The Interplay of Risk Factors Associated with Negative Outcomes among Family Caregivers: A Synthesis of the Literature

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ABSTRACT

The purpose of this project was to summarize existing knowledge on the risk factors associated with negative outcomes for family and friend caregivers, and to identify knowledge gaps and policy-relevant research questions. The literature reviewed includes Canadian and international research based on large national surveys and in-depth studies of specific samples of caregivers and their experiences. The emphasis is on material published since 2000.

Different risk factors are more salient for different outcomes and populations of caregivers/care recipients. Moreover, it is important to consider the longer-term consequences of caregiving, as well as those that are more immediate to a particular experience or particular care recipient at one point in time. Given both the complexity of the issues and significant knowledge gaps stemming from the lack of data that includes the caregiving context and impacts over time, we have focused on clearly identifying the potential costs (outcomes) that caregivers may experience and the risk factors that are evident in the literature. The review includes examples of the interplay among these risk factors for several different situations including care for seniors with and without cognitive impairment, care for children with disabilities, care for a family member with a mental illness, and (to a lesser extent) care for non-senior adults.

Multiple factors, operating together, affect the nature and intensity of caregiving, and the degree to which caregiving demands become stressors or stressful for caregivers. High caregiving costs result when caregiving demands exceed caregivers’ resources. Exacerbating factors include lack of support from family, friends and formal/professional caregivers, limited personal or family financial resources, high financial costs, stigma, and caregiving of long duration and/or with an uncertain or unpredictable trajectory. Employment-related costs that result in exclusion from or only a marginal attachment to the labour force are most evident for caregivers (notably women) with significant long-term care responsibilities that begin in the early stages of their earning career.

Resources are low for certain caregivers and caregiving situations. These include caregivers with health problems, limited income and savings, and compromised capacities for sustaining full-time employment. High caregiving demands also increase risk. Especially relevant are increasingly complex care demands for individuals with health conditions or medical problems that require intensive involvement on the part of caregivers; care for individuals with dementia, serious mental illness, deteriorating functional capabilities and problematic behaviours; and long-term, intense caregiving. The gendered impacts of caregiving are also highly visible in the research, and should not be ignored.
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EXECUTIVE SUMMARY

The purpose of this project was to summarize existing knowledge on the risk factors associated with negative outcomes for family and friend caregivers, and to identify knowledge gaps and policy-relevant research questions. The literature reviewed includes Canadian and international research based on large national surveys and in-depth studies of specific samples of caregivers and their experiences. The emphasis is on material published since 2000.

Identifying how various risk factors combine to affect a variety of different outcomes is a challenging task, since different risk factors appear to be more salient for different outcomes and populations of caregivers/care recipients. Moreover, it is important to consider the longer-term consequences of caregiving, as well as those that are more immediate to a particular experience or particular care recipient at one point in time. Given both the complexity of the issues and significant knowledge gaps stemming from the lack of data that includes the caregiving context and impacts over time, we have focused on clearly identifying the potential costs (outcomes) that caregivers may experience and the risk factors that are evident in the literature. The review includes examples of the interplay among these risk factors in several different situations including care for seniors with and without cognitive impairment, care for children with disabilities, care for a family member with a mental illness, and (to a lesser extent) care for non-senior adults. The focus of the review was on risk factors related to providing long-term family/friend care.

Negative outcomes that might be experienced by family/friend caregivers.

The organizing framework for this review is a taxonomy of the costs that may arise from the performance of caregiving tasks. Categories of caregiver costs include:

1. Economic costs: foregone income and benefits related to constraints on employment, out-of-pocket expenditures, and the costs of time spent caregiving.
   a. Employment-related costs include: job loss or early retirement, reduced or restricted work hours and work involvement, work absences, lost productivity, and opportunity costs as a result of foregoing training, a promotion, or overtime. Employment costs, in turn, often result in reduced income, lost benefits, and longer-term financial costs due to reduced savings and pension benefits. The scope/magnitude of costs differs based on the life course experiences of caregivers (the extensiveness, timing and duration of reduced employment opportunities, income, benefits and savings).
   b. Out-of-pocket expenses result from covering costs for the care recipient and from incurring costs related to the provision of care. Costs include: purchases of goods and services for the care recipient and caregiver, household adaptation and upkeep, money transfers, and transportation costs. The scope/magnitude of costs are poorly understood, though they may be especially high for parents of children with disabilities, caregivers to persons with mental illness, and for prescription drugs, treatments, and special aids.
   c. Unpaid labour costs result from time spent by caregivers in care management, emotional support and monitoring, and in providing direct services to care receivers. The scope/magnitude of costs show high levels of variability, but may include round the clock labour based on the need for vigilance or high levels of intervention.
2. **Non-economic costs**: impacts on caregivers’ physical health and emotional well-being, caregiving strain leading to depression, and impacts on relationships and opportunities for social interactions with others that promote social well-being.
   a. **Costs to physical health and well-being** include: injuries/physical stress related to caregiving tasks, increased illness/fatigue, and decreases in health-promoting behaviours. The scope/magnitude of costs includes both systemic and injury-related health outcomes; inadequate time for sleep, self care, and exercise; and increased risk of premature death.
   b. **Mental health/emotional well-being costs** include depression and anxiety, caregiver strain or distress, and a reduced sense of quality of life (life satisfaction). The scope/magnitude of costs shows that emotional consequences of caregiving are widespread, especially among those caring for family members or friends with a cognitive impairment/dementia or mental illness.
   c. **Social well-being costs** include social isolation, decreased social activities, disruption of daily routines, and reduced socializing with neighbours, friends and others due to the demands of caregiving. The scope/magnitude of costs shows that social costs may be high regardless of the caregiving situation.

**Major risk factors for experiencing these outcomes are:**

a. **Characteristics of caregivers** (including gender, age, culture/language, and employment status). Findings show complex relationships of these characteristics to costs. For example, caregivers who have other life roles (spouse/partner and parent) experience costs related to managing multiple roles, but also some benefits from having more support and positive experiences in other roles. Employed caregivers experience work and time-related costs, while caregivers who are not employed are at risk of reduced income and social isolation.

b. **Characteristics of care receivers** (including age, gender, marital status and nature of illness/disability). Care recipients’ functional capacities, cognitive capacities, problem behaviours, deterioration, pain, depression, and illness trajectory influence caregiving intensity and costs. This general statement applies across a wide range of illnesses and conditions, including dementia, cancer, and brain injury.

c. **Characteristics of the caregiver-care receiver dyad** (including the nature of kinship or friend/neighbour relationship, the quality and closeness of the relationship, and distance versus co-residency). The nature and quality of the relationship is an important determinant of a variety of costs. Co-resident caregivers are most likely to be heavily involved in all aspects of care, which may put them at greater risk for non-economic costs, while commuting caregivers experience employment and time costs.

d. **The context and nature of caregiving** (including family context such as shared care, other caregiving responsibilities, and the intensity, duration, and trajectory of caregiving). Contextual issues leading to high costs include being a rural caregiver, having poor access to formal services, having multiple, demanding roles, and having unsupportive
relationships with family and friends. There is limited research that reflects the potential life-time or long-term accumulation of costs associated with either long-term caregiving or intensive caring for a period of time in the life course.

Which caregivers are especially vulnerable to negative consequences, and under what conditions is this most common?

There is a considerable volume of research studies on the incidence of caregiving, about the types and amounts of care provided, and about the consequences of caregiving for family members and friends. However, the breadth and depth of knowledge varies substantially across groups of caregivers. Most is known about those caring for seniors; somewhat less is known about those caring for children with chronic illness or disability; and much less is known about those caring for non-senior adults with a chronic illness or disability and family members with a mental illness.

Multiple factors, operating together, affect the nature and intensity of caregiving, and the degree to which caregiving demands become stressors or stressful for caregivers. High caregiving costs result when caregiving demands exceed caregivers’ resources. Exacerbating factors include lack of support from family, friends and formal/professional caregivers, limited personal or family financial resources, high financial costs, stigma in the case of caregivers of individuals with a serious mental illness or diseases such as HIV/AIDS, and caregiving of long duration and/or with an uncertain or unpredictable trajectory. Employment-related costs that result in exclusion from or only a marginal attachment to the labour force are most evident for caregivers (notably women) who have significant long-term care responsibilities that begin in the early stages of their earning career.

Resources are low for certain caregivers and caregiving situations. These include caregivers with health problems, limited income and savings, and compromised capacities for sustaining full-time employment. High caregiving demands also increase risk. Especially relevant are increasingly complex demands related to providing care to individuals with health conditions or medical problems that require intensive involvement on the part of caregivers; care for individuals with dementia, serious mental illness, deteriorating functional capabilities and problematic behaviours; and long-term, intense caregiving. The gendered impacts of caregiving are also highly visible in the research, and should not be ignored.

Key knowledge gaps are evident in a number of areas.

Significant data gaps exist, resulting in reduced ability to address many of these knowledge areas. Main knowledge gaps are:

- How various risk factors operate in combination to affect caregiving, as well as caregivers’ health, emotional and social well-being, financial costs and employment;
- The factors that affect caregiving networks and how they function;
- How family and friend caregivers experience partnership with service providers and/or are affected by lack of access to supports and services for themselves and the person(s) they are caring for;
- The experiences of those who provide care at a distance;
- Cultural differences in caregiving expectations, experiences and access to support; and
- Caregiving trajectories and their impacts on caregivers over the long term.
Significant data gaps exist, resulting in limited ability to understand how care networks, function; the long-term impacts of caregiving, especially those that affect employment and pension benefits; and the complexity of factors that affect caregiver outcomes. The tendency to rely heavily on household surveys and cross-sectional data -- typically about individual caregiver-care recipient dyads-- are factors that affect existing knowledge. A mix of well-designed quantitative and qualitative studies is recommended, as is attention to populations that are under-represented in current research such as parents of children (including adult children) with disabilities, and caregivers to non-senior adults with disabilities, chronic illness or mental problems.

