# Employed Caregiving in Canada: A View from the Trenches

Linda Duxbury, PhD,
Sprott School of Business, Carleton University, Ottawa, Ontario

Christopher Higgins, PhD,
Ivey School of Business, Western University, London Ontario

## Preamble

Two decades ago (1991) we conducted our first national study of work-life conflict in Canada to “explore how the changing relationship between family and work affects organizations, families and employers.” Almost 21,000 employed Canadians participated in this research. Just over ten years ago (2001) we undertook our second national study of work-life conflict in Canada to determine how the "demographic, social and economic changes that occurred throughout the 1990's increased the percent of the Canadian working population at risk of high work-life conflict." Just under 32,000 employed Canadians took part in this study. In 2011-12 we undertook a third national study of work-life balance in Canada. Just over 25,000 employed Canadians participated in this study. Findings from this study are provided in a series of three research reports:

*Report One: Revisiting Work-Life Issues In Canada: The 2012 National Study on Balancing Work and Caregiving in Canada* was released in October, 2012. This report can be found at http://sprott.carleton.ca/duxbury/

*Report Two*: *Causes, Consequences, and Moderators of Caregiver Strain Among Employed Caregivers* uses the 2011-12 survey data to explore the link between caregiving demands, caregiver strain (emotional, financial and physical strain associated with the care of an elderly dependent) and role overload, work-life conflict, employee well-being, and organizational well-being.

*Report Three: Employed Caregiving in Canada: A View From the Trenches* uses qualitative interview data collected from in-depth interviews with 150 employed male and female caregivers to explore the costs and benefits of two forms of caregiving (eldercare, multi-generational caregiving) to Canadians and the firms that employ them. It also focuses on what can be done to reduce the strains associated with caregiving.

This series of reports should provide business and labour leaders, policy makers and academics with an objective “big picture” view on the current situation with respect to work-life conflict and employed caregiving in Canada. It is hoped that the production of three specialized reports rather than one massive tome will make it easier for the reader to assimilate key findings from this rich and comprehensive research initiative.

# Table of Contents

# Chapter One: Introduction

In the new millennium dependent care is not just a question of care for children. Demographic, social, economic, and policy changes have made family care of older relatives an issue of extreme importance to policy makers, families, researchers and employers (Sims-Gould & Martin-Matthews, 2008; Fast & Keating, 2000). The increased interest in eldercare as a 'work and family'' issue can largely be attributed to its position at the nexus of a number of important socio-demographic trends that have increased the number of elderly dependents requiring care (medical advances that enable people with disabilities and health problems to live longer, changes in health care policies and practices which have shifted responsibility for care from formal to informal caregivers) but decreased the number of potential caregivers (declining fertility, increased labour force participation of women). Taken in tandem these socio-demographic changes are increasing the probability that Canadians will simultaneously and/or sequentially be involved in combining paid employment with providing care and support to an ailing spouse/ partner, parent, in-law or other older relative. According to the Canadian Caregiver Coalition (2001), it is not a matter of "if you become a caregiver, but when." Clearly, the time is now for a definitive study on caregiving.

## 1.1 What do we mean by "employed caregiver?"

Before undertaking this research study we undertook an extensive review of the literature to put the study into context (see Report Two, Chapter Two). This review revealed a number of gaps in our knowledge about the challenges faced by employed caregivers in Canada. These shortcomings informed the development of our research program on employed caregivers.

A *caregiver* is operationally defined in this study as someone who provides a broad range of financially uncompensated ongoing care and assistance, either by necessity or choice, directly to family members who are in need due to physical, cognitive, or mental health conditions. Eldercare, is a form of caregiving that relates to the special needs and requirements that are unique to senior citizens. These definitions are consistent with those used by the Canadian Caregiver Coalition (2001) and Fast and Keating (2000). Eldercare is different from childcare in that it tends to increase in amount and intensity over the course of caregiving (Morris, 2001). The timing of care is also different. Caring for children spans many years, has a fairly predictable pattern, and change occurs slowly with time. Caregiving, on the other hand, is less predictable and varies widely in duration (Pavalko, & Gong, 2005).

The focus in this study is on employed caregivers – individuals who are caregivers (as defined above) but also engage in paid employment. Our definition of employed caregivers includes two main groups: (1) Employees with responsibilities for the care of an adult dependent, and (2) Employees in the sandwich group (i.e., people who are dealing with their own dependent children while at the same time attending to the needs of aging parents).

Family caregiving is a resource-intensive responsibility as the caregiver's time, energy and financial resources are diverted from their normal activities to caring for their loved one. Evidence indicates that caregiving is especially taxing on caregivers who are also engaged in paid employment as such individuals need to balance multiple roles and responsibilities - a balancing act that may result in higher levels of physical, mental, emotional, and economic strain. The research initiative that is described in this report was undertaken to increased our understanding of: (1) the factors that cause such strains, (2) the consequences that may arise as a result of caregiver strain, and (3) conditions that potentially moderate the relationship between the stressful conditions caregivers may experience and deleterious consequences.

## 1.2 Objectives of This Report

The first two reports in this series focused on quantitative data collected as part of the 2011-12 National Study on Work, Family and Caregiving. Quantitative data offers a number of advantages from a research perspective. It allows us to collect information from a large number of individuals which enhances the generalizability of the results. The use of reliable and valid measures and well established statistical procedures allow us to objectively examine the relationships as outlined in our model and test numerous hypotheses pertaining to caregiving. We can also do a number of between-group comparisons and identify moderators. In other words, survey data do a good job of telling us what is going on at a high level.

Survey data do, however, have a number of limitations when it comes to examining an emotional-laden, highly complex topic like caregiving, and often do not adequately answer the question of why people responded the way they did. These issues are more adequately addressed in an interview study where the researcher is able to explore people's attitudes, feelings and behaviours in greater depth. Accordingly, we undertook a follow-up interview study of a select group of caregivers who responded to our survey. The interview was designed to give us a better understanding of the role of employed caregiver (i.e., what employed caregivers do, why they do it, the joys and pressures of assuming the role of employed caregiver), why they took on the role (i.e. explore the issue of choice), the costs and benefits of being a caregiver and the kinds of support such individuals have found helped them balance their various roles work and family roles as well as the types of supports that they wished for from key stakeholders. More specifically, the qualitative data presented in this study should help researchers as well as policy makers better understand:

- why employed Canadians take on the role of caregiver.

- what activities are undertaken by employed caregivers in Canada.

- the issues and challenges facing employed caregivers in Canada.

- what factors put Canadian employees at risk with respect to caregiver strain.

- the impact caregiver strain has on employees who provide care as well as the social and economic institutions that support them.

- the kinds of support key stakeholders in this relationship (i.e., the caregiver, the care recipient, the family, the organization, governments) could offer employed caregivers to facilitate performance and reduce the costs (both financial and psychological/sociological) associated with employed caregiving.

- how factors such as gender, family type (sandwich, eldercare) and caregiving intensity influence each of the above issues.

The qualitative data presented in this report complement the more quantitative approach to caregiving that is featured in the first two reports in this series as well as help us understand why some family members find caregiving to be burdensome and stressful, while others derive satisfaction from caregiving (Montgomery, Gonyea & Hooyman, 1985). At this point in time, little is known about the causes of these variations in experiences which makes it difficult to design or target effective intervention strategies (Montgomery, Gonyea & Hooyman, 1985).

## 1.3 Structure of this report

This report is divided into 9 chapters in addition to this introduction. The theoretical framework guiding the study is presented in Chapter two. Chapter three outlines the methodology used to collect and analyze the data. Chapter four situates the study by providing demographic information on the interview respondents and the recipients of their care Chapter five discusses why employed Canadians engage in caregiving, the kinds of caregiving provided, and the consequences of such care to various stakeholders. In this study we followed the lead of researchers who study the stress appraisal process and used a scenario approach (i.e. anchor all research questions by asking respondents to answer them with respect to a specific situation where they were overwhelmed or stressed) to help us understand how people appraise and cope with caregiver strain. The findings obtained using this approach are provided in Chapter six. After looking at a very specific caregiving episode, we then deal more generally with the antecedents (Chapter seven), moderators (Chapter eight) and consequences (Chapter nine) of this phenomena. Our focus in Chapter seven is on the appraisal of caregiver strain, in Chapter eight with coping with caregiving and in Chapter nine with the consequences of caregiver strain. The final chapter of the report provides a number of conclusions with respect to how employed Canadians experience caregiving.

Given the sheer amount of data examined in this analysis it was necessary to draw up a number of protocols governing what we examined and how the data was presented. In all cases the findings obtained using the total sample are presented first. Only those responses given by more than 5% of the total sample or 10% of any sub-group are reported in the tables. After presenting the findings with the total sample we focus on the identification of substantive between-group differences associated with three contextual factors: gender, family type (sandwich versus eldercare) and caregiver intensity. Only differences of 8% or more are reported and discussed in the text.

# Chapter Two: Theoretical Framework

This study seeks to develop a theoretical model of the relationship between caregiving and caregiver strain. Our belief is that existing approaches to role analysis are inadequate for explaining the complexity of this relationship (Finneman & Payne, 1981; Gilboa et al., 2008; MacDermaid & Harvey, 2006; Thompson, Poelmans, Allen & Andreassi, 2007). Our research uses a stress based theoretical framework - the cognitive process of appraisal proposed by Lazarus and Folkman (1984) - to examine this phenomenon (note: caregiver strain can be considered to be a special type of stress). This approach is consistent with the majority of work in this area (Monroe & Kelley, 1995; Cohen et al., 1995; Thoits, 1991; Cooper et al., 2001). According to the cognitive appraisal model, distress does not necessarily result from a potentially stressful episode (i.e. caring for an elderly dependent) unless it is appraised as threatening or harmful in some way, thereby resulting in negative emotions. Positive emotions can result should a situation be appraised as 'challenging' or 'beneficial.' Thus, given a certain level of demands from a particular role or multiple roles, some individuals may experience high levels of stress from role overload and others may not. The cognitive model of stress thus provides a theoretical basis for understanding both negative and positive reactions to the employed caregiver role (Amatea & Fong, 1991; Ruddeman et al., 2002; Gilboa et al, 2008; Lepine, Podsakoff & Lepine, 2005).

