hours per month provided by women who were employed part-time or were not employed. In contrast, in a U.S. study of African American people age 60 and older with functionally disabilities and their primary caregivers, Bullock and colleagues (2003) found no significant differences in the average amount of care provided by employed and not employed caregivers (58 and 48 hours per month respectively). Lack of significant differences may be due in part to characteristics of the care receiver and the relatively small sample of 119 elder-caregiver dyads.

In research on Canadian elder caregivers aged 45-64, Pyper (2006) found that approximately one-third (34%) of employed male caregivers spent an average of one hour or less per week on elder care, compared to 24% of employed women caregivers. In contrast, 44% of employed women caregivers reported providing 4 or more care hours per week compared to only 27% of employed male caregivers.

Income is another caregiver characteristic that may influence the amount of caregiving labour provided. A national U. S. survey by Evercare and the National Alliance for Caregiving on caregivers of people over age 50 who provided a minimum of 5 care hours per week found an inverse relationship between income and hours of care. Caregivers in the lowest income category (less than $25,000 per year), provided a mean of 41 hours of care per week, compared to 38 hours ($25,000 to <$50,000), 36 hours ($50,000 to <$75,000), 23 hours ($75,000 to <$100,000), and 24 hours (>$100,000) (Evercare and NAC, 2007). There is a suggestion here that those with lower income provide their own labour in lieu of purchased services.

Care receiver characteristics

Care receiver characteristics that influence the amount of time spent on caregiving labour are *type and severity of disease/disability*. Dementias, including Alzheimer's disease, are often found to influence time spent caregiving. In the Netherlands, female caregivers aged 42-56 of elderly parents spent more time on care when the care recipient suffered from dementia rather than general poor health (Dautzenberger et al., 2000). Similarly in a U.S. study by Mature Metlife Market Institute, it was found that, on average, care receivers aged 65 and over with Alzheimer's disease received about 47 hours of care per week from family caregivers, compared to 33 hours for an individual with physical problems (MMMI and LifePlans, Inc., 2006). In this sample of caregivers for people with Alzheimer's disease, a larger proportion were providing more than 40 hours of care weekly than were caregivers for persons with physical disabilities (40% vs. 28%).

Type of care receiver disability is also an important determinant of type of care tasks performed. People with AD required more help from their caregivers with bathing, continence, eating, managing money, taking medication and changing bandages, while those with physical disabilities needed more help walking indoors (MMMI and LifePlans Inc., 2006).

Differences also have been found in amount and type of care to people with other categories of disability. In a study of caregivers to people with Rheumatoid Arthritis and stroke, Van den Berg and colleagues (2006) found that those caring for people with Rheumatoid Arthritis (RA) provided about 7 hours more care per week than caregivers of people who suffered a stroke. Analyses of hours provided by task showed that caregivers to people who suffered a stroke provided 14 hours of help per week with household activities of daily living (HADL) compared to 21.2 hours for RA caregivers; 1.6 hours of assistance with activities of daily living (ADLs) compared to 2.1 hours (37.3%) for RA; and 2.9 hours a week on instrumental activities of daily living (IADLs) compared to 3.7 hours for those with RA (van den Berg, Brouwer, van Exel, Koopmanschap, van den Bos and Rutten, 2006).

Severity of chronic condition as measured by the number of IADL and ADL limitations of the care receiver is positively correlated with hours of care provided (MMMI and LifePlans, 2006; Small et al., 2002). In terms of actual hours, for family and friend primary caregivers in Argentina, the time devoted to care increased with the progression of Alzheimer's Disease in care recipients, from 24.4 hours a week in mild dementia to 43.8 in severe dementia (Allegri et al., 2007). Similarly, in a Turkish sample of people with Alzheimer's Disease and their caregivers, Zencir and colleagues (2005) found that as the level of dementia increased, the average amount of time spent on care also increased (21 hours per day for severe dementia vs. 1.23 hours per day for mild dementia). Severity of dementia was associated with greater hours of caregiving labour time spent with the care recipient (feeding, dressing, bathing, and administering medication). Another study of female family caregivers in the United States found similar results using the 1998 *National Longitudinal Caregiver Study.* As the elderly male veteran care recipients' functional limitations increased, the percentage of caregivers providing physical care increased significantly (Moore et al., 2001). For other types of caregiving labour, such as housekeeping and personal management, the percentage of caregivers providing this kind of help only slightly increased with an increase in functional limitations in the care recipient (Moore et al., 2001).

When considering the type of care task provided and the care recipient's disease severity, Jonsson and colleagues (2006) found that the amount of time spent on care tasks (feeding, continence, hygiene, clothing, medication, indoor and outdoor transportation, supervision) differed by severity of cognitive impairment for care receivers. In this Scandinavian study of caregivers for people with Alzheimer's Disease, the average amount of time spent on care was 9.3 hours per day in the most severe state of cognitive impairment and, of that time, 6.1 hours were spent in supervision while the rest involved more active care tasks (Jonsson et al., 2006).

Dyad characteristics

Two dyad characteristics have been shown to be related to amount of caregiving labour: *geographic proximity* of caregiver to care receiver and *family/friend relationship*. Findings on the relationship between proximity and hours of care show two trends. First, living with the care recipient is associated with higher hours of care. Family caregivers (of persons with Alzheimer's Disease) who live with the elder care receiver provide as much as 63% more hours of care each week compared to caregivers who do not live with their care recipient (MMMI and LifePlans Inc., 2006). Caregiving is particularly time-intensive for those who live with their care recipient, spending an average of 39.3 hours per week providing care in a national American sample of family caregivers aged 18 and over (NAC, AARP and MetLife Foundation, 2009). Second, time spent commuting to provide care results in high care hours for those at a distance. Researchers in the Netherlands have found that commuting caregivers who live within 30 minutes travelling time of their parent or parent-in-law spent more time on care than those who lived further away (Dautzenberger et al., 2000). Further, the impact of proximity on care labour time is task specific. A U.S. study on long distance family caregivers found that distance between the care recipient and caregiver did not have a significant effect on the number of hours spent on some activities, such as arranging needed services, supervising or monitoring these services or helping with personal care needs. Their findings indicate that those living between 1 and 3 hours away reported fewer hours (20 hours a month) helping around the home of the care recipient than those who lived more than three hours away (25 hours a month) (NAC, MMMI and Zogby International, 2004). Additional exploration needs to be done to clarify these differences by distance and type of care tasks.

One characteristic of the caregiving context that influenced caregiving labour is the primary caregiver status. Lilly and colleagues (Lilly et al., 2010) used *primary caregiver status* as an indicator of caregiving intensity. They found that among elder caregivers aged 45 and over, primary caregivers were more likely to provide more total hours of care and more total caregiving activities than secondary caregivers.

Some groups of family members (e.g. daughters or spouses) spend different amounts of time on care compared to time spent by friends or neighbours. In their synthesis of the literature, Lero and colleagues (2007) found that overall those who were caring for a close relative (spouse or parent) spent the most time caring. In a secondary analysis of the 1996 General Social Survey, LaPierre and Keating (in review) used a sample of 324 friend and neighbour caregivers to compare amount of care and care tasks provided by each group. They demonstrated that friends provide assistance with a greater number of tasks and provide more hours of care per week than do neighbours. Given these findings, and the importance of non-kin caregivers, research is warranted to better understand their differential care commitments and how these might influence the sustainability of their caregiving.

Context characteristics

Three contextual characteristics influence amoung of care provided: the care recipients living situation, the social context of care, and the availability and affordability of formal services.

Two community characteristics, the care recipient's living situation and the social context of care, influence the amount of care labour provided by caregivers. *Living at home or in an institutional setting* influences the amount of care labour provided. For example, hours of care provided by primary informal caregivers in Israel to care receivers who were institutionalized was much less than that provided to community residing care receivers: 38.9 hours per week vs. 210 hours per week (Beeri et al., 2007). The type of care provided also differed. Community caregivers spent the most time in care management (98.6 hours per month), while caregivers of institutionalized receivers spent most of their time visiting and monitoring the care receiver (32 hours per month). A Canadian study of family caregivers for older adults found that, for home-dwelling participants, family caregivers provided nursing care 82% of the time that they were engaged in care, instrumental tasks 73% of the time and supervision 80% of the time (Hébert et al., 2001). Family/friend caregivers of recipients living in assisted living settings spent more time monitoring their medical status and well-being than caregivers of someone in a nursing home (Port et al., 2005).