**Key policy-relevant research questions and directions include:**

a) What characterizes optimal family/friend caregiver-service provider partnerships and how might they be achieved in light of the complexity and diversity of care relationships?

b) Do public policies affect the size, composition or organization of care networks? In what ways do existing policies and services strengthen or undermine the capacity of caregivers, or of the care network?

c) Under what circumstances are caregiving and care receiving voluntary? Do current constructions of care reflect lack of consideration by policy makers of health promotion and long-term consequences for caregivers?

d) To what extent do policies differentially affect different types of caregivers or networks?

e) How might public policy address the changing needs of care receivers and the changing capacities of caregivers over time, including important family and residential transitions?

f) What policy options and workplace practices could provide more flexibility and support for employees with significant caregiving responsibilities?
The Interplay of Risk Factors Associated with Negative Outcomes Among Family and Friend Caregivers: A Synthesis of the Literature

1. Introduction

The primary purpose of this project is to summarize existing knowledge on the risk factors, and the interplay among risk factors, associated with negative outcomes for family and friend caregivers. Additional purposes are to identify knowledge gaps in this area and to identify policy-relevant research questions.

This literature review identifies those risk factors and conditions - and the interplay among them - that make caregivers most vulnerable to specific adverse outcomes or costs. As such, it is intended to be useful for suggesting policies and practices to prevent or ameliorate serious consequences for caregivers’ health, social and emotional well-being, and financial security.

A combination of factors including population aging (specifically the large increase in the proportion of the population 80 years and older), medical advances that enable persons with significant disabilities and health problems to live longer, policy decisions that have favoured community care for the disabled, and significant reductions and constraints in health care and home care services define the current context in which a growing proportion of Canadians are, or will be providing significant support to an ill, aging or disabled family member. Indeed, some scholars view caregiving as a role in the life course that one is likely to enter and exit once or several times during adulthood, with consequences resulting from a variety of factors that affect one’s role and experiences (Moen, Robison & Fields, 1994).

While individuals may willingly provide care and support to close friends and family members and derive satisfaction from doing so, caregiving can result in significant personal costs to caregivers and to their families that can compromise the quality of care provided and the sustainability of family and friend caregiving. Significant health consequences; guilt, depression and anxiety; marital/family conflict; more limited opportunities for social interaction with others - sometimes leading to isolation; increased out-of-pocket expenses and employment-related costs (absenteeism, reduced hours, work-family conflict, having to quit work or turn down opportunities) are evident in various studies of caregivers. Yet not all caregivers are affected to the same degree or in the same ways. Despite considerable research, there has been little synthesis of the findings, and models of the processes that affect caregiving experiences and outcomes remain under-developed. Understanding (i) which risk factors, conditions, and combinations among them are most likely to have serious consequences for caregivers, and (ii) how stressors, resources, and caregivers’ appraisals of their experience affect them and others is an important goal that can help policy makers, physicians, and providers of community-based services support caregivers and care recipients more effectively.
Our experience in reviewing this literature confirms that these goals are quite challenging for several reasons. First, the nature of the subject matter is complex given the variety of possible combinations of stressors, supports and caregiving-care recipient experiences and contexts – only a portion of which can be included in any one study. Secondly, the needs and capacities of both caregivers and care recipients change over time and this is not captured in most research studies, nor is the concept of a caregiving trajectory. Thirdly, the research on family and friend caregivers tends either a) to provide broad social data based on national surveys that contain limited specific information about caregivers’ experiences, or b) to focus on particular clinical samples of primary caregivers to individuals with a particular illness or condition, often absent of analyses of shared care with others, the caregiver’s employment and socioeconomic characteristics, and the social and service context in which care takes place. Fourth, there is limited information on how caregivers function as part of a network or care system with other family members, how costs are shared among family members, or how relationships with health care professionals, home care providers and other services affect caregiving and caregiver outcomes. Finally, there is a dearth of longitudinal research which is necessary for fully appreciating long-term outcomes and the accumulation of caregiving costs.

These factors make synthesizing the research on how the interplay of risk factors affects caregiving outcomes very challenging. Given these challenges and the limited time available for this review, we have focused on carefully describing the nature of costs caregivers may experience and the nature of risk factors that operate in combination to produce those outcomes. We also provide many examples from the literature of the interplay of risk factors related to specific caregiver costs. In our opinion, however, it is unlikely that any single model or profile could be developed of how risk factors affect caregivers, given the variety of risk factors, caregiving situations, and outcomes one wishes to predict. That having been said, it is quite obvious that circumstances that result in caregiving demands exceeding caregivers’ resources, especially in circumstances when caregivers and their loved ones have limited access to formal and informal supports, puts caregivers and the sustainability of appropriate family caregiving at risk.

The literature reviewed for this report includes Canadian and international research based on large national surveys as well as more in-depth studies of specific samples of caregivers and their experiences. We draw on research literature describing caregivers and caregiving to individuals across the life span, including care for children and adult children, spouse/partners, aging parents, close friends and other family members, and covering a variety of illnesses and disabling conditions. The research articles we have reviewed are drawn from systematic searches of the literature in social and health science journals and scholarly books across such disciplines as gerontology, disability studies, sociology, nursing, medicine, psychology, psychiatry, family science, and public health, with an emphasis on material published since 2000.

This report is organized in 7 sections:

1) Introduction
2) What is the set of negative outcomes that might be experienced by family/friend caregivers?
3) What are the risk factors for experiencing these outcomes?
4) What models currently inform research on caregiving?
5) What does the research tell us about which caregivers are especially vulnerable to negative consequences, and under what conditions is this most common?
6) What are the knowledge and data gaps in our understanding of which caregivers are most vulnerable and what conditions are most compromising?
7) Conclusions

In this introductory section we set out key definitions and perspectives that frame our review of the risk factors associated with negative outcomes among family caregivers. We define key constructs that will be used throughout the review: family/friend caregiver, care, risks, caregiver burden, stressors, resources, and outcomes. Age, gender and the nature of the caregiver-care recipient relationship are critical starting points. We set the discussion of caregiver risks and outcomes within a lifecourse framework of care given by adults to family members/friends who have a chronic illness/disability, including individuals with significant mental health problems.

1.1 Language of the report

1.1.1. We use the term *family/friend caregiver* rather than informal or unpaid caregiver. ‘Informal’ has connotations of being casual or intermittent, yet care can be intense and long term. As well, the term “unpaid caregiver” does not reflect the nature of the relationship, since family members or friends might receive some payment or compensation (for expenses, for time etc.). Family/friend care differs from formal care in that it is provided based on a personal, often long term relationship. Our focus is on family and friends who provide care on an ongoing basis who are not paid as nurses, home care providers, or assistants to people with disabilities. We distinguish family/friend care from care by voluntary sector organizations since the latter is provided because of an organization-client relationship.

1.1.2. *Care* is defined in various ways in the caregiving literature. For example, Jonsson et al. (2006) define [informal] care as lost production and leisure time of a caregiver. We distinguish care from support and define care 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, Fast, Frederick, Cranswick, & Perrier, 1999). In this context care provision is embedded within an ongoing relationship (parent, spouse/partner, child, friend). *Dimensions of care* include the nature of tasks provided, the intensity of care (hours of care per week, perceived intensity), the duration of caregiving, and whether one is caring alone or care is shared with others.

1.1.3. *Risk factors* refer to characteristics of caregivers, care recipients, caregiving demands, and caregiving situations that are associated with an increased likelihood of negative effects on caregivers’ social, health, and economic well-being. Risk factors include both objective conditions related to caregivers, care recipients, and caregiving (stressors), as well as caregivers’ perceptions or appraisals of caregiving demands or their experiences in the caregiving role.
1.1.4. Caregiver burden, caregiver strain, and caregiver quality of life are terms used in various studies to refer to caregivers’ descriptions of the ways caregiving affects their daily life and their experiences as caregivers. Self-report measures typically include items reflecting caregiving tasks (“objective burden”) and the emotional or psychological strain that caregivers experience (“subjective burden”). Current measures (e.g., the Zarit Burden Interview, the Caregiver Strain Index) include questions that cover caregiver’s health, psychological well-being, finances, social life, and relationship between the caregiver and patient/care recipient (Deeken, Taylor, Mangan, Yabroff & Ingham, 2003). While widely used as outcome measures themselves and as predictors or mediators of other specific outcomes, such as depression, these measures consider burden as a unidimensional construct and do not provide specific information about particular costs of interest in this review.

1.1.5. Resources refers both to the capacities of individual caregivers and to the supports available to them. Caregivers who are healthy, resilient, have access to financial resources, use effective coping strategies, and have support from friends, family members, and health professionals and community agencies are likely to experience less stress and fewer negative outcomes or adverse consequences of caregiving.