Lazarus and Folkman's model is sometimes referred to as the transactional model of stress to reflect the dynamic relationship between an individual and the environment that is "appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus and Folkman, 1984, p.19). The model identifies two main evaluative appraisal forms: primary appraisal and secondary appraisal. *Primary appraisal* is defined as the evaluation of what is at stake for the person in a particular encounter with the environment (does the situation in question involve harm, a threat, a challenge and/or a benefit) and is partly defined by personality characteristics such as values, commitments, goals and beliefs about oneself and partly by situational characteristics such as novelty, predictability, ambiguity and temporal factors (Lazarus & Folkman, 1984, 1993, 1999). *Secondary* appraisal assesses the capabilities of the individual for dealing with the situation. It is also a complex process that evaluates the coping options and resources available (both personal and environmental), the ease with which they can be applied, and their potential effectiveness. Together, the primary and secondary appraisals form an iterative process and ultimately moderate the stress experienced. The concept of coping is interwoven with the appraisal process, such that coping activities will affect the ongoing appraisal process; however, theoretically it is important to keep the two concepts, appraisal and coping, separate (Cohen et al., 1995; Lazarus & Folkman, 1984).

Few studies have been conducted on the processes of primary and secondary appraisal in production of stress in the work-life area (MacDermid & Harvey, 2006; Thompson et al., 2007). MacDermaid and Harvey (2006) note that "the processes through which work, family, and perhaps other roles hinder and facilitate one another have cognitive, emotional, and behavioural elements that have not yet been fully explored" (p. 574). There is a clear need for research to examine the circumstances that contribute to the experience of stress and the process by which individuals respond to threat and challenge appraisals they encounter as an employed caregiver.

Using this model of stress as a framework for examining caregiving offers a number of benefits.

First, we can examine in more detail the process by which caregiving is appraised as stressful and in particular, how the context in which the caregiver experience unfolds determines the level of stress experienced. The objective would be to predict what characteristics of the organizational environment (employment situation), the caregiving situation (choice to care, amount; care needs of the recipient of care), or the individual (gender, family type), make employed caregiving potentially stressful and how they are likely to interact to create psychological stress. The second benefit arises from our elucidation of the impact of coping in the appraisal process. More specifically, the interview study will help to identify coping strategies and forms of support that result in positive appraisals. Third, it is hoped that this analysis will help to explain why some individuals are more likely than others to experience stress in employed caregiver situations while others will not.

# Chapter Three: Methodology

When designing this study we were guided by the recommendations given by Eisenhardt and Graebner in their seminal 2007 article in the Academy of Management Review entitled "Theory Building from Cases: Opportunities and Challenges." Following Eisenhard and Graeber's advice we:

- theoretically selected our sample
- used semi structured interviews to collect data,
- used quantitative data to triangulate and interpret key findings, and
- used content coding to analyze our data.

Future plans include using Eisenhardt's (1989) theory methodology to analyze our data and generate theory.

## 3.1 Sampling Frame

The interview sample was obtained as follows. At the end of the survey we asked respondents to give us their names if they were willing to participate in follow-up interviews designed to give us a better understanding of caregiving. Fifteen percent (n = 1175) of the 7966 individuals who filled in the "caregiver" section of the survey indicated that they would be willing to participate in our interview study.

To minimize the impact of uncontrolled confounds on the relationships under study we selected from this initial set of volunteers men and women who were: (1) married/living with a partner, (2) worked full time (i.e. 35 or more hours per week) and (3) spent at least an hour a week in eldercare.

Theoretically, we selected our sample so that we could consider the impact of three key possible caregiving differentiators: the intensity of caregiving duties, family type, and gender. Caregiving for adult family members encompasses caregiving situations where the need for care arises from a wide range of conditions: frailty that comes with aging, a variety of injuries, and many different acute and chronic illnesses (Fast & Keating, 2000). The interview sample was theoretically selected so that we could examine the impact of the care needs of the care recipient in our analysis. More specifically, we used the survey data to divide the sample into three groups (high, moderate, low) based on their caregiving intensity score[1]. We then created a list of potential interview respondents which included all respondents who met our previous criteria and reported either high or low caregiving intensity. We then subdivided the list of possible respondents into groups based on their gender and their family type (sandwich, eldercare). Respondents in the sandwich group spent at least an hour per week in childcare in addition to the one hour per week in eldercare. Our goal initially was to interview 20 people in each of the eight groups included in our sample. This was not, however, possible due to a number of reasons including the small number of men in the volunteer set reporting high caregiving intensity and the difficulty in reaching respondents and scheduling interviews within the time frame available. The final sample is as shown in Table 1.

---

[1] Caregiving Intensity was measured in this study using a modified version of the scale that was developed by Montogomery, Gonyea & Hooyman, 1985 supplemented with items from Simms-Gould & Martin Matthews, 2008.

**Table 1: Sample Distribution**

| | Sandwich | | Eldercare | | |
|---|---|---|---|---|---|
| | **Men** | **Women** | **Men** | **Women** | |
| **High Intensity** | 12 (11%) | 15 (14%) | 9 (8%) | 17 (15%) | 53 (48%) |
| **Low Intensity** | 17 (15%) | 13 (12%) | 15 (14%) | 13 (12%) | 58 (52%) |
| **Gender** | 29 | 28 | 24 | 30 | |
| | 57 (51%) | | 54 (49%) | | |

The total sample of 111 individuals is balanced with respect to gender (48% men, 52% women), caregiving intensity (48% high intensity, 52% low intensity) and family type (51% sandwich group, 49% eldercare). In fact, with one exception (males, high intensity, eldercare), the interview cell sizes were approximately equal. The fact that this group was also under-represented in the survey sample of caregivers suggests that fewer employed men find themselves in this situation.

## 3.2 The Interview

All interviews were done by telephone and recorded by three of the authors PhD students, one of which had a lot of experience in this area. We used a semi-structured interview format in this study. The interview questions were grounded in the stress appraisal framework described earlier and included the following sections: background (information on the respondent and the person(s) they were caring for), eldercare scenario, appraisal of caregiver strain, coping with caregiving, and consequences of caregiving. The complete interview can be found in Appendix A. The interview was pretested on 5 people and appropriate changes made in terms of wording and ordering. The interview took people approximately 45 to 90 minutes to complete. Most respondents noted that they found the experience to be "cathartic" and useful and thanked us for doing the study.

Also included in the interview are the prompts the interviewers were provided and asked to use whenever a respondent needed clarification. This level of specification, as well as a two hour interview training session and a monitoring of the interview process as well as a review of all completed interviews by the PhD student who had a lot of experience in this area ensured a high level of consistency with respect to how the questions were asked and the interviews conducted. After all the interviews were conducted we transcribed the tapes into word documents. Content analysis was used to analyze the data.

## 3.3 Content Analysis

The following description of content analysis is paraphrased from Busch et al`s (2012) description of the technique and can be found on the Colorado State University Web Site. According to these authors, "Content analysis is a research tool used to determine the presence of certain words or concepts within texts or sets of texts." In this case the text used was the transcribed interviews. According to Busch and her colleagues during content analysis, "the text is coded, or broken down, into manageable categories on a variety of levels--word, word sense, phrase, sentence, or theme"--and then examined using either conceptual analysis or relational analysis. This study took a conceptual analysis approach in that we "established the existence and frequency of concepts most often represented by words of phrases in a text." In conceptual analysis, a concept is chosen for examination and the number of its occurrences within the text recorded. Because terms may be implicit as well as explicit, it is important to clearly define implicit terms before the beginning of the counting process. Conceptual analysis allows the researcher to calculate the frequency with which various words, phrases, descriptors or ideas are given and then determine how these responses are associated with other variables of interest (e.g. gender, family type, intensity).

As with most other research methods, conceptual analysis begins with identifying research questions and choosing a sample or samples. Once chosen, the text must be coded into manageable content categories. The process of coding is basically one of selective reduction, which is the central idea in content analysis. By breaking down the contents of text into meaningful and pertinent units of information, certain characteristics of the message may be analyzed and interpreted. In conceptual analysis, the researcher simply wants to examine presence with respect to his/her research question (i.e. whether there is a stronger presence of positive or negative words used with respect to describing a particular situation) not in examining how they are related

In this study content analysis involved the following steps:

- Step one: Set up a spread sheet to record the data. Each row represents a different interview respondent. Each column represents a unique interview question.

- Step two: Assign each respondent a unique identifier that allows their survey data to be matched to their interview data. This linkage allows us to analyze both sets of data together, giving us a more comprehensive picture of what is going on.

- Step Three: Prepare the coding sheets: For each question in the interview we: (1) identified content categories ("buckets") that represent the responses given to a particular question (note step involved a number of iterations), and (2) assigned numeric codes to each of these categories. We then prepared our the initial coding sheet by reading 3 randomly selected interviews for each of the 8 cells within our sampling frame (see Table 1). Two researchers worked separately and then met to compare their categorization. Categorizes were merged or separated as necessary throughout the process. Multiple responses were often given for each question and recorded.

- Step Four: Three PhD students read each interview, linking codes to responses for each question as appropriate. This data was then entered into the spread sheet and the percent of the sample giving the different responses was calculated for the total sample and for each of the breakdowns of interest. Since respondents often gave multiple answers to each questions the total number of answers for each question often sums up to more than 100%. Only answers given by more than 5% of the respondents are shown in this report. Responses given by only one or two people were grouped into a category called "other" in the tables.

- Step Five: Appropriate and representative quotes were flagged for use in this report. These quotes are given in Appendix B.

# Chapter Four: Description of the Caregiver and the Care Recipient

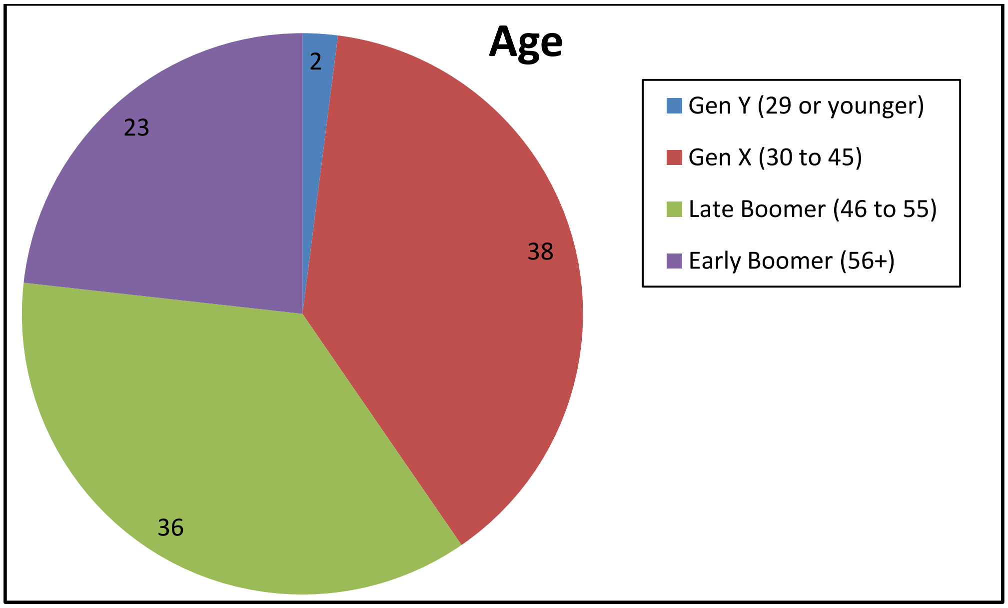
This chapter situates the study by providing demographic information on the interview respondents and the recipients of their care. The data discussed in this section comes from two sources: the survey, and the interview itself. Data on the caregiver will be provided first, followed by data on the care recipient. In all cases findings obtained using the total sample will be provided first, followed by an examination of the how gender, family type and caregiving intensity impact the results. Given the sheer amount of data examined in this analysis it was decided to focus the between-groups discussion on substantive differences (defined as differences of 8% or more) associated with these three contextual factors.