The *social context of caregiving* can also influence caregiving labour. For example, caregivers who have large social networks may provide less care. Dautzenberg and colleagues (2000) performed multiple regressions to predict the number of weekly hours of help provided by middle-aged women to parents and found that having multiple siblings reduced the amount of care tasks provided by the respondent. Research by Keating and Dosman (2009) indicates that the size and diversity of care networks influences both amount of family/friend care and the likelihood of receiving formal care services. Larger networks provided more total care while more diverse networks were more likely to link to formal care services. Further work is warranted on sharing of care labour among family members and friends.

The *availability and affordability of formal services* is a characteristic of the policy context which impacts the amount of care labour provided by family members and friends. Carers UK (2007) found that three in ten caregivers over age 18 reported that charges for services were too high, which may limit the amount of services they access thus increasing the number of care hours they provide. On the other hand, the MetLife study of Alzheimer's disease found that the provision of higher hours of paid care did not lower the hours of care to people with Alzheimer's Disease (MMMI and LifePlans, 2006). There is some evidence from this study that, under these circumstances, caregivers were able to shift their caring activities from providing for basic needs to including somewhat more companionship and emotional support.

4. A Systematic Review of the Literature on the Costs of Caregiving for Employers

4.1 Method

4.1.1 Reference Retrieval Procedure and Search Strategy

A second search was conducted in order to focus on the costs of caregiving for employers. The strategy that was utilized was quite broad, in large part to counter the paucity of literature on this topic. Resources were searched that included employment-related consequences for caregivers, business costs related to absenteeism and "presenteeism" (reduced productivity evidenced by workers while present), employer practices associated with efforts to promote work-life balance (best practices), and human resource trends. Some of the literature focused particularly on older workers as an employee population likely to have caregiving responsibilities. Often the studies reviewed equated caregiving with elder care to differentiate it from care for dependent children.

Inclusion Criteria

- Employers of people who provide care to an adult with a long-term health problem or disability
- Focus on one or more specific costs to employers and/or methods suggested to reduce costs

Definitions

- Employer refers to an individual employer or workplace in the private, public or non-profit sector.
- Employees, employed caregivers refer to individuals who are employed on an ongoing basis who have caregiving responsibilities for one or more adults or seniors with a long-term health problem or disability.

Exclusion Criteria

Business and trade publications that promote best practices by reporting findings from other studies, without adding additional information.

Research that focused on workplace policies, flexible work arrangements or other practices designed to reduce work-family or work-life conflict in general. In addition, studies that focused on human resource policies or workplace practices designed to improve employee engagement or to address the needs of a diverse workforce with little or no direct reference to employees who provide care to adults with long-term health problems or a disability were used selectively and only if information was provided about employer costs

Research that focused on parents of children under the age of 18.

Search Strategy

Keywords: employed caregivers; employer costs/ business costs/costs to employers; workplace practices/ workplace supports/family-friendly workplace practices; work and elder care/caregiving; eldercare and benefits, workplace elder care benefit programs, self-employed caregiver, low-income caregiver; caregivers and productivity, caregivers and labour force participation. Additional searches were conducted on specific keywords such as ‘absenteeism’ and ‘direct and indirect business costs’.

The search for literature on employer costs was designed to identify both references that pertained to the consequences of combining work and adult/elder care as well as economic costs to employers. This process facilitated sharing of results of to provide additional information on the employment-related costs of caregiving for caregivers.

Date: Material published or produced since 2000 was reviewed. A limited number of the most frequently cited articles and reviews that were published in the late 1990s were included.

- Particular attention was paid to finding Canadian materials, however much of the literature is based on studies in the U.S. Studies from other countries were not excluded.

Sources of Information

- Databases: Abstracts in Social Gerontology, ABI/Inform, Academic Search Complete, Business Source Complete, Business Source Elite, EconLit with Full Text, Family and Society Studies Worldwide, Family Studies Abstracts, Human Resources Abstracts, MEDLINE, PsycEXTRA, PsycINFO, Psychology and Behavioural Sciences Collection, Social Work Abstracts, SocINDEX with Full Text, Sociological Collection
- Electronic reports and studies were obtained from research centres, policy institutes, government agencies and departments, and websites of relevant organizations and associations, including those that conduct research and provide consultation to businesses and to the Human Resources field.
- Other Sources: Manual searching of reference lists, personal recommendations, existing bibliographic database, previous search results, particularly those obtained that relate to a previous review of the return on investment to businesses related to family-friendly practices, listservs related to work-family research and to caregiving.
- Disciplines and fields: Literature for this topic was found across a variety of academic disciplines and included book chapters, academic journals, government reports, business publications, and grey literature (reports produced via research centres, non-profit organizations, and professional associations). The major disciplines/fields drawn upon include sociology, family studies, industrial and organizational psychology, labour economics, business, management and human resources.

4.1.2 Screening Process for References

A description of the screening process to reach the final set of articles is presented below.

Title review
After removal of duplicates from multiple searches, the next phase of screening included reviewing reference titles. Based on titles and keywords identified by authors or journals, references were either included or excluded based on the predetermined criteria. During this stage, a total of 189 titles were chosen for the next stage of abstract review.

Abstract review
The next phase was to screen the abstracts of the remaining references for relevance. When information contained in the title and abstract was not sufficient to determine inclusion, the full text was scanned. At this stage, 86 references were included**.** Relevant articles, book chapters and reports were entered into an EndNote library file that included the abstract provided by the authors, keywords, and a brief précis by the researchers.

Full text review
Relevant articles were then read and reviewed fully and further notes were made to EndNote files and written records. After full text review a total of 35 references were selected for inclusion in the review. The major reasons for exclusion at this stage were lack of direct relevance and (more often) failure to provide any original data or new information. (A considerable number of trade publications in the business and HR field simply repeated the findings obtained from other studies, particularly the MetLife Mature Market Institute studies (MMMI and NAC, 2006; MMMI, NAC and NCWA, 1999), using them as a base to build awareness and promote consideration of the implications for business practice.) In other cases, reading of the text confirmed that the resource was too general and/or not specific to economic costs that could be attributed to adult or eldercare. After completion of the full literature search, 7 additional references were included. These references were identified through ongoing scans of the literature and as a result of announcements from research centres or organizations with a specific focus on caregiving or by experts in the field, including team members.

4.1.3 Extraction of Data from References

Similar to the process for the literature review on costs to caregivers, information was collected on sample characteristics and key findings from included studies. Domains and categories in which employers incur costs or might incur costs were noted, as well as suggestions for costs that might be reduced or avoided.

Data extraction tables for costs to employers included:

- Reference source: author, title, year, source, country
- Types of costs borne by employers related to having employees with caregiving responsibilities
- Estimates of costs
- Additional details: How costs were estimated; factors affecting costs

4.1.4 Quality Assessment

Stringent inclusion criteria and elimination of articles that did not address employer costs resulted in a small body of literature that was specifically relevant to the topic. Thus the seach strategy resulted in high topic relevance. The final review of studies on caregiving-related costs for employers drew on three bodies of literature: 1) Studies of caregivers' reports of employment-related consequences experienced as a result of caregiving and the very few studies that have used such data to estimate employer costs; 2) Research that focused specifically on absenteeism and presenteeism and on the calculation of the economic burden of illness, and 3) Selected studies from the work-family and business literature that provide the business case for reducing avoidable costs as a result of introducing practices supporting work-life balance, employee engagement and employee wellness. There are very few studies of employers' or workplaces' actual costs, although some case studies provide interesting examples of how employers can reduce or avoid costs, and even realize economic advantages as a result of introducing changes to workplace practices and workplace culture that support a diverse workforce that includes caregivers. By and large, the literature on caregiving-related employer costs is very limited and currently is dominated by one or two U.S. studies that provide a rough approximation of employer costs.

It should be noted that studies of employer costs related to employees' caregiving responsibilities are limited by the data collected by employers and by what information firms are willing to share with external researchers. Assumptions about employer costs are usually based on employees' behaviour (absenteeism if counted) or self-reported employment impacts, which are then extrapolated to estimate employer costs, based on estimated hours of absence or lost productivity at average wage rates. These are necessarily imperfect methods. As well, employers may choose whether to replace absent employees or not (and at what level), reassign work, or pay overtime to ensure work is done. Similarly, employers may offer paid or unpaid leave and other benefits/services either on a discretionary basis or as a result of collective agreements. Variations in how absences and productivity losses are handled (which can result in higher or lower costs) will depend on the length of absence or unavailability of employees, the nature of the work, and other factors. These complexities and the various assumptions and estimation procedures used all affect the magnitude of estimates of employer costs.