1.1.6 Outcomes include both short and longer-term effects of caregiving for caregivers’ health and personal, economic, and social well-being. We focus particularly on outcomes for caregivers, recognizing that there are effects that are shared with other family members, and that there are separate outcomes for care recipients, for employers, for communities, and for society at large of the extent to which caregivers are supported in their caregiving role.

1.2 Adopting a Life Course Perspective

A life course perspective views the likely consequences of caregiving and the caregiving role with respect to the developmental timing of transitions in the caregiver role, the intersection of other roles in relation to the caregiver role, and the changing historical context for enactment of the caregiver role (Marks, 1998). Having a child diagnosed with a disability is an example of a turning point in one’s life course because parents’ lives may be forever altered. These parents experience different time and care demands, economic constraints, different service needs, and have different experiences as their children age. Their experiences as parents are nonnormative, and mothers and fathers are differentially affected (Haveman, Berkum, Reijnders & Heller, 1997; Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). Parents of children who develop a serious mental illness (often first manifesting in young adulthood, age 18-25) and others who assume a major role in providing care and support to a family member with mental illness may find that their involvement is both long-term and unpredictable, given the likelihood of episodic recurrences of depression, schizophrenia and other disorders, and the possible economic, legal and social consequences that may occur. Caregivers who are young when they assume a caregiving role for a family member may incur different and longer-term costs than those who assume the caregiving role in mid- or later life. Caregiving is also different in the context of different relationships (e.g., parent, spouse/partner, adult child, friend). Gender and gender roles figure prominently in this review, both because women are more likely to provide more care and more intensive care to family members (with the
exception of care by men to their spouses), and because the consequences of caregiving are often different for men and women (Pinquart & Sorensen, 2006; Yee & Schulz, 2000).

1.3 Framing the Question

In this review, we have conceptualized risks as characteristics of caregivers, care recipients, caregiving demands, and caregiving situations that can adversely affect caregivers’ health and well-being, the quality of care provided to family members, and the sustainability of care. Caregiving, by its nature, results in various costs to caregivers in time, energy and commitment. Costs may be economic (employment-related or expenditures) or non-economic (pertaining to caregivers’ physical health, mental health, and family and social relationships). The magnitude of these costs depends on the nature of care demands and the capacities of caregivers to provide the care that is required in situations that involve more or less support to the care recipient and the caregiver. Caregiving requirements, needs and resources change over time and caregivers are often required to adapt to changing circumstances that may or may not be predictable.

We recognize that caregivers and recipients do not live in a vacuum. While much research focuses on a single caregiver-care recipient dyad, care may also be provided to more than one family member or friend at a time, and be part of life roles that include parental, partner, sibling and filial relationships, as well as involvement in employment. Care is often shared with others – both other family members (Fast, Keating, Otfinowski, Derksen, 2004; Keating, Otfinowski, Wenger, Fast, & Derksen, 2003) and various health and human service professionals (Dosman, Fast & Keating, 2005a, 2005b). The consequences of caring for a specific caregiver may very well reflect the extent to which others share caregiving tasks and responsibility. Similarly, the costs or effects of caregiving may be shared, affecting other family members and relationships. The experience of caregiving and the consequences that may result are also affected by the wider policy and social context and caregivers’/receivers’ access to services and supports.

Ideally a full understanding of caregivers’ experiences, including risk factors and their interplay, as well as rewards derived from caregiving, would be located within this wider, ecological context. We note, however, that most of the research focuses on individual caregiver-care recipient dyads that are often decontextualized and that studies are typically cross-sectional in nature. Surprisingly little research encompasses a systems perspective or acknowledges differences between caregivers and care networks that reflect different cultural backgrounds and values, urban-rural location, differential access to services, or caregivers’ economic resources or employment circumstances.

In addressing the question at hand, then - What are the major risk factors and the interplay among risk factors that affect caregivers? – we acknowledge that our synthesis of the literature is affected by the scope and quality of the research available. Our approach is to identify what we know and don’t know about the interplay of risk factors for specific outcomes for caregivers, keeping in mind the limitations of current research, the similarities and differences between different caregiving situations, and the complexity of the topic.
1.4 Methods Used for This Review

For this review, we limited ourselves to studies published in English mainly between 2000 and 2007. Literature searches were done using several databases including PsychInfo and Medline with a variety of keywords. More than 700 published articles and book chapters were originally identified. We selected for further review only those articles that provided specific information about caregivers that could help us identify risk factors and their interplay. Additional articles and reviews (usually from 1995-1999) were included that were frequently cited in the more recent literature.

A further breakdown of types of caregiving was adopted using a lifecourse perspective, though lifecourse phase and chronic illness or disability do not always correspond closely. Thus, care to older adults normally includes care of family members with Alzheimer’s disease or other dementias; however, care for individuals with a mental illness can occur across the lifecycle, as can care to people with intellectual disabilities. While care for family members with cancer or other serious diseases most often is care to adults, these diseases also affect children. Ultimately, we found it useful to consider several major groups: care for children and adult children with a physical or intellectual disability or chronic health problem, care for family members (often adult children) with a mental illness, care for non-senior family members with a chronic illness or disability, and care for seniors, including those with Alzheimer’s disease or other dementias, and those who are frail. We did not focus on particular diseases or on end-of-life or palliative care as such.

2. Negative Outcomes Experienced by Family/Friend Caregivers

The organizing framework for this section is a taxonomy of the costs that may arise from the performance of caregiving tasks developed by Fast, Keating and their colleagues at the University of Alberta (Fast, Williamson & Keating, 1999). The model was originally developed to identify the set of economic and non-economic costs that family/friend caregivers may experience as a result of providing elder care and builds on Keating and Fast’s research on the factors that influence the extent and nature of caregiving provided to seniors in Canada. We have updated the taxonomy to incorporate new empirical findings on the costs of care and broadened it to include outcomes for those caring for family members/friends across the lifecourse.

The following section describes the set of costs or outcomes included in the revised taxonomy (see Figure 1). For each of the categories of cost, we provide a definition and short discussion of current understandings of the scope of the cost. Most information on the scope of costs for caregivers to frail older adults comes from analyses of Statistics Canada General Social Surveys on Aging and Social Support. Information on the scope of costs for caregivers of people with mental illness mainly comes from a recent survey of primary caregivers to people with mental illness (Health Canada, 2004). Information on costs to parents of children with disabilities is drawn from analysis of data from the Participation and Activity Limitation Survey (PALS) 2001 and selected studies.
Figure 1: A Taxonomy of Costs Incurred by Family/Friend Caregivers

Costs to Family/Friend Caregivers

Economic
- Employment Related
  - Reduced Income and Pension
  - Loss of Benefits
  - Increased Family-Work Conflict and Productivity Loss
- Out of Pocket Expenses
- Unpaid Labour
  - Purchases for Care Recipient
  - Household Adaptation
  - Purchases for Caregiver
- Money Transfers
- Transportation Costs

Non-Economic
- Physical Health and Well-being
  - Injuries/Physical Stress
  - Increased Illness/Fatigue
- Mental Health / Emotional Well-being
  - Depression, Anxiety
  - Reduced Quality of Life
- Social Well-being
  - Relationships
  - Activities/Social Participation/Isolation

Lero, Keating, Fast, Joseph & Cook
Categories of caregiver costs include:

1. **Economic costs**: foregone income and benefits related to employment, out-of-pocket expenditures, and the costs of time spent caregiving.
   a. **Employment-related costs** result from foregone employment, taking a leave of absence (usually unpaid), reducing or restricting work hours, seeking a less demanding job, taking early retirement, turning down a promotion, refusing overtime, and work-related impacts of family-work conflict. In some cases, individuals may take more work home or change from being an employee to self-employment to provide more flexibility, although the latter option typically results in greater income insecurity. These employment-related costs include:
      i. reduced income
      ii. lost benefits for one’s self and family members
      iii. longer-term economic costs due to reduced savings and pension benefits

Scope/magnitude of costs: Cumulative lifecourse experiences of parenting children with developmental disabilities increase the risk of experiencing negative economic outcomes that extend into later life. These negative economic outcomes include reduced economic well-being, lower savings and reduced personal and family income, interruptions in employment patterns and reduced likelihood of having permanent, full-time jobs (particularly for mothers); however home ownership, home equity, and mortgage amounts may not be affected directly (Brehaut et al., 2004; Parish, Seltzer, Greenberg & Floyd, 2004). Findings from the 2001 Participation and Activity Limitation Survey (PALS) demonstrate that among children 5-14 years of age with mild to moderate disabilities, 40% had family members who experienced an impact on their employment; this figure rose to 73% for children who had a severe or very severe disability. When children had severe or very severe disabilities, parents worked fewer hours in 47% of the cases, 44% changed work hours, 42% did not take a job in order to provide care, 30% quit working at some point, and 26% turned down a promotion or a better job. In the majority of families, mother’s employment was most affected (Statistics Canada, 2003). Similarly in the United States, Lukemeyer, Meyers, and Smeeing (2000) found that 19% of all mothers reported being unable to work outside the home due to extensive care needs of their disabled child. This number rose to 34% for mothers of severely disabled children who said they had to stop work entirely. Single mothers with children with a disability are likely to be most affected if their employment is restricted. In such cases, they may have little recourse other than to rely on social assistance. Families with children with disabilities have lower incomes than families with no children with disabilities, and also typically have higher expenses (Statistics Canada, 2003).