## 4.1 Employed Caregivers

The goal of this section is to examine data that gives us a better understanding of the employed caregivers in our sample. More specifically, we examine data that speaks to who they are (demographic data) the demands on their time (hours in childcare, eldercare, work), their ability to balance work and family demands, their physical and mental health, and how often they are absent from work. Data in this section comes primarily from the 2011-12 National Survey. A description of the measures used to quantify these constructs can be found in Report One (http://sprott.carleton.ca/duxbury/).

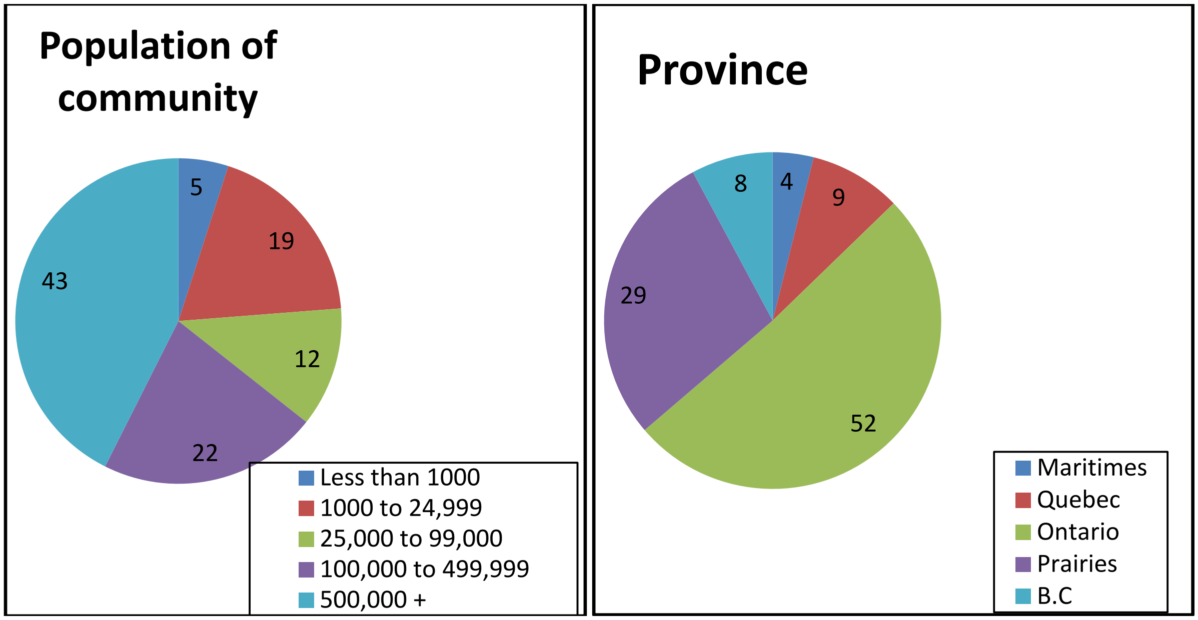
In total, 111 people took part in the interview process. The sample was well distributed with respect to age (see Figure 1), gender, family type and caregiving intensity (see Table 1).

**Figure 1: Age Distribution of the Sample**



The sample comes from across Canada and lives in a wide variety of types of communities size wise (See Figure 2).

**Figure 2: Sample: Residence**



The majority of respondents were married/lived with a partner (90%) and parents (86%). Eight percent were grandparents. As seen in Figure 3, while the majority of respondents (58%) provided care for one dependent, a substantive number cared for 2 (28%) or three (14%) elderly dependents. A plurality of the sample (44%) were parents for two children. The sample was well distributed with respect to the number of hours the parents in the sample and their partners spent in childcare (see Figure 4) with peaks at 1 to 10 hours (parents of older children) and more than 30 hours per week (parents of younger children).

**Figure 3: Sample: Number of Children and Elderly Dependents**

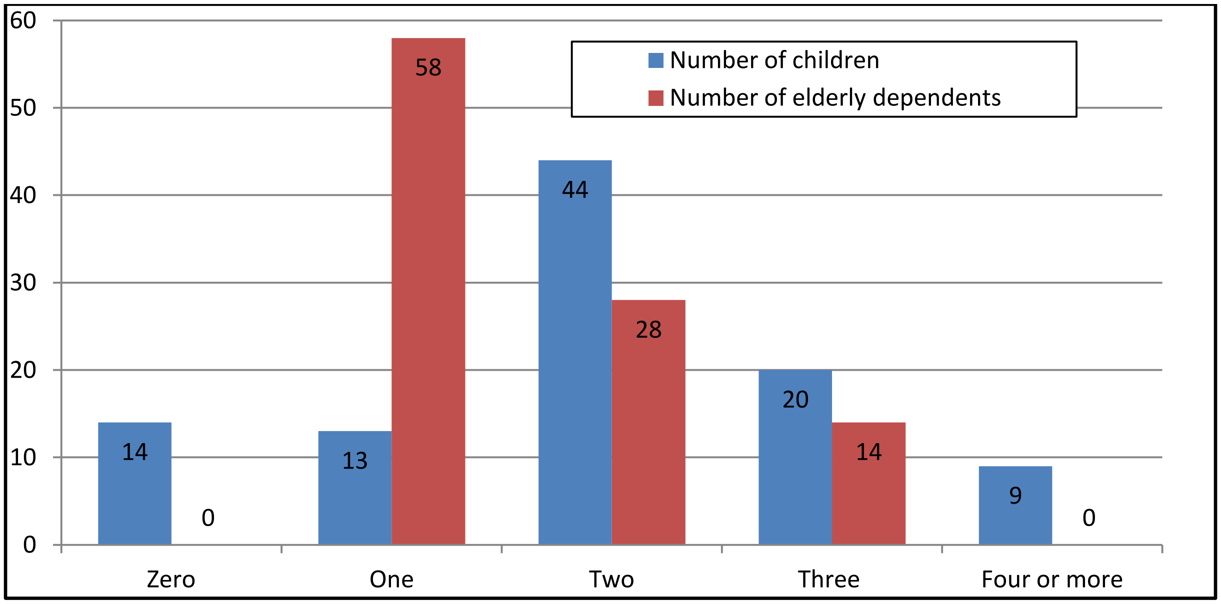
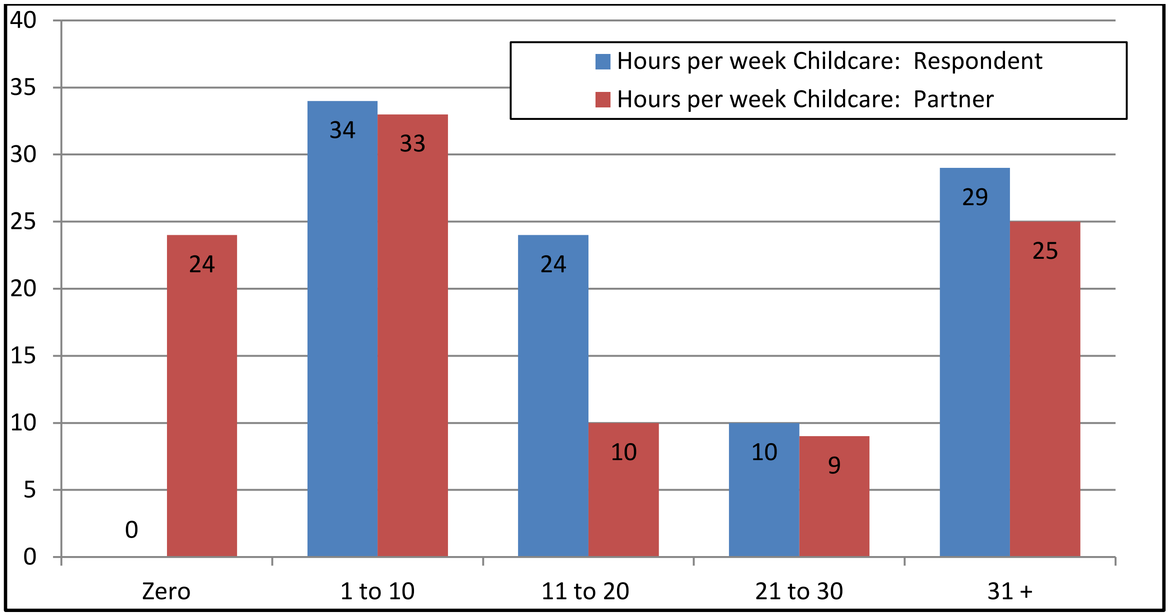
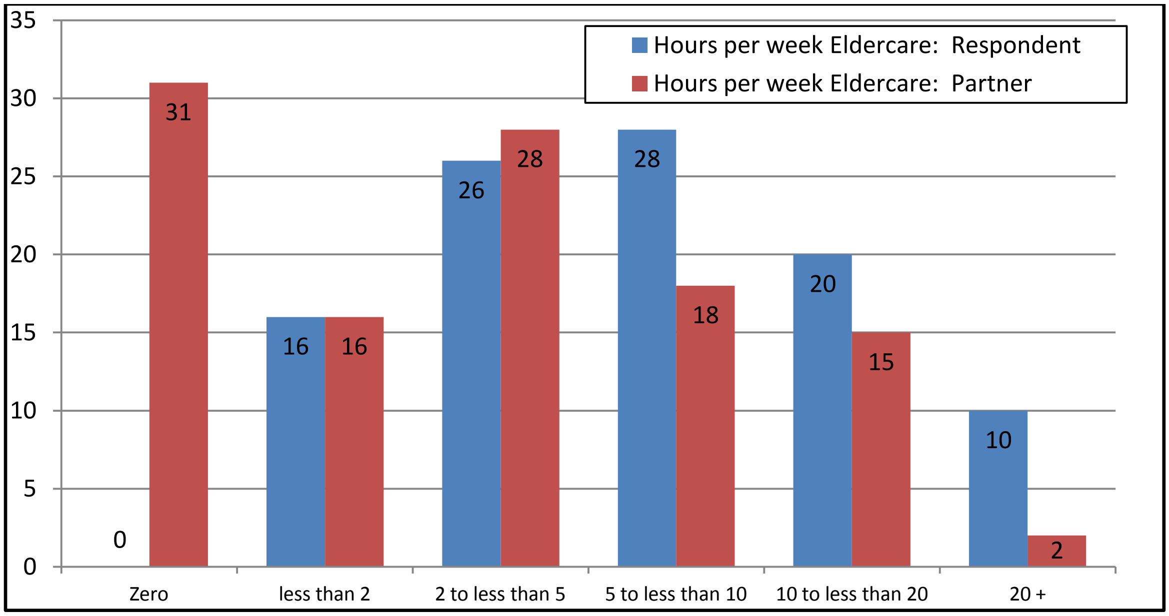


**Figure 4: Hours per week Parents in Sample Spent in Childcare**



The sample was normally distributed with respect to the number of hours respondents and their partners spent in eldercare (see Figure 5). Respondents spent an average of 10.7 (sd 13.6) hours per week in eldercare while partners spent an average of 5.6 (sd 7.1) hours per week.