4.1.5 Narrative Synthesis

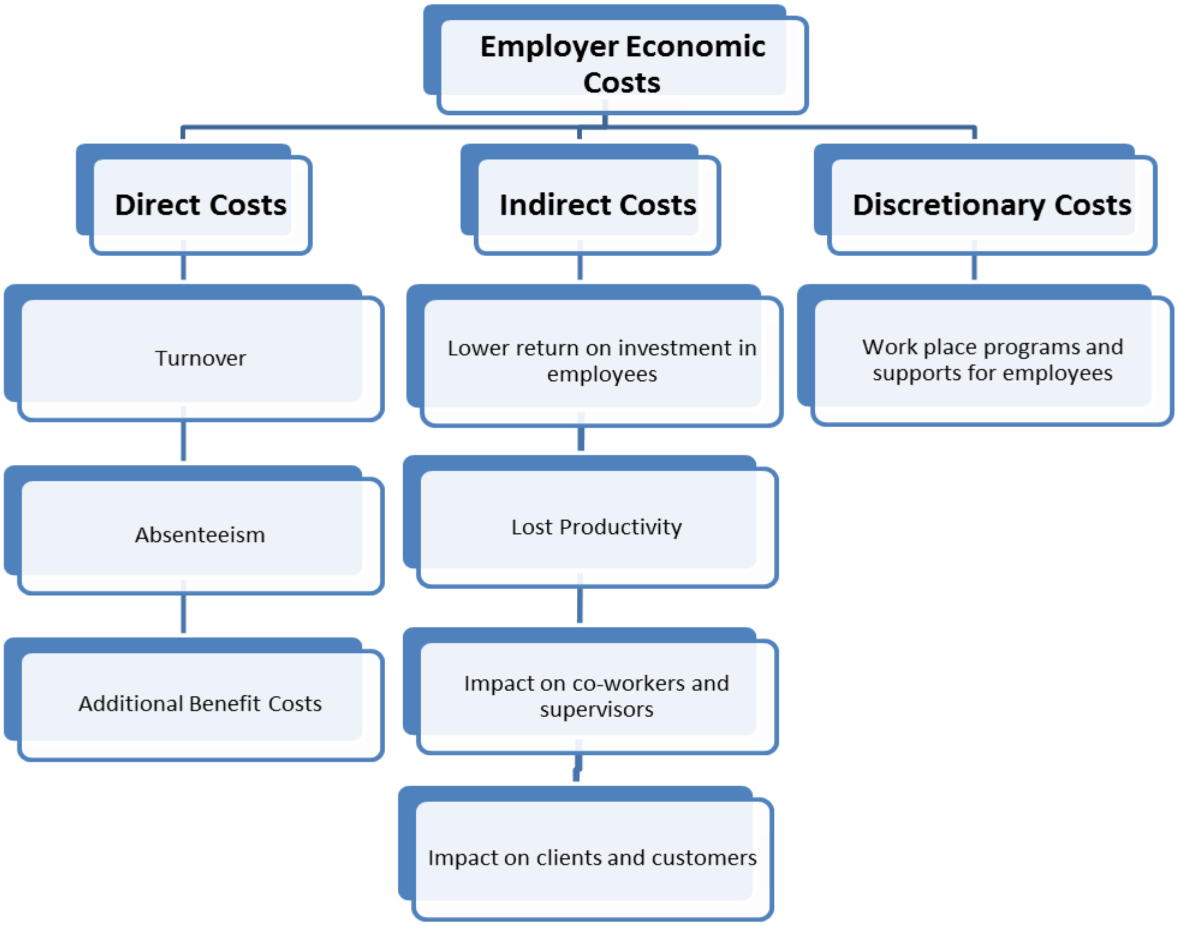
The purpose of the narrative synthesis was to identify key categories within domains of economic costs of caregiving for employers. The resulting taxonomy must be considered preliminary given the small amount of empirical research on employer costs. Many **studies** were descriptive, reporting on magnitude of costs related to absenteeism lost productivity to employers. Moreover, the use of concepts such as direct and indirect costs was not consistent across the few studies that reported actual costs. This circumstance reflects the limited development of research on, and conceptualizations of employer costs at this time. The final set of domains and categories within these domains emerged as the findings were summarized and collated and benefited from discussions with colleagues who are experts in business and human resource management. The taxonomy of employer costs presented in this report is based on our efforts to organize categories of costs in a way that can be easily understood and that wil help move forward the discourse on this subject.

4.2 Findings

In the most commonly cited study of care-related costs to employers, all costs are lumped together under the banner of productivity losses (MMMI and NAC, 2006). However, our scoping review turned up evidence of three distinct domains of costs that may be experienced by employers as a result of having employees with care responsibilities: direct costs, indirect costs, and discretionary costs. The resulting taxonomy represents an original contribution to the literature.

We define *direct costs* as costs that can be calculated most easily on the basis of expenditures that can be tracked by payroll, benefits and administrative systems and/or for which receipts can be obtained to accurately estimate costs. *Indirect costs* are those that are more difficult to quantify and relate most often to lost productivity and to the effects of the loss of personnel with training and firm-specific knowledge and experience who may retire from or quit their position as a result of being unable to combine successfully their work and caregiving responsibilities. Indirect costs also include ‘hidden costs’ or intangible costs to organizations that can extend beyond individual employees with caregiving responsibilities to their supervisors, co-workers, and ultimately the firm’s clients and customers. The third domain, *discretionary costs*, includes costs associated with the provision of additional flexibility, support, and information to employees with caregiving responsibilities. The following figure represents the taxonomy of economic costs of care to employers.

Figure 4.1: Taxonomy of the Economic Costs of Care for Employers of Caregivers



Prior to further discussion of the literature, it is worth providing a snapshot of the often-cited *MetLife Caregiving Cost Study: Productivity Losses to U.S. Business* (MMMI and NAC, 2006). The study, an update of a 1997 report, was based primarily on findings from the National Alliance for Caregiving and AARP study, *Caregiving in the U.S., 2004* with some estimates informed by other studies conducted by MetLife and by individual researchers. The base data consisted of caregivers' reports of a variety of employment-related consequences and adjustments. Estimates were based on costs for full-time employees in eight categories: replacing employees, absenteeism, partial absenteeism, workday interruptions, eldercare crisis, supervisor time, unpaid leave, and reductions from full to part-time status. All categories of costs were referred to as productivity losses. Two estimates were provided for each category, reflecting the experiences of employees with high intensity caregiving demands (based on a Level of Burden Index developed by the National Alliance for Caregiving and AARP in 1997) and all employees with caregiving responsibilities, regardless of care intensity. High intensity caregivers were those who provide personal care for an average of 12 to 87 hours per week.

Costs were estimated using the median weekly wage from the U.S. Bureau of Labor Statistics for 2004. Thus, as one example, costs due to absenteeism were based on assumptions about the number of days missed due to caregiving by men and women separately, multiplied by their respective median weekly wage. The total cost to U.S. employers across all eight categories associated with full-time employees with intense caregiving involvement was estimated at $17.1 billion dollars in annual lost productivity. The total productivity costs to employers based on all full-time employed caregivers was $33.6 billion. It is important to note that these estimates did not include costs associated with additional health claims, which is a considerable expense for many U.S. businesses, costs associated with part-time employees, or costs that may be incurred by long-distance caregivers, who may require leaves and incur more days off work to travel to provide care.

The MetLife Caregiving Cost Study (MMMI and NAC, 2006) is an example of the practice of extrapolating employer costs based on caregiver data. The estimates of employer costs reflect the strengths and weaknesses of the data available and the various assumptions made for such calculations. It is clearly the most well-known and widely reported study of employer costs related to caregiving in the extant literature and covers many of the direct and indirect costs in our model.

4.2.1 Direct Costs

We define *direct costs* as those that are related immediately to the presence and performance of an employee in an organization. Direct costs include wages and benefits paid to particular employees or those that are required for a specific purpose or function in an organization. Direct costs can be calculated on the basis of expenditures that can be tracked by payroll, benefits and administrative systems and/or for which receipts can be obtained to accurately estimate costs. The categories subsumed under direct costs in our taxonomy primarily reflect wage and benefit costs attributable to replacing employees who retire, quit or leave a job; wage and benefit costs for absent workers and their replacements; and additional costs associated with health care claims and disability leave that can be related to health consequences of caregiving experienced by employees.