Caregivers to older adults and to adults with mental illness also experience substantial economic costs. Several U.S. studies confirm that employment costs may be especially substantial. For example, Covinsky et al. (2001) found that 22% of older American adults “had at least one caregiver who either reduced the number of hours they worked or quit working to care for the older adult” (p. M707). Wakabayashi & Donato (2005) also found that caregiving leads to significant reductions of weekly work hours and annual earnings for women and that these costs are cumulative and long term.
Few attempts have been made to monetize the economic consequences of care, but in one well-known pilot study of caregivers to seniors in the U.S., lifetime losses of income, government pension benefits and private pension benefits were estimated at $1,034,117 per caregiver (Mature Market Institute, 1999). This estimate was based on in-depth interviews with a subsample of caregivers age 45 or older in 1998 who provided at least 8 hours of caregiving per week and who had made some type of work adjustment as a result of caregiving responsibilities. Estimates of income loss were based on the caregivers’ actual wage rates and, whenever possible, estimated losses were based on calculations of what the individuals would have received in lifetime wages, earnings and benefits in the absence of caregiving-related reductions in their labour force involvement.

Evandrou and Glaser (2003) similarly found that 20% of midlife British women who had ever had caring responsibilities reported having left paid work altogether, and another 20% reported that they worked fewer or restricted hours and/or were earning less. In that study, carers who left their jobs to provide care were less likely than other employees to have employer-provided pensions and had contributed for fewer years than those who continued working, which had direct implications for their pension benefits in later life. Canadian data show that in 2002, 240,000 employed caregivers reduced their hours of work and at least 20,000 more quit their jobs to provide eldercare (Walker, 2005), but research monetizing any of the economic consequences of caregiving is in its infancy in Canada.

Health Canada (2004) found that 40% of Canadian caregivers to persons with mental illness are not employed, although there is limited information about their lifetime employment-related economic costs. Cook (2007) suggests that lifetime employment-related costs for caregivers to persons with mental illness may be higher than for eldercare providers because of the longer duration and unpredictable nature of care. Most (84%) employed caregivers to persons with mental illness do incur employment-related costs due to employment disruptions (Health Canada, 2004). These disruptions arise, in part, from the unexpected and episodic nature of crises or relapses among individuals with a mental illness, resulting in the urgent need for a friend or relative to provide care at short notice (Cook, 2007). These caregivers are likely to lose work time and opportunities for advancement that involve working overtime, socializing with work colleagues, and participating in learning sessions or skill development opportunities (Appelbaum, Bailey, Berg, & Kalleberg, 2002).

b. Out-of-pocket expenses result from covering costs for the care recipient and from incurring costs related to the provision of care. These costs include:
   i. purchases of goods and services for the care recipient
   ii. household adaptation and upkeep
   iii. purchase of goods and services for the caregiver
   iv. money transfers
   v. additional transportation costs

Scope/magnitude of costs: Relatively little is known about the extent of out-of-pocket expenses of caregivers to frail seniors, with the exception of care to those at end of life. When care needs of those with terminal illness are high, families in the US reported spending 10% of household income on health care, taking out loans or mortgages,
spending their savings or working additional job/hours (Emanuel, Fairclough, Slutsman & Emanuel, 2000). A recent study of caregivers of breast cancer patients in Ontario reported cumulative out-of-pocket costs averaging $6,581.60 per caregiver, with the largest expenditures for prescription drugs and home help. Out-of-pocket costs (particularly for prescription drugs) were considerably lower for those covered by extended health insurance (Grunfeld et al., 2004).

A large share of caregivers to persons with mental illness (58%) incurs out-of-pocket expenses (Health Canada, 2004). According to the Canadian Mental Health Association (2001), “most people with serious mental illness are not employed” (p. 20). They are unlikely to have accumulated financial resources that may offset some of the costs of care, leaving caregivers to pay costs associated with the care receiver’s decisions and actions (Cook, 2007).

\textit{c. Unpaid labour costs} result from time spent by caregivers in care management and in providing direct services to care receivers. Unpaid labour costs often are operationalized as time spent on different care tasks (feeding, continence, hygiene, clothing, medication, indoor and outdoor transportation, supervision) (Jonsson et al., 2006).

Scope/magnitude of costs: Hours of care to older adults vary considerably. In a comprehensive study of eldercare in Canada, Keating et al. (1999) reported average hours of care per week ranging from a low of 1.3 to a high of 16.0 hours, dependent upon characteristics of caregivers (such as age, gender and marital status), care receiver and dyad (e.g., relationship of caregiver to care receiver). It should be noted, however, that there was a great deal of variability around these averages, with some respondents providing round-the-clock care. Those who were primary caregivers, providing end-of-life care, and caring for a close relative (spouse or parent) spent the most time caring. Unpaid labour is most commonly monetized using the hourly wage for replacement labour. Using this approach, Fast & Frederick (1999) determined the unpaid labour costs of eldercare in 1996 to be the equivalent of 275,509 full-time employees, the aggregate cost of which was estimated at between $5.1 and $5.7 billion.

Expectations are that these hours spent in care will increase in coming years. A recent Canadian study highlighted the large amounts of time and effort that were spent trying to find suitable services, the additional time costs incurred because of difficulty obtaining information about services, and the inflexibility of those few services that are available (Wiles, 2003).

The amount of care provided to children with disabilities can be high because of the nature of the disability and the long-term care requirements. Time may be required on a daily basis to assist with activities of daily living, as well as supporting children’s participation in child care, school or social activities. Additional time is often required to accompany the child for medical visits and therapeutic appointments and in finding suitable supports and services. Time demands can result in limiting parental employment or foregoing it entirely, reducing family income.
Little is known about the amount of unpaid labour being invested in care to persons with mental illness. One European study reported more than 32 hours per week of contact between European caregivers and persons with schizophrenia for whom they were caring (Meijer et al., 2004). Considering that 30% of Canadian caregivers for persons with mental illness care for that person for 11 years or more (Health Canada, 2004), the unpaid labour costs over a caregiving career must be significant. In addition, some of the care requires a high level of knowledge about assessment and illness management (Doornbos, 2001) and sometimes overlaps with care provided by professional caregivers (Clark, Xie, Adachi-Meija, & Sengupta, 2001).

3. Non-economic costs result from caregiving strain, foregone healthy behaviours (such as eating well, getting enough sleep, getting exercise), and opportunities for social interactions with others that promote social well-being.

a. Physical health and well-being refers both to the absence of disease and a state of vitality. Adverse health outcomes/costs for caregivers may include:

i. injuries/physical stress related to caregiving tasks
ii. increased illness/fatigue
iii. decrease in health-promoting behaviours, increased weight, use of alcohol and prescription medications

Scope/magnitude of costs: Caregiving can have both systemic and injury-related health outcomes for caregivers. A broad set of physical costs of caregiving has been documented. These include: lowered immune system functioning, altered response to influenza vaccination, slower wound healing, and increased blood pressure (Haley, 2003; Tsukasaki, Teruhiko, Makimoto, Naganuma, Ohno & Sunaga, 2006). Brehaut et al. (2004) reported that parents of children with cerebral palsy had a higher incidence of a variety of physical problems, including migraine headaches, ulcers, arthritis pain, and chronic health conditions compared to other parents. Compared to non-caregivers, caregivers are more likely to experience inadequate time for sleep, self care and exercise (Connell, Janevic & Gallant, 2001). These physical symptoms can combine to increase the risk of premature death. Haley (2003) found that caregivers who feel highly stressed had a 63% higher mortality rate over a 4-year period compared to non-caregivers or caregivers who did not report being highly stressed.

Constant vigilance is a frequent theme expressed by caregivers for persons with mental illness and/or dementia. Providing high-intensity care has been found by Navaie-Waliser et al. (2002) to be a risk factor for physical and mental health problems.

b. Mental health / emotional well-being costs are described as “psychological stress, poorer morale, and loss of control and independence” (Fast, Williamson, & Keating, 1999: 304). Caregivers’ costs related to emotional well-being and mental health manifest in the form of resentment over their loss of independence and control (role captivity). Stress as a result of involvement in caregiving manifests in symptoms such as feelings of guilt, anxiety, and burden. The extreme outcome of caregiver strain may be clinical depression with decrements in physical, emotional and mental well-being and an increased use of prescription drugs and alcohol in some cases (Fast, Williamson, & Keating, 1999: 310).
Adverse mental health outcomes/costs of caregiving include:
   i. depression, anxiety
   ii. caregiver strain, distress
   iii. reduced sense of quality of life or life satisfaction

Scope/magnitude of costs: Emotional consequences of caregiving are believed to be widespread. They may be experienced as a sense of being tied down, lack of time for oneself, difficulty in getting a break (Kuuppelomaki, Sasaki, Yamada, Asakawa & Shinmanouchis, 2004). Common outcomes in the literature are feelings of guilt, anger, anxiety and depression.

In their review of 41 studies published between 1990 and 1995 on caregivers to someone with dementia, Schultz, O’Brien, Bookwala, and Fleissner noted a consistent finding of elevated levels of caregiver depression. They concluded that “the population prevalence of psychiatric morbidity effects is clearly higher among caregivers, [which] suggests that the primary stressors confronted by caregivers are fundamentally psychological in nature” (1995: 788). A second conclusion was that negative effects of caregiving on caregivers’ mental health and emotional-well-being are related to caregiving tasks, and worry about the decline and anticipated death of the care receiver. Grov, Gossa, Sorebo & Dahl (2006) found that depression was the largest contributor to caregiver burden and mediated the effects of other variables on caregiver burden, such as patient symptoms and social support.