**Figure 5: Hours per week Respondents Spent in Eldercare**



Other key data describing our sample is presented in Table 2. This data presents the means obtained for the total sample describing demands (hours in childcare), outcomes (employee wellbeing, absenteeism, caregiving), and moderators (perceived control over work and family, choice to care). This data will be discussed in more detail when we examine the impact of gender, family type and caregiving intensity on the respondents.

**Table 2: Characteristics of the Respondent: Survey Data**

| | **Total** |
|---|---|
| Mean hours per week in childcare: Respondent | 14.72 |
| Mean hours per week in childcare: Spouse | 22.10 |
| Mean hours in paid employment per week | 51.41 |
| **Employee Well Being** | |
| Perceived Stress | 2.84 |
| Depressed Mood | 2.36 |
| How would you describe your usual state of health? | 3.33 |
| **Impact of Caregiving on Absenteeism** | |
| Total days absent from work in six months | 9.42 |
| Days absent 6 months: emotional, physical, mental fatigue | 2.54 |
| Days absent 6 months: challenges associated with caring for an elderly dependent? | 1.94 |
| Days absent 6 months health problems? | 3.41 |
| **Caregiving** | |
| Caregiver Strain | 1.92 |
| Subjective Caregiving Burden | 2.94 |
| Caregiving Intensity | 1.93 |
| **Perceived Control** | |
| Control at Home | 3.41 |
| Control at Work | 2.82 |
| Respondent chooses to provide the care | 4.02 |
| **Overload** | |
| Total overload | 3.53 |
| Family Role Overload | 3.24 |
| Work Role Overload | 3.25 |

## 4.2 Recipient of Care

We began the interview by asking respondents a number of questions on the dependent(s) they were providing care for (see Appendix A). Responses to these questions are summarized for the total sample in Table 3. In those cases where the respondent cared for multiple dependents we asked them to think about the "dependent who occupies most of your time and energy" when respondent to questions in the interviews (the pretest indicated that the interview was much too long if we did not use this strategy).

Most respondents cared for a family member with 58% indicating that they cared for their mother and 17% their father. The fact that most (70%) care for mother or mother-in-law is consistent with the fact that women in Canada have a higher life expectancy then do men. While the mean age of the care recipient was 77.9 years of age (sd 9.3) it is interesting to note that 13% of the sample were caring for someone under the age of 65 while 23% cared for someone over 86 years of age (what is typically referred to in the literature as "the fragile elderly"). On average, the respondents have spent 6.3 years (sd 5.8) caring for this particular dependent who lives an average of 192 kms (sd 624.3) away from their house. That being said, the majority of respondents (68%) care for someone who is nearby (i.e. within 30 km of their house).

**Table 3: Characteristics of the Care Recipient**

| Relationship to Respondent | Total |
|---|---|
| Mother | 58% |
| Father | 17% |
| Mother-in-Law | 12% |
| Father-in-Law | 5% |
| Other relative | 5% |
| Other | 4% |
| **Gender of Dependent** | |
| Male | 25% |
| Female | 75% |
| **Age of Dependent** | |
| 65 and under | 13% |
| 66 to 75 | 22% |
| 76 to 85 | 42% |
| 86 and over | 23% |
| **Years Caring for Dependent** | |
| Less than 2 years | 18% |
| 2 to 5 years | 46% |
| 6 to 10 years | 22% |
| More than 10 years | 15% |
| **Distance to Dependent's House/Residence** | |
| Less than 30 Kms. | 68% |
| 31 to 100 Kms | 8% |
| 100 to 200 Kms | 6% |
| 201 to 500 Kms | 8% |
| 501 to 1000 Kms | 6% |
| 1000+ Kms | 3% |

## 4.3 Gender Differences

Data discussed in this section are given in Table 4 (characteristics of the respondent) and Table 5 (characteristics of the care recipient). Examination of these data indicate that there were no gender differences in the sample with respect to age, likelihood of having grandchildren, and the number of elderly dependents an individual cared for. It is also interesting to note that there were no gender differences in hours per week in childcare, employee wellbeing, absenteeism due to ill health, caregiver strain, caregiving intensity (probably an artifact of how the sample was selected) and control over work (see Table 4). There were, however a number of gender differences in the sample worth noting. More specifically, when compared to the women in the sample, the men were more likely:

- To be married/living with a partner (96% versus 74%),
- To have 3 or more children (37% versus 21%),
- To care for their father (23% versus 12%) or their mother in law (16% versus 8%), and

- To have a partner who spent a substantial number of hours in childcare per week,

The women in the sample, on the other hand, were more likely than their male counterparts:

- To care for their mother (68% versus 47%),
- To be absent from work because of emotional strain and eldercare,
- To report high levels of subjective caregiver burden,
- To report high levels of perceived control over their family domain, and
- To report high levels of all three types of role overload.

**Table 4: Gender Differences: Characteristics of the Respondent**

| | Male | Female | Total |
|---|---|---|---|
| Mean hours per week in childcare: Respondent | 15.51 | 14.01 | 14.72 |
| Mean hours per week in childcare: Spouse | 27.88 | 15.87 | 22.10 |
| Mean hours in paid employment per week | 53.02 | 49.94 | 51.41 |
| **Employee Well Being** | | | |
| Perceived Stress | 2.80 | 2.88 | 2.84 |
| Depressed Mood | 2.34 | 2.37 | 2.36 |
| How would you describe your usual state of health? | 3.30 | 3.36 | 3.33 |
| **Impact of Caregiving on Absenteeism** | | | |
| Total days absent from work in six months | 7.83 | 10.88 | 9.42 |
| Days absent 6 months: emotional, physical, mental fatigue | 1.23 | 3.74 | 2.54 |
| Days absent 6 months: challenges associated with caring for an elderly dependent? | 1.19 | 2.62 | 1.94 |
| Days absent 6 months health problems? | 3.42 | 3.41 | 3.41 |
| **Caregiving** | | | |
| Caregiver Strain | 1.89 | 1.95 | 1.92 |
| Subjective Caregiving Burden | 2.78 | 3.08 | 2.94 |
| Caregiving Intensity | 1.94 | 1.91 | 1.93 |
| **Perceived Control** | | | |
| Control at Home | 3.25 | 3.56 | 3.41 |
| Control at Work | 2.75 | 2.89 | 2.82 |
| Respondent chooses to provide the care | 4.17 | 3.88 | 4.02 |
| **Overload** | | | |
| Total overload | 3.40 | 3.64 | 3.53 |
| Family Role Overload | 3.15 | 3.33 | 3.24 |
| Work Role Overload | 3.10 | 3.38 | 3.25 |

Gender was not associated with the number of years caring for the dependent. It was, however, associated with the distance to the dependent's home as well as the number of hours spent in eldercare per week by both the respondent and their partner. More specifically the men in the sample:

- lived closer to the dependent they cared for than their female counterparts,
- spent more hours/week in eldercare and paid employment than their female counterparts, and
- had a partner who spent more hours in eldercare per week than the partners of their female counterparts.

**Table 5: Gender Differences: Characteristics of the Care Recipient**

| | Male | Female | Total |
|---|---|---|---|
| Years caring for dependent | 6.09 | 6.51 | 6.30 |
| Distance to dependent's home | 111.72 | 261.34 | 192.07 |
| Hrs/wk in activities for dependent | 13.77 | 8.16 | 10.70 |
| Partner Hrs/wk in activities for dependent | 6.62 | 3.34 | 5.06 |

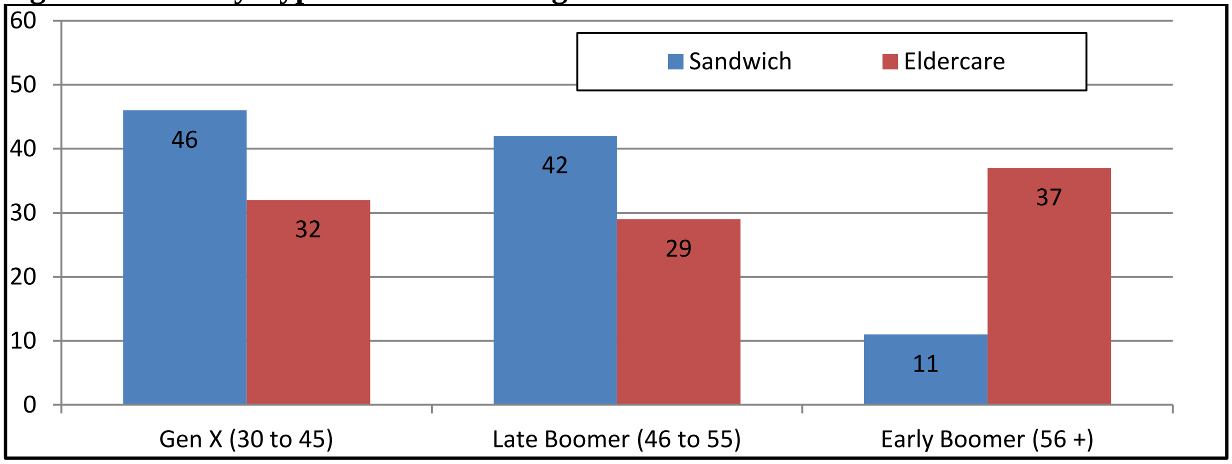
## 4.4 Differences Associated with Family Type

Data discussed in this section are given in Table 6 (characteristics of the respondent) and Table 7 (characteristics of the care recipient). Examination of these data indicate that family type was associated with most of the demographic characteristics and outcomes considered in this analysis. More specifically, compared to their counterparts in the eldercare group, respondents in the sandwich group:

- Are younger (see Figure 6),
- Are less likely to have grandchildren (15% versus 1%),
- Spend more hours in paid employment per week,
- Are more likely to be caring for 2 or more dependents (55% versus 29%),
- Are more likely to be caring for their father (22% versus 11%),
- Report higher levels of stress and depressed mood,
- Are more likely to be absent from work due to emotional fatigue and less likely to be absent from work due to physical health problems,
- Are more likely to report higher levels of caregiving intensity,
- Are less likely to report higher levels of perceived control over either their work or their family domains, and
- Are more likely to report higher levels of all three forms of overload examined in this study.