Turnover

Costs related to recruiting, selecting and training personnel who retire, quit or leave their job can be significant. Indeed, the desire to retain experienced, skilled employees and reduce the costs associated with staff turnover is often cited as reasons employers introduce work-life initiatives, especially given concerns about looming labour and skill shortages (AARP, 2008; Lilly, 2010; Yeandle, 2006.)

The variety of factors that should be included when assessing turnover costs include: i) separation costs, including the administrative costs associated with termination, exit interviews and severance packages; ii) replacement costs, including the expense of tasks such as attracting applicants, interviews, testing, moving expenses and pre-employment administrative expenses; and iii) training costs (Deares et al., 2008). Several studies suggest that the direct cost of replacing employees could be as high as 150% of annual salary for those with specialized skills (Bachmann, 2000). Recruiting and replacing more senior and specialized individuals can be particularly costly.

The MetLife Caregiving Cost Study used a conservative base of 50% of median annual wage as the cost of replacing an employee who left their job because of their care responsibilities, resulting in an estimated total cost to employers of $6.6 Billion to replace 2.4% of full-time employees (almost 382,400) who quit due to caregiving responsibilities (MMMI and NAC, 2006). In Canada, analyses of 2007 GSS data on the impacts of caregiving on employees age 45+ indicated that 2.0% of employed women caregivers and

0.5% of employed male caregivers quit or lost a job related to caregiving and 4.4% of women and 1.1% of men retired early to provide care to a family member or friend (Fast et al., 2011). This corresponds to nearly 184,000 Canadian employees who left their jobs in order to provide care. Applying the same method that was used in the MetLife study, care-related employee turnover can be estimated to have cost Canadian employers $3.8 Billion in 2007.

Absenteeism

Absenteeism and its related costs are primary areas of study. The desire to reduce absenteeism, particularly unscheduled absenteeism, is a key concern of employers, particularly in service industries and in manufacturing (CCH, 2005). A general rule of thumb in assessing direct costs of absenteeism is to multiply the number of days absent by an employee's salary. One specialist in such estimations suggests that the true cost of absenteeism is actually a minimum of two times the actual hourly wage of employees, since employers must take into account the employee's actual wage, benefits, supervisor's time, and lost opportunities resulting from absenteeism (Gatti, as cited in Shellenbeck, 2004). Other direct costs that could result from absenteeism include the wages and benefits paid to replacement personnel and to pay for overtime on the part of other employees who must assume the absent employee's responsibilities (Lero, Richardson & Korabik, 2009).

The MetLife Caregiving Cost Study provided estimates for absenteeism related to full days of work based on median weekly wage rates, as well as costs due to partial absenteeism (reporting for work late and leaving early). The total estimated cost of full days and partial absences in the U.S. in 2004 was just over $ 7 Billion based on all full-time employed caregivers (MMMI and NAC, 2006). More recently, the Gallup organization estimated that absenteeism among full-time working caregivers in the U.S. amounts to 126 million missed workdays each year, which translated into an estimated $ 25.2 Billion in lost productivity (Witters, 2011). Recent analyses of Statistics Canada's 2007 General Social Survey (GSS) data by Fast et al. (2011) suggest that over 520,000 employed caregivers missed one or more days of work per month to provide care, with women missing an average of 3.1 days and men 2.4 days per month. Collectively, this amounted to nearly 1.48 million missed days of work related to caregiving for employees age 45 years and older.

While costing absenteeism seems reasonable, a recent report by the Conference Board of Canada (Hughes, 2010) suggests that many organizations do not track absenteeism rates and only a select few track absenteeism costs. This may suggest that the concept of tracking absenteeism is less important and appropriate when more employees have flexible work schedules or can work at home, making up for time lost. A shift to focusing on results or work accomplished rather than 'face time" may also result in a more lenient approach to absenteeism. Nonetheless, the costs of absenteeism, particularly unplanned absences, can be considerable, especially when direct costs, indirect costs (lost productivity related to the absence) and administrative expenses are combined (Kronos/ Mercer, 2010). There continues to be significant interest among Human Resources professionals in disability plans and absence management.

In addition to absences of a few days or partial absenteeism, costs also can arise from longer periods of paid or unpaid leave, including caregiving leave, stress leave and short-term or long-term disability leave. Costs associated with leaves may include wage and benefits costs for an absent employee and for any replacement workers hired during the employee's absence and/or overtime costs if co-workers take on some of the work that would otherwise have been done by the absent employee. The MetLife Caregiving Cost Study estimated the cost of an average of 10 days of unpaid leave for 16% of men and 16% of women caregivers at approximately $ 3.4 Billion U.S. (MMMI and NAC, 2006).

Additional Benefits Costs

The cost of additional health care claims and disability leave specific to employees with caregiving responsibilities has received little attention, but is an emerging concern. A body of research confirms that employees with long-term and/or intense caregiving responsibilities are likely to be in poorer health as a result of fatigue, stress, lack of sleep, and less healthy behaviours (Duxbury, Higgins & Smart, 2011; Edwards, Higgins, Gray, Zmijewski & Kingston, 2008; NAC, AARP and MetLife Foundation, 2009). Based on data from the 2007 Statistics Canada General Social Survey, Fletcher, Fast and Eales (2011) found that more than 19% of women and 8% of men caregivers age 45 and over in Canada reported that their health suffered because of their caregiving responsibilities. This amounted to more than 537,000 Canadians age 45 and older.

Over time, high levels of caregiver strain and associated states of anxiety and depression can lead to higher medical and prescription drug costs, greater use of sick days as a result of caregiving, and higher rates of short-term disability leave (Burton et al., 2004; Duxbury et al., 2009). Poor health among employed caregivers can thus contribute to absenteeism, disability program and extended health benefit use, as well as work limitations on the job that can affect productivity. On the job decrements in attention, engagement and performance are typically included as indicators of job productivity losses referred to as "presenteeism" (Burton et al. 2004; Goetzel et al., 2003), which is considered an element of the domain of indirect costs in our taxonomy. Recent examinations of the impacts of mental health in the workplace suggest that mental illness is linked to more lost work days than any other chronic condition, and is more likely to result in short-term and long-term disability leave, resulting in higher costs for insurers and employers (Dewa, Chau & Dermer, 2010; Lim et al., 2008). One estimate based on U.S. firms suggested that employers may experience an additional 8% in direct health care costs (doctor's fees, prescription drug costs and increased health premiums) for employees with caregiving responsibilities who experience additional physical and emotional health problems due to caregiving (MMMI and NAC, 2010).

While there are marked differences between the U.S. and Canada with respect to health care insurance coverage, even in Canada only basic physician and hospital services are covered by provincial insurance programs, such that employer-provided extended benefit plans are important (though potentially costly) recruitment and retention tools for Canadian employers. Care-related illness and disability that increases caregiving employees' reliance on these benefit plans thus have the potential to impact Canadian employers' bottom line as well.

4.2.2 Indirect Costs

We define *indirect costs* as those that are less visible or easily quantified in organizations, including overall effects of employees' care demands on productivity and organizational effectiveness. Indirect costs thus include the impacts of caregiving that "spill over" employees other than those with direct caregiving responsibilities when caregiving employees leave their job, retire, reduce their work hours, are absent from their jobs, or distracted while at work. It is believed that indirect costs related to reduced productivity can be more detrimental and more financially costly to employers than the direct costs associated with employees' absenteeism, leave or turnover. The categories subsumed under indirect costs in our taxonomy reflect secondary effects of turnover and absenteeism, including reduced performance on the job, as well as impacts on co-workers and supervisors, and potential impacts on customers and clients.

Lower Return on Investment in Employees

Reduced return on employers' investments in employees' human capital is a concept that refers to the loss of an experienced employee with firm-specific knowledge, skills and experience. Literature on the value of older workers reinforces the importance to organizations of maintaining employees with institutional knowledge and unique understandings from long term experience within that organization, a situation expected to grow worse as more members of the Baby Boom generation retire (Dembe, Dugan, Mutschler and Piktialis, 2008). The "brain drain" that results from loss of highly experienced workers who retire early or leave the workforce because of caregiving responsibilities who would otherwise have continued is an indirect employer cost. In this case, other employees may lose the opportunity to be mentored by the missing employee and the organization may also lose the leadership provided by managers and senior members of work teams. Departures of key employees can also affect customers or clients who had a unique relationship with the employee who is leaving.