A recent survey of almost 32,000 Canadian employees in medium to large organizations revealed that approximately one in four employees can be considered to be experiencing high levels of caregiver strain (physical, financial or mental stress) as a result of elder care responsibilities. The most significant predictor of caregiver strain among employees was the amount of time they spent providing care to an elderly dependent (Duxbury & Higgins, 2005).

c. **Social well-being costs** include “increased risk of social isolation, decreased levels of social activities, disruption of daily routines, and reduced socializing with neighbours, friends and others due to the demands of caregiving. Decreased social activities can also produce a sense of interpersonal loss for the caregiver, and lead to a loss of intimacy and affection…and increased feelings of resentment” (Haley, 2003: 154). Kuuppelomaki, Sasaki, Yamada, Asakawa & Shinmanouchis describe social costs as “restricted social life…and life revolving around the home and coping with their caring responsibilities” (2004: 698). These restrictions result in feelings of loneliness, isolation, boredom and frustration. For caregivers of persons with mental illness and diseases such as HIV/AIDS, social isolation may be made worse by stigmatization (Byrne, 2001).
Adverse social well-being outcomes/costs of caregiving include:
  i. Relationship difficulties (marital conflict or estrangement, family stress, isolation from friends)
  ii. constrained activities/social participation (foregone vacations, leisure, social activities with family, friends, community involvement)
  iii. work-family conflict that may result in difficulties with coworkers or work disruption

Scope/magnitude of costs: Caregivers to older adults experience a number of social costs. In a study of 1229 caregiver-care receiver dyads in the United States, Stevens et al. (2003) found dissatisfaction with time to be alone (26%); attend church and other group activities (36%); pursue hobbies (44%); go out for meals (34%); do fun things with people (41%); or visit family and friends (30%). In a review article of research on caregiving to older adults, Haley (2003) concluded that family caregivers perceive a lack of support from family members.

Among caregivers to adults with mental illness or disability, social costs can include the breakdown of marital and long-term relationships (Ogilvie, Morant & Goodwin, 2005). More than two thirds of family caregivers to persons with traumatic brain injury report disturbances in family problem solving, communication, and roles (Ergh, Rapport, Coleman & Hanks; 2002). Earlier studies indicated high rates of separation and divorce in families with children with disabilities. More recent studies identify difficulties in communication and sharing roles equitably, in large part because of a tendency for women to have primary responsibility for children’s care and therapeutic appointments (Lero, 2006; McNeill, 2004; Quittner et al., 1998). Social costs to caregivers of children with disabilities include adverse family outcomes such as disruptions in family relationships due to increased fatigue (Rogers and Hogan, 2003) and fewer vacations or other leisure activities as a result of less time and financial resources (Parish & Cloud, 2006).

3. Risk Factors for Experiencing These Outcomes

In this section we update and expand previous work on risk factors for the negative outcomes described above. Based on our previous research and current review of the caregiving literature, we organize these factors into four main categories (See Figure 2). These are: characteristics of caregivers (such as gender, age, and employment status); characteristics of care receivers (including age, gender, marital status and nature of illness/disability); characteristics of the caregiver-care receiver dyad (including proximity, kin/friend relationship; quality of relationship) and the context and nature of caregiving (including family context such as shared care, other caregiving responsibilities, and the intensity, duration, and trajectory of caregiving).
Figure 2: Risk factors for Negative Caregiver Outcomes

Risk Factors for Family/Friend Caregivers

- Caregiver Characteristics
  - Gender
  - Age
  - Marital Status
  - Income/Wealth
  - Employment Status & Working Conditions
  - Caregiver’s Own Health
  - Culture/Language

- Care-Receiver Characteristics
  - Age
  - Gender
  - Marital Status
  - Illness/Disability
  - Rural/Remote/Urban Residence
  - Age of Onset of Disability

- Dyad Characteristics
  - Proximity
  - Kin/Friend Relationship
  - Quality of Relationship
  - Amount and type of care provided
  - Duration and Trajectory of Care

- Context and Nature of Care
  - Care arrangement shared with other family members
  - Other caregiving responsibilities
  - Social support from friends, family, and professionals

Lero, Keating, Fast, Joseph & Cook
3.1. Characteristics of Caregivers Influence Caregiver Costs

Caregiver gender has been widely studied, with gender often considered as a strong predictor of caregiving outcomes. It is important to note the difference between gendered differences in the likelihood of becoming a caregiver and gendered differences in consequences for those who already are caregivers. While the research is not always consistent, more often than not women are primary caregivers and consequences of caregiving are greater for women. Cook (2007) found that women are more likely than men to become caregivers of adults with mental illness; but among those who are caregivers, there was no significant difference in the proportion of men and women who experienced high costs as a result of caregiving. In contrast, Keating et al. (1999) found few differences in the likelihood that women and men will become eldercare providers; yet among those who do provide care to seniors, women did more unpaid labour. Wakabayashi & Donato (2005) found that care to older adults is provided mostly by women and that caregiving leads to significant reductions in weekly work hours and annual earnings for women.

Several studies note that women caregivers to older adults experience more burden, distress and depression than men, assume more responsibility for care, are less likely to relinquish caregiving, and incur greater costs in the form of foregone employment, earnings, and family-stress spillover to work (Pinquart & Sorensen, 2006; Raschick & Ingersoll-Dayton, 2004; Yee & Schultz, 2004). Women typically assume a higher level of involvement in intense personal care, and receive less additional support from others than do men (Marks, 1998). Men appear to be most involved and affected as caregivers when they are providing co-resident care for a frail partner or parent (Keating et al., 1999).

Marital status also may influence the risk for negative consequences. Sarkisian and Gerstel (2004) used the US National Survey of Families and Households to examine help given to parents. They found that being unmarried/unpartnered increases the risk of caregiver burden. Caregivers who have other life roles (spouse/partner and parent) may experience some stress in managing multiple roles, but also benefit by potentially having more support and positive experiences in other roles that can buffer the effects of stress experienced as a caregiver.

Caregiver age also is associated with the risk of experiencing negative consequences. Older caregivers may have more health limitations and less physical strength. Older caregivers who are closer to retirement are at higher risk of quitting their jobs and jeopardizing their pension income (Evandrou & Glazer, 2004); however younger caregivers may experience longer-term impacts on employment and more distress at being confined by caregiving responsibilities, especially if caring alone.

The caregiver’s employment status is another factor affecting a number of negative consequences of caregiving. Fast, Niehaus, Eales & Keating (2002a, 2002b) found that employed caregivers reported a higher incidence of health impacts, stress, guilt, out-of-pocket expenses, and social consequences than their non-employed counterparts.
There has been a recent upsurge in interest in the relevance of culture/ethnicity for caregiving. It often is argued that differences in cultural norms and values regarding felt obligation to care make caregiving a different experience for ethnic minority immigrants. For example, filial piety is often argued to be stronger among Asians and African and Latino Americans, resulting in a stronger belief that care should be provided by family (most typically daughters) without reliance on outside help (Pinquart & Sorensen, 2005). Indeed, research to date supports the notion that culturally appropriate caregiving behaviours vary from one culture to another, and individuals respond differently to support seniors with chronic conditions based on their cultural beliefs (Dilworth-Anderson et al., 2002).

The impact that immigration status has on the availability of family/friend care is unclear. Some people migrate with their relatives or for the purpose of family reunification, and they are likely to be surrounded by close family members in the new country. However, the immigration literature suggests that immigrants tend to have fewer social ties than non-immigrants and also to their previous environments. Yoshino, Fast, Lai, Dosman & Keating (2006) found few differences in the size of care networks surrounding immigrant seniors but differences were evident in the composition of those networks: they were more female-dominant, had slightly higher proportions of close kin, and a smaller proportion of employed caregivers. Recent immigrant seniors also were found to receive more care from family/friend network, even after controlling for level of disability.

There also is evidence that cultural background and immigrant status serve to reduce access to formal services (Pinquart & Sorensen, 2005). Immigrants, especially those who have arrived most recently, reportedly use fewer health care services than those born in Canada due to language barriers, lack of knowledge about the Canadian health care system, and perhaps cultural norms. As a result, family/friend caregivers of older immigrants may be under heavier pressure to provide care without support from health care professionals. In a recent Canadian study, Chinese family caregivers were found to encounter multiple service barriers. The five most commonly reported barriers (experienced by more than half the survey participants) included lengthy waiting for professionals who do not speak the service user’s language or understand the Chinese culture, services that are not specialized for the Chinese community, and service providers who are not themselves Chinese. While lengthy waiting lists are a universal problem in today’s health care system, the remaining service barriers relate to language, cultural, or ethnic differences. Caregivers at highest risk of encountering service barriers included those who were younger, reported their financial status to be less adequate, reported lower English competency, and had immigrated to Canada more recently. Native communities in Canada also frequently lack formal, community based services (Buchignani & Armstrong-Esther, 1999).

Pinquart & Sorensen (2005) also reported differences in consequences of care for ethnic minority caregivers. Their meta-analysis of 116 empirical studies, mainly from the US, showed that African-American caregivers had lower levels of caregiver burden and depression than White caregivers, that Hispanic and Asian-American caregivers were more depressed than their White non-Hispanic peers, and that all groups of ethnic minority caregivers reported worse physical health than their White counterparts. Explanations for these differences between groups are not fully developed, but are
interpreted as reflecting differences in expectations for care and support from family members, cultural norms, and coherence/dissonance between one’s values and expectations and one’s lived experience.