Family type is not associated with days absent due to eldercare, caregiver strain, subjective caregiver burden.

**Figure 6: Family Type Differences: Age**



## Table 6: Family Type Differences: Characteristics of the Respondent

| | Sandwich | Eldercare | Total |
|---|---|---|---|
| Mean hours per week in childcare: Respondent | 21.69 | 7.49 | 14.72 |
| Mean hours per week in childcare: Spouse | 26.86 | 14.33 | 22.10 |
| Mean hours in paid employment per week | 53.11 | 49.54 | 51.41 |
| **Employee Well Being** | | | |
| Perceived Stress | 2.93 | 2.75 | 2.84 |
| Depressed Mood | 2.46 | 2.24 | 2.36 |
| How would you describe your usual state of health? | 3.33 | 3.44 | 3.33 |
| **Impact of Caregiving on Absenteeism** | | | |
| Total days absent from work in six months | 10.73 | 8.05 | 9.42 |
| Days absent 6 months: emotional, physical, mental fatigue | 3.05 | 2.00 | 2.54 |
| Days absent 6 months: challenges associated with caring for an elderly dependent? | 1.89 | 1.98 | 1.94 |
| Days absent 6 months health problems? | 3.31 | 3.53 | 3.41 |
| **Caregiving** | | | |
| Caregiver Strain | 1.92 | 1.93 | 1.92 |
| Subjective Caregiving Burden | 2.94 | 2.93 | 2.94 |
| Caregiving Intensity | 2.25 | 1.59 | 1.93 |
| Employment Change index | 4.21 | 3.81 | 4.02 |
| **Perceived Control** | | | |
| Control at Home | 3.24 | 3.59 | 3.41 |
| Control at Work | 2.65 | 3.00 | 2.82 |
| Respondent chooses to provide the care | 4.21 | 3.81 | 4.02 |
| **Overload** | | | |
| Total overload | 3.59 | 3.47 | 3.53 |
| Family Role Overload | 3.35 | 3.13 | 3.24 |
| Work Role Overload | 3.31 | 3.18 | 3.25 |

## Table 7: Family Type Differences: Characteristics of the Care Recipient

| | Sandwich | Eldercare | Total |
|---|---|---|---|
| Years caring for dependent | 6.41 | 6.19 | 6.30 |
| Distance to dependent's home | 75.73 | 312.81 | 192.07 |
| Hrs/wk in activities for dependent | 11.27 | 10.07 | 10.70 |
| Partner Hrs/wk in activities for dependent | 5.75 | 4.30 | 5.06 |

Family type was not associated with either the number of years the respondent has cared for the dependent or the hours per week the respondent devoted to eldercare. It was, however associated with the distance that the elderly dependent lived from the caregiver (those in the eldercare group lived further away) and the hours per week spent by the partner of the respondent in caregiving (partners of those in the sandwich group spent more time in caregiving than did the partners of those in the eldercare group).

**Table 8: Caregiving Intensity Differences: Characteristics of the Respondent**

| | **Low** | **High** | **Total** |
|---|---|---|---|
| Mean hours per week in childcare: Respondent | 18.96 | 10.17 | 14.72 |
| Mean hours per week in childcare: Spouse | 29.53 | 12.26 | 22.10 |
| Mean hours in paid employment per week | 51.83 | 51.04 | 51.41 |
| **Employee Well Being** | | | |
| Perceived Stress | 2.48 | 3.23 | 2.84 |
| Depressed Mood | 1.95 | 2.80 | 2.36 |
| How would you describe your usual state of health? | 3.53 | 3.11 | 3.33 |
| **Impact of Caregiving on Absenteeism** | | | |
| Total days absent from work in six months | 8.89 | 10.01 | 9.42 |
| Days absent 6 months: emotional,, physical, mental fatigue | 2.41 | 2.68 | 2.54 |
| Days absent 6 months: challenges associated with caring for an elderly dependent? | 1.75 | 2.14 | 1.94 |
| Days absent 6 months health problems? | 2.72 | 4.18 | 3.41 |
| **Caregiving** | | | |
| Caregiver Strain | 1.32 | 2.58 | 1.92 |
| Subjective Caregiving Burden | 2.26 | 3.67 | 2.94 |
| Caregiving Intensity | 1.07 | 2.97 | 1.93 |
| Employment Change index | 1.73 | 1.97 | 1.84 |
| **Perceived Control** | | | |
| Control at Home | 3.40 | 3.43 | 3.41 |
| Control at Work | 2.95 | 2.68 | 2.82 |
| Respondent chooses to provide the care | 4.17 | 3.85 | 4.02 |
| **Overload** | | | |
| Total overload | 3.41 | 3.66 | 3.53 |
| Family Role Overload | 3.06 | 3.44 | 3.24 |
| Work Role Overload | 3.10 | 3.40 | 3.25 |

## 4.5 Differences Associated with Caregiving Intensity

Data discussed in this section are given in Table 8 (characteristics of the respondent) and Table 9 (characteristics of the care recipient). Examination of these data indicate that intensity was associated with almost all of the demographic characteristics and outcomes considered in this analysis. More specifically, compared to their counterparts in the low caregiving intensity group, respondents reporting high caregiving intensity:

- Are less likely to live with a partner (while no one in the low intensity group did not have a partner, one in four in the high intensity group were in this situation),
- Are more likely to care for their mother (68% versus 48%) and less likely to care for their mother-in-law (20% versus 4%)
- Spent more hours per week in childcare and eldercare,
- Had a partner who spent more hours per week in childcare and eldercare,
- Have spent a longer period of time caring for this particular elderly dependent,
- Are more likely to report high levels of perceived stress and depressed mood and lower levels of perceived health,
- Are more likely to be absent from work (no matter the cause),
- Are more likely to say work-life issues have had a negative impact on their productivity at work (employment changes index),
- Report higher levels of caregiver strain and subjective caregiver burden,
- Are less likely report high levels of control over their work domain, and
- Are more likely to report higher levels of all three forms of role overload.

Caregiving intensity was not, however, associated with age, hours per week in paid employment, gender of the care recipient, age of the care recipient, distance required to travel to visit the dependent, parental status and perceived control over the family domain.

**Table 9: Caregiving Intensity Differences: Characteristics of the Care Recipient**

| | **Low** | **High** | **Total** |
|---|---|---|---|
| Years caring for dependent | 5.55 | 7.13 | 6.30 |
| Distance to dependent's home | 192.20 | 191.94 | 192.07 |
| Hrs/wk in activities for dependent | 8.94 | 12.54 | 10.70 |
| Partner Hrs/wk in activities for dependent | 6.63 | 3.25 | 5.06 |

These data support the idea that employees with higher levels of caregiving intensity will experience greater problems at work. They also support the idea that caregiving intensity has a strong negative association with employee wellbeing.

# Chapter Five: Description of the Caregiving Situation

This chapter provides information gathered during the interview to help us better understand why people chose to provide caregiving, the kinds of caregiving provided, and the consequences of such care. Answers to the questions presented in the box below are provided in the following section. The findings obtained using the total sample will be provided first, followed by an examination of the how gender, family type and caregiving intensity impact the results. Again, the focus of this second discussion is on identifying the differences associated with these three contextual factors.

**Interview Questions: The Caregiving Situation**

Why have you assumed the role of caregiver for this person?

How many hours per week do you spend in activities with or for this dependent? What kinds of activities do you engage in during this time?

How many hours per week does your partner spend in activities with or for this dependent? What kinds of activities do they engage in during this time?

Looking after an elderly dependent can contribute to physical strain if the care recipient needs help with feeding, bathing etc. How often does caring for this dependent cause you physical strain? (never, monthly, weekly, several times a week or daily).

Looking after an elderly dependent can contribute to financial strain if the care recipient needs to purchase support, help pay for housing etc. How often does caring for this dependent cause you financial strain? (never, monthly, weekly, several times a week or daily).

Looking after an elderly dependent can contribute to feeling overwhelmed. How often does providing care for this dependent leave you feeling overwhelmed? (never, monthly, weekly, several times a week or daily). If they answered several times a week or daily respondents were asked " In what ways is it overwhelming?"

Note: Sample sizes are too small to report findings with respect caregiving being physically or financially overwhelming.

## 5.1 Why have you assumed the role of caregiver?

Respondents identified ten reasons for assuming the role of caregiver (see Table 10). Examination of the responses show that in many cases the reasons for taking on this type of commitment are pragmatic (i.e. I am nearest, I am the only child, there is no one else). Responses also indicate that in many cases respondents feel that they have no choice but to provide care (I have no choice, their partner cannot provide care, my siblings can't or won't provide care, the dependent was having health issues). Very few respondents (9% of the sample) stated that they wanted to take on this role ("it is payback for the care they provided to me when I was young"; "my partner is providing care - and I do it to support them").

**Table 10: Why have you assumed the role of caregiver?**

| | Total |
|---|---|
| I am nearest (physically) | 22% |
| My place in family structure (I am only child, eldest, etc) | 20% |
| I have no choice, there is no one else | 19% |
| Dependent has no partner or partner cannot provide care/needs help | 16% |
| My siblings/relatives can't or won't | 13% |
| Dependent was having health issues | 13% |
| I want to - payback for what they did for me | 9% |
| It is a shared responsibility with siblings | 8% |
| To support my partner (they were/are caring for dependent) | 6% |
| Other | 6% |

## 5.2 Caregiving activities

Respondents identified ten different activities that they engaged in that they considered caregiving (see Table 11). According to our respondents, the most common caregiving activity by far involves offering emotional support. Emotional support can take many forms but most often involves the caregiver sitting and talking to the dependent. Caregivers who live at a distance provide similar support when they "touch base" with their dependent by phone. Phone calls are also done to reassure the caregiver that "everything is alright" with the dependent.

A substantive number of respondents engage in activities that involve "running around" such as taking the person they are caring for to appointments (mostly medical) and/or running errands for them (i.e. pick up medications, do grocery shopping). In most cases this form of support is necessary because the dependent has either lost their driver's license or is too frail (mentally or physically) to take public transit. Doing housework for the dependent is also a common form of caregiving. Most respondents who talked about doing housework said that they cooked, cleaned and put out the garbage. One in four provide administrative support to their dependent (i.e. plan their medical appointments, organize their meals). A minority help out by doing physical tasks around the house (yardwork, cutting the lawn). The other two activities, the provision of physical care and financial support, were done by only one in ten of the respondents in our sample.