Lost Productivity

By far the dominant theme that runs through the existing literature on employer costs related to caregiving is productivity losses that result from absenteeism, from reduced physical and mental health, and from decreased energy, engagement and performance when at work (Burton et al., 2004; Duxbury et al., 2009; Fast et al., 2001; Lilly, 2010; Sherman and Reed, 2008). The latter circumstance is referred to as burnout or "presenteeism" and is not uniquely an effect of caregiving. In the business literature, presenteeism is seen as an invisible drain on productivity, with hidden costs that are likely to be much more damaging to organizations than the more visible costs associated with absenteeism, short and long-term disability and medical and pharmaceutical costs (Hemp, 2004). There is no consistent or agreed upon measure of presenteeism or decrements in employees' productivity. Some suggested measures include the costs associated with reduced work output, errors on the job, and failure to meet company production standards, as well as dollar estimates of the proportion of an employee's time that is considered unproductive (Schultz, Chen and Edington, 2009). Other researchers rely on self-report measures of difficulties experienced being productive at work, using work limitations questionnaires. The MMMI Caregiving Cost study included an estimate of costs resulting from workday interruptions as one of their categories of cost reflecting productivity losses. Their estimate of one hour per week for 50 weeks for 34% of male caregivers employed full time and 52% of their female counterparts resulted in an estimated financial cost of $ 6.2 Billion to U.S. employers (MMMI and NAC, 2006).

In their review of the concept, Schultz et al. (2009) suggest that there are two different types of presenteeism, the first due to an acute illness and the second due to chronic conditions. These authors, citing Ruez (2004), note that presenteeism is “driven by several interacting factors that are common in today’s workplace: stress, employee health and work/life balance” (p. 367). Based on their review of the literature, Burton et al. (2004) concluded that the “effects of caregiving burden on workers may be similar to having a chronic physical or psychological ailment” (1049). These researchers studied absenteeism and self-reported work limitations while on the job in a two week period by caregivers employed in a large financial service company in the U.S. The sample of caregivers was defined broadly and included parents of children caring for a sick child, as well as those providing care for adults with an acute or chronic health problem.

Burton and colleagues’ (2004) results confirmed that caregivers reported more physical health and emotional problems than non-caregivers. Caregivers lost more time from work (absenteeism), and reported more difficulty with time management, being distracted while at work, and requiring more help from others to get work done (presenteeism), along with higher stress, anxiety and depression, and less time for sleep and physical exercise. The pattern of work limitations was noted even among those with low levels of caregiving responsibility, but increased commensurately with increases in caregiving time. These authors concluded that employer initiatives that could help employees balance caregiving responsibilities for ill dependents could have a positive impact on employees’ health and productivity.

Impacts on Co-workers and Supervisors

While the majority of attention has been focused on the effects of caregiving on individuals, the concept of indirect costs includes effects on co-workers and supervisors that result from absenteeism and reductions in work performance. Co-workers may have to assume additional tasks or work overtime. Work tasks that are performed in teams may require adjustments and task reallocation. Co-workers may spend time providing support and advice for employees with difficult caregiving situations. Some may experience stress contagion. Similarly, supervisors may spend more time in management and support provision, reallocating job tasks and problem solving with employees. There is very little research on these topics, but anecdotal evidence of such impacts is common.

The MMMI Caregiving Cost study included an estimate of additional supervision costs arising from caregiving. Based on an assumption of 12 hours of additional supervisory time per year for each caregiving employee who reported having a supportive supervisor, they arrived at an estimate of close to $1.8 Billion for additional supervisory time for more than 7.2 million full time employees with caregiving responsibilities (MMMI and NAC, 2006).

Impacts on Clients and Customers

No research studies could be found that directly related lost revenue in the form of sales, foregone contracts, or other business income arising from caregiving employees' employment consequences. It stands to reason, however, that such costs would result when individuals who provide direct services to the public or to specialized clients are absent from work or fail to provide the quality or timeliness of service expected. Delays in fulfilling orders for products could also carry financial penalties. Similarly, absences or lack of responsiveness to clients and customers who depend directly on the services of key individuals could result in financial losses for an organization. In all likelihood such circumstances are most likely to affect specialized service organizations in such fields as research, financial, legal and consulting services for whom loss of billable hours and dissatisfaction or loss of key clients could have significant financial impacts.

4.2.3 Discretionary Costs

Work Place Programs and Supports for Employees

The third domain in our model of employer costs is one that is not referenced directly as a cost to employers. It is included given the frequency with which human resource and management specialists refer to the "business case" for employers adopting a range of human resource practices and strategies to reduce avoidable direct and indirect costs. Such practices include offering more flexible work schedules and options to allow employees to better manage work and caregiving responsibilities, paid family care days and paid leave options, additional or enhanced Employee Assistance services costs and benefits, and involvement in providing additional informational supports to employed caregivers. Despite interest in this topic, there are few estimates of the cost or cost-benefits ratios of introducing such programs and practices (Conference Board of Canada, 2011; Lero et al., 2009).

Organizations such as the Families and Work Institute, the American Association of Retired Persons, the National Alliance for Caregiving, the Conference Board of Canada, MetLife Mature Marketing Institute, and the Society for Human Resource Management, as well as individual authors (eg. Lilly, 2010; Yeandle et al., 2006) promote the use of best practices in human resource management as tools for reducing turnover, absenteeism, and productivity losses. Increased flexibility, caregiving related benefits, and access to information and services are typically suggested as tools to promote work-life balance, employee health and wellness, and employee engagement and effectiveness. Yeandle and colleagues (2006) and others repeatedly make the point that supporting working carers is a business imperative. While such initiatives may be particularly beneficial for caregivers, service costs (e.g. for EAP services) are spread across all employees and serve a variety of employees' needs. Similarly, flexibility in work scheduling may be used to accommodate a variety of individual and organizational purposes that include, but are not restricted to helping employees with care responsibilities better balance their care and paid work responsibilities.

The costs associated with introducing more flexible schedules, providing paid leave options, and offering additional services and supports through EAPs and other organizations can thus be seen as an investment, potentially reducing costs and increasing an organization's reputational advantage – a significant tool for recruiting new talent and retaining valued senior staff in a tight labour market. Spreading those costs across all employees, including new parents, those with caregiving responsibilities, and individuals with a growing diversity of interests and commitments in their personal lives is promoted as good business.

U.S. studies suggest that in recent years we have witnessed an increase in the proportion of employers providing flexible work arrangement and elder care supports and services (Galinsky, Sakai, & Wigton, 2010; Society for Human Resource Management, 2010, 2011). In a recent case study by the European Foundation for the Improvement of Living and

Working Conditions (2010) British Telecom's (BT) initiatives to address the needs of working carers were described as part of the company's commitment to flexible working in general (Byrne, 2011). They reported that seven out of ten BT employees use some form of flexible working arrangement, such as limited or annualised hours or a compressed week. An internal evaluation concluded that the range of flexible working options the company had implemented increased their productivity by as much as 21% (the equivalent of €6 - 7 million per year) and reduced stress-related absence by 26.

There is little, if any, data on the extent to which Canadian employers provide flexibility, access to a variety of leaves, and information and support services that would be particularly beneficial for employed caregivers, and none on the costs of providing such supports. Analyses based on Statistics Canada's Workplace Employee Survey conducted between 1998 and 2006 suggest that Canadian employers have provided limited access to caregiving supports and services, particularly related to elder care (Ferrer & Gagné, 2006). A current survey of employer practices and supports being conducted by Lero, Spinks and Fast will provide additional information on this topic.

4.2.4 Factors Influencing Costs for Employers

Given the very limited research on employer costs related to having caregiving employees, there is little guidance as to how we might specify the factors that influence the prevalence and magnitude of such costs. Related literature would suggest that the prevalence and magnitude of direct, indirect and discretionary employer costs are likely to depend on a) characteristics of an organization's workforce, b) a variety of organizational characteristics, and c) public policy and contextual factors.

Workforce Characteristics

Workforce characteristics that likely to affect potential costs to employers include the demographic composition of the workforce – specifically the proportion of employees who have or are likely to have caregiving responsibilities for adult family members with acute or chronic health conditions. Clearly, employer costs reflect the nature of employees' caregiving responsibilities and the challenges employees experience combining paid employment and caregiving. Proxy variables that might be used in the absence of employee surveys include data on the age and gender distribution of the workforce.