3.2 Characteristics of Care Receivers Influence Caregiver Costs

Characteristics of those receiving care can greatly influence the likelihood that caregivers will experience negative consequences. The majority of the research focuses on the nature of care recipients’ physical, cognitive, and behavioural capacities; illness or condition; requirements for assistance with (personal) activities of daily living; problem behaviours; and mental health.

Care recipients’ functional capacities, cognitive capacities, problem behaviours, deterioration, pain, depression, and illness trajectory influence both caregiving intensity and stress. This general statement applies across a wide range of illnesses and conditions, including dementia, cancer, and brain injury. For example, parents of children with severe juvenile arthritis and parents of children with significant mental health problems including schizophrenia are strongly affected by their child’s condition, changing and uncertain circumstances, and uncertain long-term prognosis (Cook, 2007; McNeill, 2004). In a study of family caregivers to persons with traumatic brain injury, Ogilvie et al. (2005) found that one third of caregivers had high levels of caregiver distress and more than two thirds reported disturbances in family functioning such as problem solving, communication, and roles (Ergh, Rapport, Coleman & Hanks; 2002). Rogers and Hogan (2003) point out that providing care for disabled children with self-care limitations (particularly children with asthma) leads to adverse outcomes such as sleep disruptions and sleep deprivation, which may lead to other social costs such as disruptions in family relationships due to increased fatigue (Willette-Murphy, Todero & Yeaworth, 2006).

Elevated costs of raising children with disabilities leave families with less time and financial resources for vacations and other leisure activities. Of six million disabled children in the United States in 2002, more than one-fourth lived in poverty (Parish & Cloud, 2006: 225). Lukemeyer, Meyers, and Smeeding (2000) found that a significant proportion of low-income families in the United States provide care for disabled children or children with chronic illnesses and that about 40% of children in poor families run the risk of being disabled. Almost half of the families in their sample incurred out-of-pocket costs in the month preceding their study.

Cognitive impairment among older adults is associated with a high risk of negative outcomes for their caregivers. Ory, Hoffman, Yee, Tennstedt, and Schulz (1999) found that caregivers for adults with dementia in the US reported higher impacts on care time, employment complications, caregiver strain, mental and physical health problems, time for leisure, and family conflict. Compared to caregivers to persons without dementia, dementia caregivers were more likely to take early retirement (5.9% of dementia caregivers v. 2.8% of non-dementia caregivers), leave work entirely (9.2% v. 5.6% of non-dementia caregivers), turn down a promotion (6.7% v. 3.1%), lose work-related benefits (7.5% compared to 3.7%) and reduce work hours (3.4% v. 6.6%). Dementia caregivers report sleeping less and having more sleep problems, lower levels of exercise, significant weight gains and a variety of adverse physical and psychological
consequences, such as high blood pressure which increases the risk of mortality (Connell et al., 2001; Patterson and Grant, 2003).

Some care receiver characteristics may be most strongly associated with economic costs. In her doctoral dissertation on care to adults with mental illness, Cook (2007) found that the care receiver’s income may affect the costs incurred by the caregiver, since higher care receiver’s income may preclude eligibility for services. A US study of caregivers to elderly persons dying at home found that they were likely to experience high rates of out-of-pocket expenses and family financial hardship (Tilden, Tolle, Drach, Perrin, 2004). A British study highlighted the significant correlation between degree of disability in children and their care needs, and financial cost. Similarly, Kuhlthau, Hill, Yucel, and Perrin (2005) found that 40% of families with children with special health care needs nation-wide in the United States experience financial burden due to direct and indirect costs of care.

Other characteristics are more closely associated with social or emotional costs. Symptoms of pain in care receivers is related to caregiver distress, particularly when families are required to learn clinical skills in the absence of available health care providers (Tilden et al., 2004). Individuals who provide care to family members with a mental illness or HIV/AIDS may be affected by the stigma attached to these conditions (Cook, 2007; Ergh et al, 2002; Haley, 2003; Vithayachokitikhun, 2006).

3.3 Dyad Characteristics Influence Caregiver Costs

Dyad characteristics include the nature of kinship or friend/neighbor relationship, the quality and closeness of the relationship, and distance versus co-residency. Research findings are not consistent in identifying whether the caregiver of a spouse, adult children, or parents of an ill or disabled child experiences more negative outcomes. Some studies suggest that older caregivers, spouse caregivers and those who are employed may experience less psychological distress than younger caregivers, including adult children. While caregiving can adversely affect employment and increase family-work conflict, employment may act as a buffer for certain caregivers, especially if one’s work is perceived positively (Edwards, Zarit, Stephens & Townsend, 2002).

Relationship is an important determinant of a variety of costs. In a study of 305 family caregivers of memory-impaired older adults, Chumblar, Grimm, Cody and Beck (2003) found that caregiving adult daughters had greater caregiver burden compared to more distant relatives but had similar burden scores to wives, sons and husbands. Being a daughter or daughter-in-law of the older adult, and/or living with the older adult are dyad characteristics associated with an increased risk of reducing employment hours (Covinsky et al., 2001).

Seltzer & Waling (2000), in a US study of caregiving transitions of wife and daughter caregivers of an older person with disabilities, found that wives were more likely to experience negative outcomes than daughters. These authors believe that older wife caregivers experience more negative outcomes because of the higher salience of the wife versus daughter role. Further, they note that wives’ leisure pursuits and family relations are compromised because her social and marital partner is now compromised, while a
caregiving daughter’s main family relationships with her husband and children remain unchanged. Seltzer & Waling also believe that daughters in midlife have other roles that provide a buffer against caregiver stresses, but wives have no such buffers.

Co-resident caregivers (most often a spouse/partner or parent) are most likely to be heavily involved in all aspects of personal care, including care at night, which may put them at greater risk for physical and mental health costs and social isolation. Tsukasaki et al. (2006) found that caregivers who provided care at night were more likely to suffer from a general sense of fatigue, physical disorders and reduced mental energy. Parents whose children with developmental disabilities or mental illness have lived with them throughout their lives also are at risk for negative consequences (Botsford & Rule, 2004; Horwitz, Reinhard, & Howell-White, 1996). Considerably less attention has been given to studying caregivers who provide care from a distance on a regular basis, which involves costs such as taking time off from work, transportation costs, and the emotional costs of trying to monitor and manage care needs and care quality (Campbell & Martin-Matthews, 2000; Smith, 2006). Keating et al. (1999) reported that caregivers living at a moderate distance from the care receiver (less than a half day’s drive away) were most likely to report that caregiving affected their social lives, their psychological well-being and their employment. They concluded that these caregivers lived close enough to be expected to help, but far enough to find the commute stressful and time-consuming.

The quality of the relationship between caregiver and receiver has seldom been explored, but in the few studies available it has been found to have a profound impact on the amount of stress caregiving produces. Poorer quality relationships are associated with more frustration, anxiety, time stress, depression and socio-economic consequences (Keating et al., 1999; Schultz & Williamson, 1991; Walker, Martin & Jones, 1992; White-Means & Chang, 1994), but less guilt and fewer adjustments to paid work arrangements (Keating et al., 1999).

3.4. The Context of Caregiving Influences Caregiver Costs

The caregiving context includes the nature and duration of care; 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.

Bedard, Koivuranta & Stuckey (2007) note that rural caregivers have higher caregiving demands than urban caregivers and, thus, are at risk for poorer health status. Limited services in rural areas mean that rural caregivers may have less formal assistance (Dobbs, Swindle, Keating, Eales & Keefe, 2004). Families with children with special needs living in rural and Northern Canada experience considerable difficulty accessing services for their children and accessing specialized respite care. In many of these communities, high proportions of First Nations and Francophone families with children with special needs lack access to the supports, services and therapies their children need (Varga-Toth, 2006).

Neufeld and Harrison (2003), in a study of women caregivers to older adults with dementia who had experienced unsupportive relationships with family and friends, found that lack of friend support led to social isolation. Many other studies have confirmed that social support for caregivers is a critical moderator of caregiving stress and family
dysfunction (Ergh et al., 2002; Savage & Bailey, 2004). Essex and Hong (2005), in a study of 126 families caring for adult children with intellectual disabilities, found that women caregivers in households in which they were satisfied with the division of other household labour had lower levels of stress.

Greenberger and Litwin (2003), in a study of family caregivers of older, community-dwelling adults in Israel, found that caregiver burden is not readily reducible given the chronic nature of caring for older adults. However, formal services can help considerably in increasing caregivers’ resources and helping them to cope. These authors found that higher levels of burden were related to lower levels of caregiver resources and suggest that resources protect against burden. Some burdened caregivers received formal support only when they were already manifesting considerable distress.

The importance of sensitive, informative support from health professionals (family-centred care) has been identified as a particularly important factor for parents of children with a developmental disability and other serious health conditions (King, King, Rosenbaum & Goffin (1999).

Wright (2000), in a UK study of community-dependent older adults who no longer were receiving family care, found that spouse caregivers who had higher levels of burden before caregiving ceased had had less home care support. Kumamoto, Arai and Zarit (2006) found that having home care services effectively reduced burden in a sample of Japanese caregivers of disabled older adults.