**Table 11: What activities do you do for the elderly dependent?**

| Activity | Total |
|---|---|
| Emotional support, companionship (sit and talk, listen) | 69% |
| Take to appointments (e.g. Doctors, chiropodists) | 45% |
| Grocery shopping and errands (pick up medications, make sure they eat well) | 44% |
| Housework (put out the garbage, cooking) | 41% |
| Talk on phone | 30% |
| Administrative tasks (organizing, planning) | 23% |
| Yard work (shoveling snow, cutting lawn, repairs etc) | 17% |
| Physical care (feeding, bathing etc) | 11% |
| Provide financial support | 8% |
| Other | 3% |

We also asked the respondent to tell us what caregiving activities were performed by their spouse/partner. Almost half the sample (41%) indicated that either their partner did not engage in any caregiving activities or that they had no partner. With one exception (no one indicated that their partner provided any form of financial support) the type of caregiving activities engaged in by the respondent's partner were almost identical to those performed by the respondent. What is important, however, is to note that partners were less likely to provide each of these forms of care than were the respondents.

**Table 12: What activities does your partner do for the elderly dependent?**

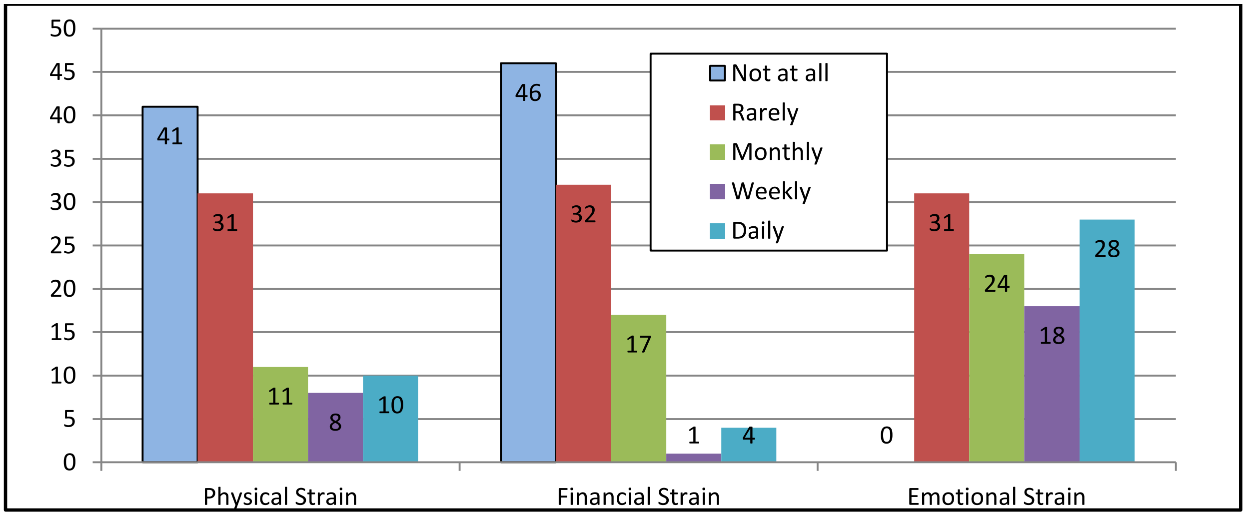
| Activity | Total |
|---|---|
| Emotional support, companionship (sit and talk, listen) | 43% |
| Partner does not help with care/no partner | 41% |
| Take to appointments (e.g. doctors, chiropodists) | 23% |
| Housework (cleaning, baking, make sure eats well) | 23% |
| Grocery shopping and errands | 16% |
| Talk on phone | 11% |
| Yard work, gardening, repairs etc | 8% |
| Administrative tasks (organizing, planning) | 7% |
| Physical care (feeding, bathing ) | 5% |
| Financial support | 3% |

In summary, the most common form of care offered is emotional support followed by activities to help the dependent with respect to health and daily living. Only a minority of the caregivers in this sample provide physical care or financial support.

## 5.3 Link Between Caregiving and Strain

Respondents were asked how often caregiving caused them physical, financial and emotional strain. Responses to these questions are provided in Figure 7.

**Figure 7: Extent to which eldercare causes different forms of strain: Total Sample**



The majority of the respondents indicated that they rarely or never experienced physical strain (72%) or financial strain (78%). By comparison, none of the caregivers in our sample said that they never experienced emotional strain from caregiving and only one in three reported that they rarely felt overwhelmed. Physical strain is reported more frequently than financial strain (18% experience physical strain weekly or more versus 5% reporting financial strain).

The data in Figure 7 support a strong link between the caregiving and emotional strain for the employees in this sample. In fact, almost half the sample reported experiencing this form of strain weekly or more. The data in Table 13 help us understand this connection. Most of the strain seems to be associated with worry about the dependent (their health, their death, the quality of care they are receiving) teamed with a lack of time for themselves and their families and the amount of work that has to be done.

**Table 13: In what ways is it overwhelming? (n = 54)**

| | Total |
|---|---|
| Emotional strain (idea of dependent dying, worries about dependents well being, quality of care, etc.) | 49% |
| I have no time for myself/ for social life/home life | 47% |
| Amount of work/coordinating/planning that had/has to be done | 31% |
| Other | 11% |

## 5.4 Gender Differences in the Caregiving Situation

Men and women have different reasons for taking on the role of caregiver and engage in a different mix of caregiving activities (see Table 14).

Women were more likely than men to feel obligated to take on the caregiving role (the dependent needs help and my place in the family structure -- the daughter - means that is it up to me to provide such care). Men, on the other hand, were more likely than women to take on the role because there was no one else who could or say that they shared the responsibility with their siblings.

Women were more likely to say that they help out by doing errands for the dependent and by talking to them on the phone. Surprisingly, it was the men in the sample who indicated that they took physical care of the dependent (feeding, bathing). This finding is opposite to what is reported in the literature and may be an artifact of the sample. It does however indicate that men provide physical care when there is no one else available to provide such support.

The women in the sample were more likely than the men to say that their partner did not provide any form of eldercare support. Those women who did receive support from their husband were more likely to note that their partner helped by doing yardwork and gardening (i.e. traditional male tasks).

The men in the sample were more likely than their female counterparts to receive support from their wives with respect to caregiving. More specifically, they were more likely to note that their partner helped by providing emotional support, taking the dependent to appointments, doing housework, groceries and errands, and providing physical care. Many of these tasks (cleaning, shopping, feeding, bathing) that they women took on have traditionally been viewed as "women's work".

**Table 14: Gender Differences in Caregiving Situation**

| **Why have you assumed the role of caregiver?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| My place in family structure (I am only child, eldest, etc) | 16% | 25% | 20% |
| I have no choice, there is no one else | 22% | 14% | 19% |
| Dependent has no partner or partner cannot provide care/needs help | 8% | 25% | 16% |
| It is a shared responsibility with siblings | 16% | 0% | 8% |
| **What activities do you do for the elderly dependent?** | | | |
| Grocery shopping & errands | 35% | 53% | 44% |
| Talk on phone | 19% | 41% | 30% |
| Physical care - feeding, bathing etc | 17% | 5% | 11% |
| **What activities does your partner do for the elderly dependent?** | | | |
| Emotional support, companionship - sit & talk | 54% | 39% | 43% |
| Partner does not help with care/no partner | 30% | 43% | 41% |
| Take to appointments (e.g. doctors, chiropodists) | 30% | 20% | 23% |
| Housework, cleaning, baking, make sure eats well | 28% | 20% | 23% |
| Grocery shopping and errands | 22% | 14% | 16% |
| Yard work, gardening, , repairs etc | 4% | 14% | 8% |
| Physical care - feeding, bathing etc | 10% | 0% | 5% |
| **In what ways is caregiving overwhelming?** | | | |
| I have no time for myself/ for social life/home life | 52% | 36% | 47% |
| Amount of work/co-ordinating/planning that has to be done | 44% | 18% | 31% |

Gender was not associated with the incidence of any of the forms of strain considered in this study - a result that is likely due to how the sample was selected. That being said, it is interesting to note that men were more likely than women to attribute their emotional strain to the lack of time they had for themselves and the amount of co-ordination and planning related to caregiving.

## 5.5 Differences in the Caregiving Situation Associated with Family Type

Employees in the sandwich group have different reasons for taking on the role of caregiver and engage in a different mix of caregiving activities than their counterparts in the eldercare group (see Table 15). They also experience different levels of strain (Figure 8).

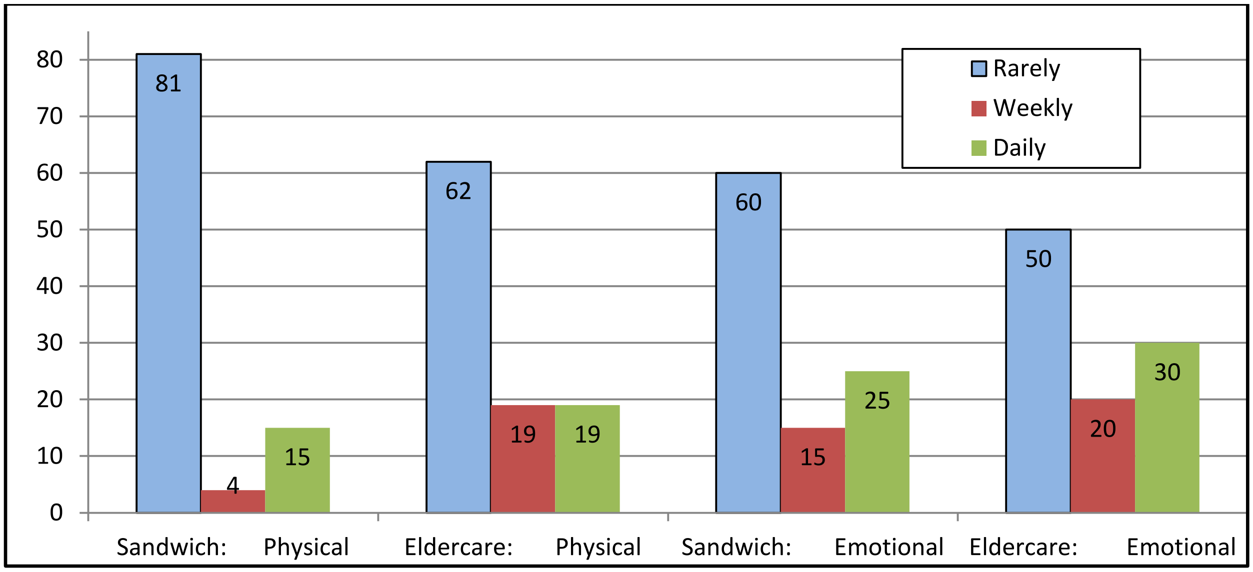
Employees in the sandwich group were more likely to say that they had assumed the role of caregiver because they lived near the dependent and because the dependent was experiencing health problems and needed care. Those in the eldercare group were more likely to take on the role because the dependent needed help and no one else could or would take on the responsibility (partner cannot do it, siblings can't or won't).