Organizational Characteristics

Organizational characteristics also appear to be important factors. Differences are evident in absenteeism rates and in the provision of various benefits and HR practices designed to promote work-life balance across organizations that are associated with firm size, industry, sector, and whether the workforce is unionized (Evans, 2001; Ferrer & Gagné, 2006; Statistics Canada, 2011). Beyond these features, research suggests that an organization's work-family and business culture affects the provision of flexibility and supports, including management practices that could affect the ease or difficulty employees experience combining work and caregiving, and hence costs associated with turnover, absenteeism and productivity losses.

Public Policies and Contextual Factors

Finally, public policies and contextual factors influence employers' policies and practices and employees' experiences. Such policies include legal rights such as the legislation conveying the right to request flexibility in work schedules in the UK and Australia for those with caregiving responsibilities. Provincial/territorial employment standards legislation and Canada Labour Code provisions also affect employees' access to paid or unpaid family and compassionate care leave. Other factors that may affect employers' costs and employees' experiences include the availability of a range of community-based services and supports provided through provincial and local governments or by private or civil sector agencies and organizations.

Growing awareness of caregiving as a factor affecting an increasing number of Canadians and businesses can be considered to have longer term effects as individuals, employers and governments become more knowledgeable about this important issue.

5. Knowledge and Data Gaps

The two taxonomies of economic costs of care have provided a framework for a systematic evaluation of domains of costs borne by caregivers and by employers of caregivers. Given high levels of concern about public costs of care, as well as growing concerns about the availability and sustainability of the family/friend care sector, a more complete view is warranted of the state of the 'private' side of public-private partnerships in caring for adults with long term health problems and disabilities. As is evident in the preceding sections of the report, our knowledge of these costs is fragmented and uneven.

In this section of the report we discuss gaps in knowledge of the extent, and magnitude of costs within the domains and the interactions among them (Objective 3), and of data gaps that inhibit further understanding these costs (Objective 4). These are discussed for the two private sectors of interest in this report: family/friend carers and employers of carers.

Knowledge creation should be based on a clear sense of gaps that need to be addressed. In the areas of economic costs of care, we have found these to be substantial. They are reviewed from the perspective of what Canadian data are needed to inform the 'need for care' element of the agenda on managing population aging.

5.1 Knowledge Gaps

5.1.1 Definitions and Scope

Definitions of both care and of caregivers differ widely across studies and jurisdictions making it difficult to evaluate relative costs and to build a coherent body of knowledge about them. We have worked closely with Statistics Canada over several years in the development of their definition of care which is tasks or services provided to someone because of that person's long term health problem or disability. This definition has the advantage of distinguishing care from the everyday division of labour in a household or family, and from supportive exchanges resulting from ongoing relationships with friends or family. It also provides a conceptual separation of tasks from reasons for providing the task. For example, preparing meals is an everyday activity in families. Yet it also can be an essential caregiving task, making a difference in whether a care recipient is adequately nourished and can remain at home.

There also are considerable differences in the tasks and services included in what is considered as care and hence the magnitude of caregiver costs. Narrowest definitions include primarily personal tasks such as bathing, dressing or transfers since personal care is labour intensive and requires daily face to face attention. Other high intensity tasks such as meal preparation and household activities (e.g. laundry and cleaning) also can be costly in terms of caregiving labour. Some caregiving activities such as care management and caregiving commuting time have been more recently included in research assessments of caregiving. Such activities may be invisible to the care receiver but can be costly to caregivers in terms of time spent and out-of-pocket and employment related costs. Many of the care tasks that have been on the periphery of costing analyses are those for which there are few formal sector options for assistance. Social care tasks including housekeeping, meals and transportation are now primarily within the voluntary or private sectors when not provided entirely by family/friend caregivers. Similarly, management of all caring activities may be beyond the capacity of health care systems that are under resourced. Thus it seems especially important that we document the full set of care costs across the full set of care tasks incurred by caregivers. Data on the full set of caregiving costs could contribute in valuable ways to planning for ways in which to sustain the family/friend care sector.

A related knowledge gap lies in understanding costs across the diverse group of caregivers. Caregivers are defined by their kinship, friend or neighbour relationship to the recipient, yet most assessment of caregiver costs has been of a subset of relatives, mostly adult children and spouses. Estimates of time spent by spouse caregivers (and thus their care costs) are consistently low, resulting from difficulties for these caregivers in disentangling care from everyday activities, or from practical data collection challenges such as gathering information from a caregiver without the presence of the recipient. This challenge must be addressed if we are to reduce costs of this group of vulnerable caregivers. Little is known about friend and neighbour caregivers although estimates are that approximately 20% of caregivers are non-kin. Recent Canadian research on the differentiation of types and intensity of care tasks between friend and neighbour caregivers has shown considerable differences in the amount and types of care provided. Friends provide more hours of care and more intimate tasks than do neighbours (LaPierre and Keating, in review).

A further constraint to knowledge of the scope of caregiving responsibilities stems from an emphasis on care provided to a care receiver by an individual (often called primary) caregiver. We know from previous research that caregivers may be caring concurrently for more than one person and that care to a particular care recipient often is shared. These are two major gaps in our knowledge of total costs of care. Information on the total costs to a caregiver of all current care responsibilities would be a major step forward. While we have long been concerned about caregiver 'burden' we have yet to build our understanding of full costs to those caring for more than one person.

Information on total costs of care to a care recipient would serve a different purpose. It would be particularly useful in determining comparable 'unit' costs borne by the family/ friend sector and by the public or private sector. To determine these family/friend costs requires understanding costs for each member of the group of family and friends providing care to an individual recipient. While network analytic methods are well established (Keating and Dosman, 2009), they have been used rarely in estimating costs of care. Information on how costs of care are apportioned among network members could provide valuable insights into how 'families' share costs, whether non-family members incur costs and even who is viewed as a normatively obligated family member in the face of long term, perhaps expensive care requirements. We continue to be poorly informed about how families provide care despite the fact that they do most of the caring labour.

5.1.2 Extent of Costs in each of the Cost Domains

A major challenge that became apparent in our scoping review is that there have been few systematic attempts to build knowledge within each of the caregiver cost domains. The extent of Employment consequences is perhaps best understood. A number of studies have examined the impact of labour force participation, hours of paid work and the care work/paid work relationship over the life course on lost wages and benefits. However, there are relatively few studies that estimate the financial value of lost wages and benefits. A notable gap is in information about cumulative losses of people who have foregone employment or left the labour force early because of long term care responsibilities. National surveys often restrict questions to labour force participation within the past 12 months, resulting in exclusion of those who have left the labour force and who may have the highest long term employment-related costs.

We expected to find that out-of-pocket expenses had been well-documented since they seem the most tangible/measurable of caregiving expenses. However, there has been relatively little research activity around tracking these caregiver costs, perhaps because academics such as economists whose areas of expertise lie in costing theory and methodologies tend not to focus on costs incurred informally. Yet the importance of this cost domain should not be underestimated. Care decisions can be heavily influenced by affordability of services and equipment and by access to housing and transportation. Little is known about out-of-pocket expenses of caregivers who commute to provide care or those who travel long distances or about caregivers who live in poverty and how they manage their caregiving responsibilities. Little is known about the interrelationships between employment costs and out-of-pocket expenses. While there is speculation that those who are not in the labour force incur caregiving labour costs rather than financial costs, the two types of costs are not interchangeable. To our knowledge, there have been no comparisons of such exchanges.

Costs of caregiving labour are, in some respects, most poorly documented. As evident from the review, there is much information on the difficulties of providing care and some documentation of hours spent by different caregivers across a set of care activities. While there is a large body of research on caregiving and caregivers, the vast majority of studies of the consequences of caregiving assess the social and health impacts of caregiving. As a result, we have surprisingly little information on the economic consequences of time spent in caregiving labour. Good methods are available for tracking and costing time spent caregiving. In a report on time spent by family/friend carers in Australia (Access Economics Pty Limited, 2005) two common costing methods are described. These are opportunity costs of time that cannot be spent in the paid workforce; and replacement costs assessed as the value of purchasing an equivalent amount of care from the formal sector. The authors add a self-valuation measure which is an assessment by the caregiver of the value of their time. Each method can result in different estimates of the economic value of time spent. In the Australia study, the authors argue that the opportunity cost method results in a lower value placed on care than does the replacement cost method.