Evandrou & Glaser (2004), in a large-scale secondary analysis of birth cohorts of people age 49-64 in Britain, found that combining several major roles (caregiver, worker, and parent) in midlife increases risks for caregivers, particularly for women, in the long run. Economic well-being in later life is placed at risk, and there are pension penalties for caring. Combining multiple intense roles (caregiving and paid work, and parenting) also may put caregivers at risk of negative health outcomes. Similarly, having a spouse who provides care puts persons in midlife at risk of significant reductions in social participation. For men, in particular, having simultaneous intensive parental and caregiver roles put themselves and their wives at risk of having fewer social contacts.

Parish, Seltzer, Greenberg & Floyd (2004) used the Wisconsin Longitudinal study to examine the life-course impact of parenting children with developmental disabilities. They found evidence of an accumulation of negative outcomes of caregiving to children with disabilities over time. By the time parents become older, they will have substantially less income and savings in comparison to peers who did not have disabled children and didn’t care for such children in mid-life. This is particularly true for mothers who, in mid-life, have foregone employment opportunities, promotions, or full-time jobs in order to care for disabled children. As they age these mothers also are at greater risk of becoming widowed and no longer having financial and other support from their husbands. Families of children with disability continue to experience financial effects even after the death of the disabled child: government benefits, which may constitute a significant proportion of such families’ income due to parents’ forgone employment opportunities, immediately drop by as much as 72% (Corden, Sloper, & Sainsbury, 2002).
4. What Models Currently Inform Research on Caregiving?

It is obvious from the literature that “responses to the caregiving situation vary considerably, depending on caregiver vulnerability and strengths, the demands of the care situation, social support, characteristics of the care recipient, and the type and quality of the dyad’s relationship, and health” (Young, 2003: 113). The various risk factors and the taxonomy of costs identified thus far capture most of the stressors and outcomes that have been included in various research studies. Few models have been developed of the processes that explain how stressors or risk factors result in various outcomes and how such outcomes are moderated and mediated.

The most commonly cited model in the literature is one articulated by Pearlin, Mullan, Semple and Skaff in 1990, who based their Stress-Process model on earlier theoretical work on stress and coping. Their model was developed with caregivers of patients with Alzheimer’s disease in mind, but it has been widely employed by researchers studying other care situations. The model is psychological in nature and focuses particularly on explaining caregiver stress-related outcomes (depression, anxiety, irritability, cognitive disturbance), as well as physical health and yielding of the caregiver role. The model includes four domains: background and context variables (which correspond to characteristics of the caregiver and caregiving context); primary stressors (reflecting the nature and intensity of care tasks and subjective caregiving burden); secondary stressors (that include strain experienced in other roles such as employment and family relationships, as well as economic strains, and restricted social life that results from caregiving) and intrapsychic strains. The latter term refers to how one appraises one’s experiences as a caregiver and the caregiving experience. Intrapsychic strains potentially are manifested in decreased self-esteem and a reduced sense of mastery, as well as specific strains related to a sense of role captivity, loss of self and diminished competence, even while one might experience a sense of personal gain, enrichment or meaning through caregiving. Coping skills and social support are seen as important potential mediators of the outcomes or effects of the various stressors and the way caregivers’ lives have become organized around caregiving.

This model includes many of the variables studied in the literature and included in our figures, but is not as effective in explaining longer-term outcomes, and mental health outcomes take precedence over others. It also does not quite stretch to embrace a family systems approach that would allow for a more detailed understanding of shared caring.

More recently, Raiana et al. (2004) have proposed a multidimensional model of caregiving processes and caregiver burden specific to caregivers of children with disabilities. Their model includes background and context variables, child characteristics, caregiver strain and stresses, perceptions of formal care support, intra-psychic factors (self perceptions), and coping and social support as predictors of parents’ physical health and psychological health. No reference is made to economic costs, despite the fact that these are well documented as consequences of providing significant care for children with disabilities and long-term health problems.
5. What Does the Research Tell us About the Interplay of Risk Factors and the Conditions that Make Caregivers Particularly Vulnerable to Adverse Outcomes?

The research we have reviewed clearly confirms that multiple factors, operating together, affect the nature and intensity of caregiving, and the degree to which caregiving demands become stressors or stressful for caregivers. Most authors would agree that high caregiving costs result when caregiving demands exceed caregivers’ resources. Exacerbating factors include lack of support from family, friends and formal/professional caregivers, limited financial resources, high financial costs, stigma in the case of caregivers of individuals with a serious mental illness or diseases such as HIV/AIDS, and caregiving of long duration and/or with an uncertain or unpredictable trajectory.

Resources are low to start with for certain caregivers and caregiving situations. Caregivers who have health problems or are frail themselves face significant challenges in meeting the physical and psychological demands of caregiving. Caregivers who have limited personal and family income and savings face considerable hardship from foregoing employment (including employer-provided health benefits and pension contributions) and meeting significant out-of-pocket costs associated with caregiving. Longer-term financial hardship can result when caregiving extends over many years, as is the case for parents of children with disabilities and adult children with mental health problems, especially when parents’ capacities for sustaining full-time employment are compromised and the costs of medications, treatments and other expenses are high.

High caregiving demands are clearly a factor that must be considered, and several authors refer to the fact that caregivers are increasingly providing care to individuals with significant medical problems that require a level of skill in performing procedures (use of a ventilator, tube feeding, or use of a catheter or artificial bowel, for example) or monitoring change that many family members do not have or feel hesitant about. Caring for individuals with dementia, serious mental illness, deteriorating functional capabilities and problematic behaviours (aggression, in particular) affects caregiver outcomes by increasing caregivers’ perceptions of stress and burden, ultimately resulting in anxiety, depression and distress. Long-term, intense caregiving, including 24-hour care, is also an obvious stressor that is more likely to have impacts on caregivers’ physical health and well-being. The gendered impacts of caregiving are also highly visible in the research, and should not be ignored.

The research also confirms the importance of social support (perceived and enacted), socioeconomic status, and coping resources as factors that impact on caregiver distress, depression, and family functioning. Emotional costs to caregivers of older adults are exacerbated as a result of personal and social losses, and limited communication and contacts with friends, family members, and neighbours (Kramer & Lambert, 1999). This fact has often led authors to conclude that providing appropriate social support for caregivers should be a specific focus of health and human services professionals. Wiles (2003) has observed that caregivers who cannot get access to formal support may be at risk of employment-related and out-of-pocket expenses. The lack of home care and
respite care has been referred to as significant deficiencies that could support caregivers and care recipients.

Connell et al. (2001), in reviewing the impacts of dementia on caregivers, concluded that caregivers who perceived greater levels of burden, spent more hours per day providing care, and had less confidence in their ability to take care of themselves and their spouse were most at risk for experiencing negative health behaviour change” (p. 183). Ergh et al. (2002), in studying predictors of caregiver distress and family functioning in caregivers to individuals with traumatic brain injury, concluded that, in the absence of adequate social support, caregiver distress increased with longer time after injury and more serious cognitive dysfunction in care recipients. These two studies, among many others, attest to the fact that there is no single or simple profile that would likely be appropriate for identifying caregivers at greatest risk for negative outcomes. Consideration of caregiver characteristics; care recipients’ abilities, functioning and care needs; the nature and intensity of caregiving required; and the extent to which caregivers have personal, family, and community resources to support them are all important elements in accounting for the likelihood of serious adverse outcomes for caregivers as well as broader societal costs.

6. What Are the Knowledge and Data Gaps Regarding Research on Which Caregivers are Most at Risk of Negative Outcomes?

There is a considerable volume of research studies on the incidence of caregiving, about the types and amounts of care provided, and about the consequences of caregiving for family members and friends. However, the breadth and depth of knowledge varies substantially across groups of caregivers: the most is known about those caring for seniors; somewhat less is known about those caring for young children with chronic illness or disability; and much less is known about those caring for non-senior adults with chronic illness or disability and family members with a mental illness. Within this last group the literature is further divided according to type of illness or disability such that there is even greater variability in how much we know about care to non-senior adults. There are pockets of studies on care to adults with cancer, ALS, stroke, HIV/AIDS, multiple sclerosis, mental illness, and so on. We have little Canadian information on caregiving among same-sex couples or singles, but we do know that the gay and lesbian communities have formed support organizations and care services, especially for those suffering from HIV/AIDS. Synthesizing the literature across these many categories and circumstances of caregiving is very challenging, because the nature of care can be quite different in different circumstances; care demands and experiences often change over time; and each field or discipline tends to focus on particular variables of interest. As is common in any area, widely different samples, measures and methodologies are employed.

Knowledge and data gaps also reflect the strengths and weaknesses of particular research methodologies. Large national surveys, such as the GSS, provide broad self-report information about the incidence of caregiving (time spent, tasks performed, and to/for whom) and about the socioeconomic characteristics of caregivers. These surveys often
provide information about caregivers’ labour force attachment and caregiving-related labour force accommodations for a particular window of time. A weakness is that broad surveys of caregivers are often not linked to the specific characteristics of care recipients, and also fail to capture information about care networks (shared care among friends and family members) or care trajectories (care provided over a longer period of time). Statistics Canada collects information from caregivers and care receivers independently, but the information is not linked, providing limited capacity to appreciate both sides of the caregiver-care receiver relationship. Studies of caregiver-care receiver dyads, which are common in clinic samples, tend to be disease-specific and may provide detailed information about caregiver strain and the care recipient’s condition, but that information is often decontextualized from other information about the caregiver’s life, including employment, financial resources, and other family responsibilities, and also fails to uncover care networks or circumstances where the caregiver provides care and support to more than one person. Qualitative studies can provide detailed information about caregivers’ experiences, including experiences over time and situations including various types or levels of partnership with health service providers, community agencies, and family members. These studies make a unique and important contribution to the literature, but may not be given much credibility by policy makers because they are based on smaller, non-representative samples.