Employees in the sandwich group were more likely than those in the eldercare group to engage in four of the ten caregiving activities identified by the respondents: provide emotional support, take dependent to appointments, shop and run errands for the dependent and do housework for the dependent. Many of these activities are very time consuming. There were no cases where those in the eldercare group were more likely than those in the sandwich group to provide care.

**Table 15: Differences in Caregiving Situation Associated with Family Type**

| **Why have you assumed the role of caregiver?** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| I am nearest (physically) | 29% | 14% | 22% |
| Dependent has no partner or partner cannot provide care/needs help | 12% | 21% | 16% |
| My siblings/relatives can't or won't | 9% | 18% | 13% |
| Dependent was having health issues | 20% | 6% | 13% |
| **What activities do you do for the elderly dependent?** | | | |
| Emotional support, companionship - sit & talk | 70% | 59% | 69% |
| Take to appointments (e.g. Doctors, chiropodists) | 47% | 37% | 45% |
| Grocery shopping and errands | 53% | 35% | 44% |
| Housework, putting out garbage, cooking | 44% | 35% | 41% |
| **What activities do your partner do for the elderly dependent?** | | | |
| Emotional support, companionship - sit and talk | 53% | 40% | 43% |
| Partner does not help with care/no partner | 31% | 42% | 41% |
| Grocery shopping and errands | 22% | 15% | 16% |
| Talk on phone | 18% | 6% | 11% |
| **In what ways is it overwhelming?** | | | |
| Emotional strain (idea of dependent dying, worries about dependents well being, quality of care, etc.) | 52% | 33% | 49% |
| Amount of work/coordinating/planning that has to be done | 38% | 25% | 31% |

**Figure 8: Extent to which eldercare causes different forms of strain: Family Type**



Note: Financial Strain not associated with family type

Those in the eldercare group were more likely than those in the sandwich group to say that their partner did not provide any form of eldercare. Those in the sandwich group, on the other hand, were more likely to say that their partner helped them in the provision of eldercare by talking to the dependent (either in person or on the phone) or by doing shopping and errands.

Family type is associated with the incidence of two out of three of the forms of caregiver strain considered in this study. More specifically, respondents in the eldercare group were more likely to report that they experienced both physical and emotional strain weekly or more. The greater levels of physical strain might be due to the fact that those in the eldercare group were older than those in the sandwich group. The higher levels of emotional strain, on the other hand, might be due to the fact that they have little support for the role from either their partner or their family.

## 5.6 Differences in the Caregiving Situation Associated with Caregiving Intensity

While caregiving intensity is associated with the reasons given for taking on the role of caregiver, caregiving activities undertaken (see Table 16) and caregiver strain (Figure 9), there are more similarities between these two groups than differences. That being said, those differences that can be observed do help us understand what factors are associated with higher levels of caregiving intensity.

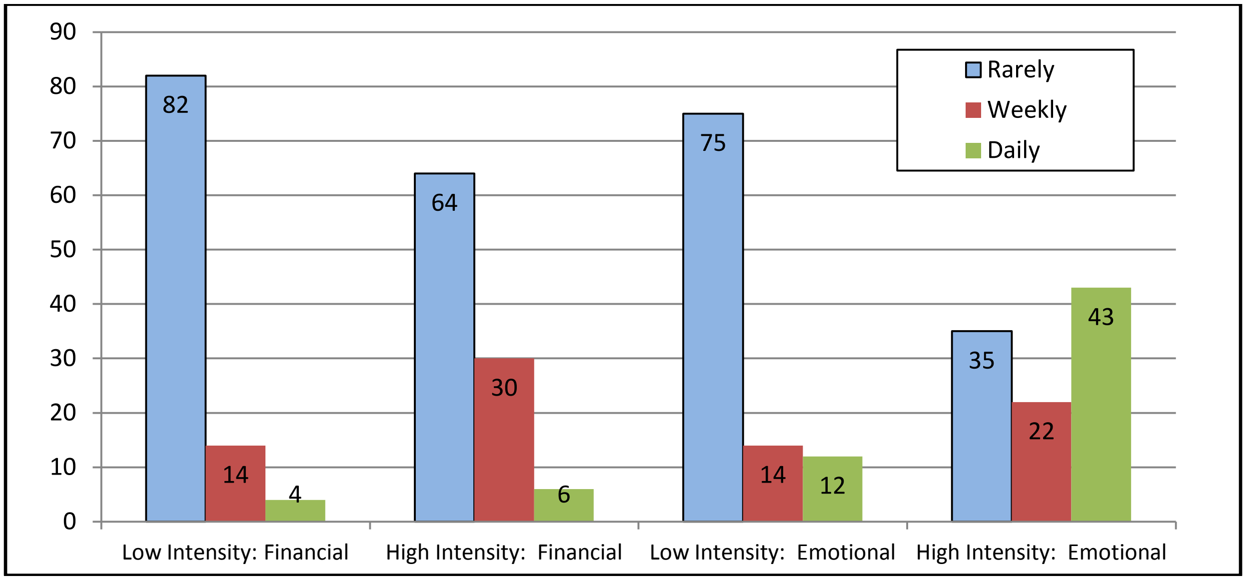
**Table 16: Differences in Caregiving Situation Associated with Caregiving Intensity**

| **Why have you assumed the role of caregiver?** | **Low** | **High** | **Total** |
|---|---|---|---|
| I am nearest (physically) | 8% | 34% | 22% |
| I have no choice, there is no one else | 13% | 24% | 19% |
| To support my partner (they were/are caring for dependent) | 10% | 2% | 6% |
| **What activities do you do for the elderly dependent?** | | | |
| Housework, putting out garbage, cooking, | 30% | 51% | 41% |
| **What activities does your partner do for the elderly dependent?** | | | |
| Emotional support, companionship - sit and talk | 59% | 33% | 43% |
| Partner does not help with care/no partner | 25% | 50% | 41% |
| Grocery shopping and errands | 25% | 11% | 16% |
| **In what ways is caregiving overwhelming?** | | | |
| I have no time for myself/ for social life/home life | 29% | 48% | 47% |

Examination of the data in Table 16 and Figure 9 indicate that people with higher levels of caregiver intensity are more likely that those with lower intensity to:

- Live close to the dependent they care for,
- Feel that they had no choice but to take on the caregiver role,
- Do housework for the dependent they are caring for,
- Have a partner who does not provide any form of support (half of the individuals with high intensity are in this situation),
- Attribute their feelings of being overwhelmed to a lack of time for themselves and their family,
- Report higher levels of financial strain, and
- Report higher levels of emotional strain.

**Figure 9: Extent to which eldercare causes different forms of strain: Family Type**



Note: Physical Strain not associated with caregiving intensity

The fact that intensity is not associated with the incidence of physical strain suggests that intensity is more likely related to the emotional aspect of caregiving than the provision of physical care (i.e. feeding, bathing).

# Chapter Six: Eldercare Scenarios

In this study we followed the lead of researchers who study the stress appraisal process and used a scenario approach (i.e. anchor all research questions by asking respondents to answer them with respect to a specific situation where they were overwhelmed or stressed) to help us understand how people appraise and cope with caregiver strain. The scenario format is provided in the box below.

## Interview Questions: Eldercare Scenarios

In this section of the interview we are going to focus on a thing called caregiver strain. Caregiver strain is defined as *"feeling overwhelmed, overloaded or stressed by the pressures associated with the duties and responsibilities associated with the caregiver role"*. In order to understand how people respond and cope with caregiver strain I would like you to think about a situation where you felt strained– where the duties and responsibilities associated with the eldercare role were overwhelming. I'm going to walk you through the experience by asking you a number of questions to help me understand the situation, how it unfolded, how you felt about the situation, what you did to try and reduce the strain, and how you now evaluate your actions. So – to start. Think about a situation that occurred in the past six months where you experienced caregiver strain: Please keep this situation in your head when you are answering the following questions.

First, what made you feel overwhelmed or stressed? What was it about the situation itself? What was your over riding feeling about the situation?

Now let's focus on the potential consequences of the situation if it were not resolved successfully:

- How was it likely to affect the person you were caring for?
- How was it likely to affect other family members?
- How was it likely to affect your situation at work?
- Finally, what were the potential consequences for you if this issue were not resolved?
- How did these potential consequences make you feel? Why?

This next set of questions were included to help us determine how well prepared you were to respond to this situation.

- How confident were you that you could deal with the situation?
- Initially how did you think you would deal with the situation?
- What was the single most important factor that made this situation potentially overwhelming or stressful for you?

Now I am going to ask about what you did to cope with the situation you just described .

- What actions did you take? Why these actions? Did they work or not?
- What actions did others (your employer, your family) take? Did they work or not?
- What did you do to deal with the emotional aspects of the situation? Did this work or not?

How did the situation end? How did you feel at the end of the situation? (or, if on-going, how do feel about it now)

Thank you for sharing this experience with us. I am now going to ask you four questions to help me better understand the situation you just described. So, all thing considered:

- how effective do you feel you were at dealing with the situation?,
- how overwhelming was this situation?,
- how stressful with this situation?, and
- how satisfied were you with how this situation ended

Respondents were asked to use a give point scale when giving their answers (see Appendix A)

The answer to the above questions are provided in this chapter which is divided into the following sections: (1) feeling overwhelmed, (2) consequences, (3) ability to deal with the situation, (4) coping, and (5) resolution. In each of these subsections, findings obtained using the total sample will be provided first, followed by an examination of the how gender, family type and caregiving intensity impact the results.

## 6.1 Feeling Overwhelmed

One in five of the respondents could not identify a situation where they felt overwhelmed. The rest gave one or more of the thirteen reasons outlined in Table 17. One in four attributed their feeling overwhelmed to their interactions with the person they were caring for. More specifically they were frustrated that the person would not listen to them, was angry with them and generally acted in a way that the respondent felt made it more difficult for them to provide care. An equal number of respondents mentioned that the emotional intensity of the situation was what made the situation overwhelming (they felt powerless, the person was dying and they felt helpless, they had little control over the situation). Other common factors making caregiving overwhelming for the employees in this sample pertained to time (it is unexpected, it is urgent, it requires a lot of my time), demands (on their time, the amount of planning and work required), emotional attachment (emotional intensity, concern for wellbeing of dependent), and a lack of choice/control (feeling powerless, feeling trapped, only one available, it all fell on me). Very few respondents mentioned either distance or financial concerns as issues that made them feel overwhelmed.