The most commonly used methods of collecting information on time spent caregiving are 24 hour recall diaries, real time recording of daily activities and estimates of weekly time spent over a longer period such as one month or one year. Relative accuracy and feasibility of these methods also are well understood (see for example Bittman et al., 2005). The time commitment required of participants to ensure highest accuracy, such as with written diaries as activities occur, must be weighed against somewhat less precise and immediate measures but which result in higher response rates.

Results from some of these time estimates have been used to calculate the aggregate value of caregiving at a national level which have been important in bringing attention to the heavy work load of Canadian caregivers. Further exploration of detailed assessments of care labour costs by type of caregiver, by number of concurrent care responsibilities, and by membership in different configurations of family/friend care networks is a necessary element of documenting costs of caring.

5.1.3 Interrelationships among Domains of Costs

Given the uneven nature of knowledge of family/friend costs within the three domains of employment consequences, out-of-pocket expenses and care labour, it is not surprising that little is known about the interrelationships among these costs. We don't know for example the circumstances under which caregivers might substitute caregiving labour for labour force participation or what are the short and long term economic consequences of these decisions. We don't know whether employed carers incur more out-of-pocket expenses for the care recipient than those who are not employed or whether the latter reduce their standard of living in order to afford the best possible care. We don't know the extent to which more distant members of care networks take on the main out-of-pocket expenses while nearby members do more direct labour. These questions at the interface are the new frontier of knowledge on the costs of care.

Evaluation of lifecourse issues that influence caregiving costs could move forward our understanding of the balance of employment, out-of-pocket and care labour costs at different lifecycle stages. We know for example that transitions into parenthood increase out-of-pocket expenses and caregiving time and often lead to employment consequences such as reduced labour force participation. Transitions into and out of caregiving to adults can occur across the lifecourse, layered onto such other transitions. Similarly, career stage or type of employment of one or more members of care networks may influence the ways in which they negotiate who will shoulder costs in each of the three domains.

5.1.4 The Prevalence of High Costs for Specific Groups

A key concern for policy makers and service providers is identifying which caregivers are at highest risk for adverse economic and health outcomes. Our analyses of the literature indicate that a mix of caregiver, care receiver and caregiving context factors affect the magnitude and prevalence of economic costs for individual caregivers. Additional data and more systematic analysis would be helpful in this regard.

5.1.5 Private-Public Cost Sharing

The research in this report was limited to costs incurred by two groups of 'private' stakeholders in care: family/friend caregivers and employers of caregivers. In recent years there has been considerable interest in tracking the apportioning of costs across public and private stakeholders. These assessments have been quite focused on specific areas such as the proportion of home care provided by formal versus family/friend caregivers and have not included such comparative evaluations as expenses for supplies and equipment or for medications.

The templates provided here for the assessment of family/friend costs and employer costs sets the basis for a more inclusive evaluation of the types of costs incurred by these different stakeholders and for evaluation of how public policy, private policy and population aging might influence this apportioning. The addition of employers to this debate has the potential to provide a much more in depth understanding of a key private sector element that otherwise has been missing from private-public cost sharing. Given the fact the majority of caregivers are in the labour force, this addition seems timely.

5.1.6 The Heterogeneity of Caregivers

There has been long term awareness of the diversity among caregivers and among the persons to whom they provide care. Our review of factors influencing costs of care was useful in documenting state of knowledge of key factors such as gender, age (especially working age), and to a certain extent relationship between caregiver and care receiver. There was surprising little information on rural-urban differences in care despite longstanding concerns about lack of proximate services, high costs, difficult winter driving conditions and higher rates of poverty in rural and remote regions.

Focus on young carers (i.e. under the age of 18) is an emerging area of special interest. In the UK for example, The Princess Royal Trust for Carers in Scotland has a young carers branch and Carers UK released a report in 2004 on “Young Carers in the UK” (Dearden & Becker, 2004). In Canada, Dr. Grant Charles at the University of British Columbia has just launched an exploratory study of the phenomena of young carers in British Columbia. Further work will be needed to identify economic costs of caregiving for these young caregivers. Youth and young adults caring for a parent or sibling risk both social isolation from peers and curtailing their education and early career development, which has a long term economic impact. Methodological challenges, discussed previously for spousal caregivers, as well as consent issues in gathering caregiving labour data from youth caregivers makes comparisons among kin caregivers difficult.

There is also little information on economic costs for certain minority groups of caregivers such as caregivers who are lesbian, gay, bisexual, or transgender (LGBT), low income caregivers, those in immigrant or ethnic minority families or transnational caregivers. Much of the research with LGBT caregivers has focused on health and social consequences of caregiving such as depression and social isolation rather than on economic costs. Research on ethnic minority caregivers has found that they provide more care on average and face additional difficulties such as language barriers and access to culturally appropriate services (Carers UK, 2011; Lai & Leonenko, 2007). These difficulties place minority groups at increased risk of poverty and loss of employment

In our view, key priorities in this area are to use national data sets to provide baseline information on these factors to the extent possible. Further research using more focused surveys or case studies will be needed to determine costs of these minority caregivers whose experiences are not captured by such secondary analyses.

5.1.7 Employers' Costs

Currently there are no estimates available of caregiving-related costs to employers in Canada. Any such estimates require Canadian data that is informed by the various policy factors that affect employers and employees, and by the distribution of employees in organizations that vary by sector, firm size and unionization status.

There are major gaps in our knowledge of employers' costs. Further information about caregivers' experiences, including but not limited to employment-related impacts, can help provide a starting point for preliminary estimates. Accurate estimates depend on the accuracy of data available. Other challenges, however, derive from the fact that many employers and organizations do not track absenteeism or costs and may not be inclined to do so. While payroll, benefit and health care claims data are available, they often are not collected in a manner that is amenable for this purpose or made available to external researchers. In addition, it can be difficult and inappropriate to try to estimate what proportion of costs associated with a particular benefit or employee assistance program are attributable to supporting employees with adult and eldercare responsibilities when HR practices and initiatives are bundled together to achieve several purposes (employee wellness, workforce diversity, employee engagement, work-life balance).

While these gaps and challenges are formidable, the importance of developing greater understanding of employers' costs cannot be denied. Employers face many challenges in a competitive environment that will include a growing number and proportion of employees with significant adult and eldercare responsibilities. Addressing the need for additional flexibility and support will only grow as an important business issue, directly affecting employers' costs and capacities and to recruit and retain valued employees.

At the same time, it is important to add that caregiving is only one factor that can affect employees' health, productivity, and use of leaves and benefits. Research conducted by Goetzel et al. in the U.S. in 2003 and Dewa et al. in Canada in 2010 indicate that absenteeism, disability leave, and productivity costs to employers vary across physical and mental health conditions. As well, to our knowledge, no study has yet compared employer costs related to employees parenting young children to those who provide care for adults and seniors. While we are particularly interested in understanding the nature of employer costs related to caregiving for this review, it would be most unfortunate if such costs were used inappropriately or taken out of context.

5.2 Data Gaps

Although Objective 4 is not an usual element of a critical review, we believe that without clear, concrete information about the potential to fill knowledge gaps with existing data sets or with strategic methodological approaches, gaps will remain, leaving researchers and policy analysts without sound knowledge on which to base their efforts and resources. Through consultations with colleagues from Statistics Canada and other researchers, we scanned the data environment for the best extant Canadian data sets to provide evidence of economic costs of care by domain and stakeholder group, and propose methodological approaches and data sources to address remaining gaps.

5.2.1 Employment Consequences

Surveys from the Statistics Canada General Social Survey (GSS) series Cycles 21 (Family, Social Support and Retirement, 2007) and 26 (forthcoming, 2012) both have information on domains of costs of care as set out in the family/friend taxonomy. Employment consequences are addressed in Cycle 21 with questions on whether as a result of care responsibilities the person had missed full days of work, reduced hours of work, quit or lost a job, postponed educational plans, or retired early in order to provide care. For those who have been employed in the previous year, there is information on the impact of care responsibilities (including intensity, duration, etc.) on labour force participation, hours of work and income. Those who had left the labour force more than 12 months previously to provide care are not captured in this survey. In Cycle 26 the problem of exclusion of those who have withdrawn from the labour force should be resolved. Duxbury's survey of employees (in progress) will provide detailed information on employment experiences including total work overload and interference between work and family.