We also know much less about some consequences than others. For policy decision-making purposes it would be especially useful to know more than we do about the economic consequences experienced by family/friend caregivers. While we know something about the incidence of out-of-pocket and selected employment-related costs, our ability to monetize these costs is extremely limited.

A good deal of the research on family/friend caregiving is about care to close relatives, especially care provided by mothers, wives, daughters, and husbands, including those whose partner has dementia. Yet, in the two most recent national Canadian surveys on care and support (cycles 11 and 16 of Statistics Canada’s General Social Survey), distant relatives and friends comprise substantial minorities of caregivers. In fact, 24% of all care networks were made up almost entirely of distant kin and friends (Keating et al. 1999; Keating, Dosman, Fast & Koop, 2005).

Almost all of the clinic sample studies, which comprise a majority of the studies on caregivers, focus almost entirely on care dyads - usually a “primary” caregiver and one care receiver. Yet GSS data and other studies suggest that care is often provided to more than one person and that care is often shared among family, friends and others. Some recent research is starting to tell us a bit about the size and composition of care networks (Fast, Keating, Otnowski & Derksen, 2004) and some, largely theoretical work is providing a perspective on the relationships among social, support and care networks (Keating et al., 2003), but little is known about how care networks are organized, or how they come to be organized in a particular way.
We also know little about the dynamics of caregiving over time—how care needs change over the life course or over the course of a disability/illness, how caregivers’ capacity to care change over a caring career, or about the long-term consequences of either a single caregiving episode, or a career of caring.

As indicated above, surprisingly little research has taken a systems perspective which would take account of differences among caregivers and care networks that reflect different cultural backgrounds and values, urban-rural location, differential access to services, or caregivers’ economic resources or employment circumstances. Almost none of the existing research takes account of more than a very few of these characteristics simultaneously. While research on cultural diversity among caregivers is becoming more common, it is still rather scarce, especially within the Canadian context. It also tends to be rather fragmented by ethnic origin, with some cultural groups more extensively studied than others.

In part, these knowledge gaps stem from data gaps. We know less about care to non-senior adults or to children with chronic illness and disability than we do about eldercare in Canada because the last two surveys on support and care (Cycles 16 and 21 of Statistics Canada’s General Social Survey) have focused exclusively on eldercare. We know little about the groups, or networks, of caregivers surrounding persons in need of care because most research has focused on a single, “primary” caregiver. Cycles 11 and 16 of Statistics Canada’s General Social Survey are notable examples, but even they include limited information on the structure and composition of networks and nothing on their dynamics (e.g., relationships or negotiations among network members or the evolution of networks over time). On the latter point, we also lack longitudinal, or even retrospective, data on caregiving or care networks that would allow us to truly employ a life course perspective. Lack of longitudinal or retrospective data, especially data that could link different elements of the life course (such as care trajectories and employment trajectories), also limit our ability to monetize economic consequences that tend to accrue over the medium to long term and to be cumulative in nature. Socio-economic status is difficult to study because of high non-response rates on income variables and lack of data on occupation for those not currently in the labour force in national surveys. Cultural diversity tends to be studied in small, one-off studies of specific ethnic groups. While it is possible to link data on ethnic origin to cycle 16 of the GSS survey referenced above, sub-samples of individual ethnic groups are too small to support comprehensive comparative analysis.

The fact that most national surveys in Canada are household surveys exacerbates the problem. Even those surveys in which relevant data are collected miss much of the picture. For example, so-called family surveys that collect data from and about only those family members who reside in the same household do not provide a complete picture of the family network from which care may be forthcoming, or to which care may be provided. Two longitudinal surveys that are in the planning stages (the Canadian Longitudinal Study on Aging and a household panel survey) will similarly be household surveys.
In some cases the depth of knowledge required to understand the phenomena of interest is best generated using qualitative research approaches. A case in point is the need to understand the complex interplay among factors identified as putting caregivers and/or receivers at risk. Findings from largely quantitative studies reviewed in this report have proven less than helpful in understanding relationships among risk factors. In-depth interviews or case studies that are designed to reveal complexity would likely shed more light on these questions. Yet the usefulness of such research for informing policy decision making often is questioned because it is viewed as idiosyncratic and ungeneralizable.

In summary, we have noted the following knowledge and data gaps that impede theory development about risk factors and the processes that reflect the interplay among them which affect caregiver outcomes:

1. Information about caregiving for under-represented groups in the literature – specifically caregiving for adult children with disabilities, caregiving for family members with a mental illness, and caregiving for non-senior adults.

2. Information about caregiver and care receiver characteristics that may shape access to health and caregiving resources and the costs of caregiving. Such characteristics include urban/rural location, language and cultural variation, income, and the nature of formal and informal services provided, or that are lacking, that affect caregivers and care receivers.

3. Longitudinal data – both to understand caregiving trajectories and how caregiving and caregivers’ needs and experiences change over time and in relationship to transitions, such as changes in the care receiver’s living arrangements and, particularly to assess longer-term consequences for caregivers, particularly economic consequences.

4. Information about care networks, including their composition, organization, functioning, and how they change over time, and the various influences on the nature of shared care involving family members, friends and paid caregivers. The literature and current models of caregiver risks identify social support as an important moderating factor of the effects of caregiving, but more needs to be known about the nature of that support.

5. Research on how family/friend care works in partnership with, or as a complement to formal care services. Wilkins & Beaudet (2000), among others, have observed that formal care services can actually extend the capacity of the family/friend care network and that the informal network operates in concert with the formal delivery system. More needs to be understood about the stresses, strains and optimal ways to support effective shared caregiving.

6. Finally, research on caregiving should be considered within the context of employment policies, benefit programs, and workplace practices, and with respect to other public policies. Such policies affect caregivers directly (e.g., by providing or restricting the opportunity to take family leave or compassionate care leave, or to reduce or restructure work hours more flexibly; by affecting access to and the
costs associated with prescription drugs and special devices; and by providing access to information and caregiving supports, including respite and home care services. These factors can strongly affect caregiver strain, the quality of caregiving and the sustainability of family/friend caregiving.

Until better data are available, much that we need to know about caregiving and its consequences will remain hidden.

7. Conclusions

This review of the literature has confirmed the fact that there is considerable variability in the needs, capacities and supports available to family/friend caregivers of individuals with significant disabilities or chronic health problems. The research is very scattered, both across disciplines and with respect to different categories of caregivers and specific illnesses or conditions. Fortunately, there are some excellent Canadian studies of caregiving and a growing network of researchers with interests and expertise in this area.

However, there are significant gaps in our understanding of
- how various risk factors operate in combination to affect caregiving, as well as caregivers’ health, emotional and social well-being, financial costs and employment;
- the factors that affect caregiving networks and how they function;
- how family and friend caregivers experience partnership with service providers and/or are affected by lack of access to supports and services for themselves and the person(s) they are caring for;
- the experiences of those who provide care at a distance;
- cultural differences in caregiving expectations, experiences and access to support; and
- caregiving trajectories and their impacts on caregivers over the long term.

Caregiver needs and capacities are strongly influenced by caregiver characteristics, the specific needs of care receivers, and the context in which caregiving is provided. That context includes the extent to which care is shared with other family members or friends (in small or large, close or dispersed networks, that function effectively or with difficulty in meeting the needs of one or more care recipients and the primary caregiver). We also note that the context that affects caregiving includes relationships with service providers and/or community agencies - or the lack thereof. These individuals, programs, and professionals can affect the ease or difficulty caregivers experience directly (by providing caregivers with access to information and support that enhances their capacities) and indirectly (by providing therapy and support to the care recipient).

Most research focuses on the current or recent experiences of individual caregivers, with particular attention to caregiver strain, burden and psychological impacts, such as depression. The research confirms that depression is a common problem among caregivers who provide many hours of care over a long period of time, especially care provided to individuals with Alzheimer’s disease or other dementias. Considerably less research considers longer-term impacts, particularly economic and employment costs that
can result from care that precludes or severely limits employment and is of long duration. In such cases, women bear considerably more costs, as is evident in studies of mothers of children with disabilities and primary caregivers of family members (often adult children) with significant mental health problems.

While it may be tempting for policy makers and service providers to want to develop a handy screener or profile to identify which caregivers are most at risk of adverse outcomes for the purposes or prioritizing access to limited services, that approach is not likely to be very useful. While some circumstances are obvious ones where additional support is required (e.g., care for an individual who requires constant supervision, care that disrupts sleep and weakens caregivers’ health and capacities to provide responsive care, care for an individual who is deteriorating, in significant pain, and/or who manifests increasingly problematic behaviour for caregivers), other situations can also be highly problematic for caregivers and care recipients. These include care that is required over a long period of time, caregivers who are themselves limited or have health problems, and caregiving in isolation.

Each type of care presents its own challenges and stresses that require understanding. Providing access to information about conditions and care recipients’ needs in ways that are useful and supportive of caregivers’ concerns; and information about services and supports, including home care, respite care, and alternative living circumstances would likely be beneficial for many current and future caregivers. The fact that caring, care needs, and care resources change over time and require adaptation must also be considered. Appreciating how public policies, workplace practices and supports, alternative housing options, and health and human services can support caregivers is timely, as is continued research on caregiving across the life course.
REFERENCES