5.2.2 Care Labour Consequences

Across Statistics Canada surveys, information on care labour is not structured to allow for detailed analyses of consequences. There is some information on how much time is spent on what kinds of care tasks in the Participation and Activity Limitations Survey (PALS), Canadian Community Health Survey (CCHS) and GSS Cycles 21 and 26. PALS has a module on care tasks received and amount of time the caregiver spends from the perspective of the respondent receiver collected through a post-censal survey of people identified in the census as having an activity limitation. There are no plans to continue this survey. In the 2009/2010 CCHS there is a module on 'home care and care receiving' but only 1 or 2 questions about whether any of the 'home care you received was provided by a family member or friend' and thus no option for costing care labour time. In GSS Cycles 21 and 26 there are questions about time spent in general categories of care tasks. Estimates of time spent are crude because they are based on recall questions for the last 12 months.

The GSS time use surveys have the most detailed information on all activities throughout the day, although these data sets (the last one was 2009) have not been used extensively to estimate care time. There are questions about time spent on care tasks in the recall diary in which the respondent is asked to report on activities during the last 24 hours starting at 4am and there are some stylized estimates on time spent providing care to someone who lives outside of your household. Questions are asked about two different groups of people. There are activity codes for 'personal care' and 'medical care' provided to someone inside the respondent's household. When a respondent reports doing housework, meal preparation, home maintenance/repair, etc., they are asked whether or not they did these things for someone outside of their household. In some of the surveys they were then asked whether that person was over age 65 and whether they had a disability. The advantages in this survey of detailed information on daily use of time must be balanced with disadvantages including the fact that many care tasks are not done daily and these may be underestimated in a 24 hour recall diary. Attempts are made to address this issue through the stratification of the sample by day of the week and month. Perhaps a more important disadvantage is that only personal or medical care to someone in the household are coded. Thus care tasks such as meal preparation, laundry and transportation are excluded. Coverage of care tasks for recipients outside the household is broader but nothing is known about the care recipients.

5.2.3 Out-of-pocket Expenses

Here too there are some data that could be used for costing analyses though they are at a global level. The GSS Cycle 21 (2007) has some global questions on out-of-pocket expenses, but the categories are very broad with no breakdown by type of cost. The stem question is: "In the last 12 months, has assisting someone caused you to have extra expenses?." If the response is yes, they are asked: "On average how much did you spend per month on these extra expenses?--less than $500, $500-2000, over $2000?" Some questions are asked about access to government benefits, government programs, tax benefits, gifts from the person they helped, whether they had received any financial support from family members or friends that might off-set out-of-pocket expenses and other costs. There are plans for Cycle 26 (2012) to include more detailed data on out-of-pocket expenses though these are not yet confirmed. Planned questions include a breakdown of expenses by type: home purchase, maintenance and modification, professional services for care receivers health care or rehabilitation, hiring people to help with care receivers daily activities, transportation or travel related to care responsibilities, specialized aids or devices, prescription or non-prescription drugs and other (open ended question). For each category the respondent is asked to estimate expenses. If they are unable to give a precise estimate, they can respond with categories from under $200 through $5000+. Respondents also are asked whether they have experienced financial hardship because of their caregiving responsibilities. Overall data from these Statistics Canada sources still have only broad categories. There is better coverage on out-of-pocket expenses but only for those associated with care to older adults. Costs of care for younger adults with chronic health problems/disabilities can be substantial. For example younger adults may have high costs for assistive devices; parents of children with disabilities who now survive into late adulthood have lengthy caregiving careers and need to develop long term financial plans for care of their dependent adult children after they are gone.

A national survey on care to people with disabilities has information on employment consequences, out-of-pocket expenses and perceived economic security, as well as social and health consequences (Fast et al., 2008).

Other methodological approaches are needed to augment and move forward these basic data on domains of care consequences. Case study and small scale surveys of caregivers can be employed to evaluate the relevance of the subcategories within each consequences domain and to develop methods for more systematic assessment of their magnitude. Narrative methods could be used to advantage to better understand the relative importance of domains of costs and the relevance of particular items within them. We would recommend these studies with groups such as immigrant caregivers, those living in poverty and people caring for younger adults with disabilities to assess the financial impact on their lives resulting from caregiving.

5.2.4 Employer Costs

To say that there are substantial data gaps for understanding the costs to employers related to employees' involvement in caregiving would be a gross understatement. U.S. data sources, particularly those provided by the MetLife Market Institute in conjunction with the National Alliance on Caregiving, are based on large surveys of caregivers with specific questions about a variety of employment related accommodations made related to caregiving. Employer costs are extrapolated from those data using a variety of assumptions and provide a crude approximation of employer costs. Differences between Canada and the U.S. in the distribution of workers in different industries and firm sizes and differences in labour, health care and social policies are all likely to affect caregivers' behaviour (e.g. leave taking and absenteeism) and employer costs. As a result, even these crude U.S. data are not easily generalized to the Canadian situation. In February 2012 Statistics Canada will send into the field Cycle 26 of the General Social Survey focused exclusively on caregiving. For the first time since 1996 the survey will provide data on caregiving by persons over the age of 15 and care receiving by persons of any age. A sincere attempt has been made to obtain better data on the care-related employment consequences for caregivers. These data may facilitate to some extent our ability to estimate employer costs, but this was not a central objective so there will be substantial limitations and many data and knowledge gaps will remain.

Surveys of employers and senior HR professionals are another option. Ideally a National Survey of Employers using a panel design to track changes over time would be of benefit in allowing us to estimate direct, indirect, and discretionary costs. Limitations in employers' ability to capture, and willingness to share data on absenteeism and health care claims costs imposes further limitations.

Finally, there is little, if any, data on the extent to which Canadian employers provide flexibility, access to a variety of leaves, and information and support services that would be particularly beneficial for employed caregivers. Analyses based on Statistics Canada's Workplace Employee Survey conducted between 1998 and 2006 suggest that Canadian employers have provided limited access to caregiving related supports and services, particularly related to elder care. A current survey of employer practices and supports being conducted by Lero, Spinks and Fast will provide additional information on this topic.

Knowledge and data gaps are therefore substantial with respect to employer costs. Understanding of the relative distribution of costs among individuals, employers and government, even for such specific issues as compassionate care leave, will require new studies and data sources designed specifically for that purpose.

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7. Appendices

7.1 Quality Assessment in Qualitative and Quantitative Methodologies

Table 7.1 Questions for Assessing Quality in Qualitative and Quantitative Research
(adapted and modified from Merriam, 2002, p. 23; Smith-Sebasto, 2001)

Qualitative Research Designs (Merriam, 2002)	Quantitative Research Designs (Smith-Sebasto, 2001)
Problem • Is the problem appropriate for qualitative inquiry? • Are the researcher's perspective and relationship to the problem discussed? Are assumptions and biases revealed?	*Problem* • Is the problem appropriate for quantitative inquiry? • Has the researcher clarified how the research is relevant?
Methods • Is the particular qualitative research design identified and described (e.g. ethnography, grounded theory, narrative inquiry)? • Is sample selection described including criteria used in the selection? • How were the data collected? • How were the data managed and analyze? • What strategies were used to ensure for validity and reliability? • What ethical considerations are discussed?	*Methods* • If a hypothesis is used, has the researcher stated that it has been tested against the null? • If research questions are posed, are they clearly identified? • Does the review include literature focusing on theory as well as methodology? • Has the nature of the sample (e.g. random, convenience, purposeful)? Been identified? • Has the use of research instruments been justified as appropriate for the hypothesis or research question? • Have the statistical techniques used been clearly identified? • Is the alpha level for significance been clear and a priori? Has the p value identified? • Have the data been described in sufficient detail. (E.g. standard deviation, mean, standard error)?
Findings · Are the findings clearly organized and easy to follow? · Do the data presented in support of the findings provide adequate and convincing evidence for the findings?	*Findings* • Have the findings been objectively interpreted? • Have you answered the research question without bias? • Has there been an identification and discussion of how the findings from the study contribute to the literature?

Findings · Are the findings clearly organized and easy to follow? · Do the data presented in support of the findings provide adequate and convincing evidence for the findings?	*Findings* • Have the findings been objectively interpreted? • Have you answered the research question without bias? • Has there been an identification and discussion of how the findings from the study contribute to the literature?