**Table 17: What made you feel overwhelmed?**

| | Total |
|---|---|
| Dependent's difficult personality (e.g. forgets and scolds me, angry at me, is unhelpful, won't listen) | 24% |
| Emotional intensity for me (e.g., feeling powerless, dealing with death, lack of control) | 24% |
| Timing, unexpected urgent situation | 20% |
| Could not think of a situation - never felt overwhelmed | 19% |
| Amount of time the situation required | 18% |
| Concern for wellbeing/welfare of dependent | 17% |
| Balancing work/life/care giving - impacts home or work | 15% |
| Amount of planning/coordinating/work required | 13% |
| Being put in situation I shouldn't be/feeling trapped/taken advantage of | 11% |
| Other | 10% |
| I was only one available - it all fell on me - no help | 7% |
| Distance | 5% |
| Financial implications | 5% |

As can be seen by examining the data in Table 18, caregiving appears to be associated with a number of negative emotions and feelings for the employees in our sample with almost half of the respondents (40%) indicating that their overriding feelings about the situation were anger and frustration. One in four felt worried/anxious (25%), guilty (22%), and overwhelmed/overloaded (22%). Others felt hopeless, powerless and trapped (15%) and concerned (13%). None of the respondents responded to this question by identifying a positive feeling (i.e. hopeful, useful).

**Table 18: What was your overriding feeling about this situation?**

| | Total |
|---|---|
| Frustration/anger | 40% |
| Worried/anxious | 25% |
| Guilty | 22% |
| Overwhelmed/overloaded | 22% |
| Hopeless, powerless, trapped | 15% |
| Concerned | 13% |
| Other | 10% |

### 6.1.1 Impact of Gender on "Feeling Overwhelmed"

As shown in Table 19, gender played a role in what made people feel overwhelmed but had little impact on the feelings generated by caregiving. Men were more likely than women to say that they were overwhelmed because they felt powerless, the lack of control over the situation teamed with the fact that the situation was unexpected and urgent and required a lot of their time. The women in the sample, on the other hand, were the only ones that talked about how distance contributed to their feeling overwhelmed.

In terms of the feelings generated by caregiving, women were more likely to mention feeling trapped, hopeless and powerless while men were more likely to mention feeling concerned.

**Table 19: Gender Differences: Feeling Overwhelmed**

| **What made you feel overwhelmed?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Emotional intensity for me (e.g., feeling powerless, dealing with death, lack of control) | 29% | 18% | 24% |
| Timing, unexpected urgent situation | 26% | 14% | 20% |
| Amount of time the situation required | 23% | 12% | 18% |
| Amount of planning/coordinating/work required | 21% | 4% | 13% |
| Distance | 0% | 9% | 5% |
| **What was your overriding feeling?** | | | |
| Hopeless, powerless, trapped | 7% | 22% | 15% |
| Concerned | 21% | 4% | 13% |

### 6.1.2 Impact of Family Type on "Feeling Overwhelmed"

As shown in Table 20, family type played a role in what made people feel overwhelmed but had no impact on the feelings generated by such activities. More specifically, those in the sandwich group were more likely to link the time demands and the emotional intensity of the situation with their feeling overwhelmed while those in the eldercare group were more likely to be overwhelmed by the timing of the situation (urgent, unexpected) and the fact that they had no one to help them deal with the issue.

**Table 20: Family Type Differences: Feeling Overwhelmed**

| What made you feel overwhelmed? | Sandwich | Eldercare | Total |
|---|---|---|---|
| Emotional intensity for me (e.g., feeling powerless, dealing with death, lack of control) | 31% | 15% | 24% |
| Timing, unexpected urgent situation | 13% | 26% | 20% |
| Amount of time the situation required | 21% | 13% | 18% |
| I was only one available - it all fell on me - no help | 1% | 14% | 7% |

### 6.1.3 Impact of Caregiving Intensity on "Feeling Overwhelmed"

The data in Table 21 give us some insight into what it is about caregiving that contributes to high levels of caregiving intensity. It would appear that intensity increases when the care recipient is difficult (i.e. will not listen, angry, scolds), and the person feels powerless and very emotional about the situation. Respondents with high levels of caregiving intensity were also more likely to note that they felt hopeless, powerless and trapped by the situation. Surprisingly, urgent situations are less likely to be associated with high intensity. Taken together these data suggest that the ongoing nature of caregiving may contribute to higher levels of caregiving intensity.

**Table 21: Caregiving Intensity Differences: Feeling Overwhelmed**

| What made you feel overwhelmed? | Low | High | Total |
|---|---|---|---|
| Dependent's difficult personality (e.g. forgets and scolds me, angry at me, is unhelpful, won't listen) | 14% | 31% | 24% |
| Emotional intensity for me (e.g., feeling powerless, dealing with death, lack of control) | 12% | 35% | 24% |
| Timing, unexpected urgent situation | 25% | 15% | 20% |
| **What was your overriding feeling?** | | | |
| Hopeless, powerless, trapped | 10% | 20% | 15% |

## 6.2 Potential consequences

We asked five questions to help us understand what respondents felt was at stake with respect to the caregiving situation they were thinking of. More specifically, we asked the respondents to identify how the situation was likely to affect the person they were caring for (Table 22), other family members (Table 23), their situation at work (Table 24) and them personally (Table 25). We also asked them how these potential consequences made them feel (Table 26).

*Consequences to care recipient*: Only 17% of the sample identified a situation where the care recipient was not impacted. Impacts identified by the rest of the sample fell into three buckets: emotional, physical, and care-related. Most commonly people talked about the emotional fall out of the situation on the person they were caring for. Half indicated that the situation was very stressful for the person they cared for (they were worried, stressed, would have been hurt), 12% noted that the person would need to move, and 10% talked about how demoralizing the situation was for a "proud person." In terms of physical consequences, one in three respondents indicated the situation they were thinking of could very easily result in physical harm and/or the death of the care recipient. Finally, 14% talked about how the care of the individual could be impacted or delayed by the situation. Few people talked about physical strain on the care recipient.

**Table 22: What was the potential effect on the person you were caring for?**

| Reason | Total |
|---|---|
| Emotional stress (e.g., would have hurt dependent's feelings, worried them) | 50% |
| Physical harm or death of dependent | 32% |
| There was no effect on them | 17% |
| Care impacted or delayed (e.g., care delayed, appointment missed) | 14% |
| Dependent would need to move | 12% |
| Demoralizing for a proud person (e.g. because they can't manage as they used to be able to intellectually or physically) | 10% |
| (S)he doesn't remember/isn't aware of what's going on | 5% |
| Financial strain | 5% |

*Consequences to other family members*: One in four respondents felt that the caregiving situation that they had identified would not impact other family members. The rest of the sample noted a number of ways in which the situation could potentially impact their family. Most commonly they noted that their family was also stressed and overwhelmed by the situation (50%) and that the situation would require their family (defined quite broadly) to contribute time and energy to caregiving. Just under one in five noted that their family would be negatively impacted by the situation. Finally, one in ten said that the situation had increased conflict within their family. It should be noted that when answering this question respondents used a broad definition of family (siblings, partner, children) suggesting that all these groups may be impacted, either directly and/or indirectly, by caregiving.

**Table 23: What was the potential effect on other family members?**

| Reason | Total |
|---|---|
| Also stressed and overwhelmed by the situation | 50% |
| My partner/ siblings/family would have to help/contribute time and energy | 39% |
| No real impact on other family members | 27% |
| Children/family are negatively affected (e.g. schedules had to change, lose relationship with grandparents) | 16% |
| Creates conflict among family members (siblings, partner) | 8% |
| Other | 3% |

*Consequences to paid employment*: While 40% of the respondents felt that the caregiving situation that they had identified would not impact their work, in 16% of these cases the respondent noted that the lack of impact could be attributed to their coping strategies (i.e. I separate work and family). The rest of the sample noted a number of ways in which the caregiving situation could potentially negatively impact either their productivity (i.e less productive, distracted, not enough time, find it hard to focus at work) and/or their career (i.e. have to use vacation days, take sick days off work, fear that they will lose their job). While these data suggest that many employed caregivers minimize the impact of caregiving on their work - the strategies they use (i.e. calling in sick, using vacation days) may come at a personal cost in terms of exhaustion, stress etc.

**Table 24: What was the potential effect on your work?**

| Reason | Total |
|---|---|
| Less productive/not enough time/worry about not getting job done, distracted, difficulty focusing | 37% |
| Have to take time off, use vacation days or sick days | 31% |
| No potential to impact my work | 24% |
| No impact/minimal impact because I separate work and personal life/ try not to think about it at work | 16% |
| Lose job (fired, would have to quit/leave) | 5% |
| Other negative impacts on work | 5% |
| Other | 3% |

*Consequences to employed caregiver*: All of the respondents were able to identify ways in which the caregiving situation had impacted them personally. Also of note is the fact that all talked about how caregiving had (or could) impact them negatively (no spontaneous discussion of benefits). Again, we note that the most common response to this question related to the emotional aspect of caregiving (stress, anxiety, frustration). Others talked about how caregiving had/could negatively impact their health (less sleep, no downtime, negative impact my health), their family (relationship with partner negatively impacted, things in my life do not get done) or their career.

**Table 25: What were the potential consequences for you?**

| Reason | Total |
|---|---|
| Emotional consequences (e.g. stress, anxiety, frustration) | 63% |
| Less sleep | 24% |
| Negatively affected my health | 13% |
| No downtime for me | 11% |
| Financial strain | 11% |
| Job/career implications (i.e. have to take time off, retire, will affect career progression) | 11% |
| Things in my life don't get done | 10% |
| Relationship with partner negatively affected | 5% |
| Other | 3% |

*How did the employed caregiver feel about these consequences?:* The responses given to this question were very similar to those given earlier. Caregivers were frustrated (30%), worried and anxious (23%), stressed (16%), helpless (15%) overwhelmed (15%), angry, (14%) and guilty (14%). Of note though is the fact that 8% of the sample talked about being at peace with the situation.

**Table 26: How did you feel about these potential consequences?**

| Reason | Total |
|---|---|
| Frustration | 30% |
| Worried, anxious | 23% |
| Stressed | 16% |
| Helpless | 15% |
| Overwhelmed | 15% |
| Angry | 14% |
| Guilty | 14% |
| At peace (acceptance) | 8% |
| Exhausted, tired | 8% |
| Other | 5% |

### 6.2.1 Impact of Gender on "Potential Consequences"

Data showing the impact of gender on the perceived consequences of caregiving are given in Table 27. Examination of these data indicate gender differences in the frequency with which employees identified the following four consequences of the situation to the care recipient: physical harm/death, care negatively impacted, dependent would need to move, and the situation was demoralizing for the individual. In all four cases, men were more likely than women to identify the issue as one that concerned them.

**Table 27: Gender Differences: Potential Consequences**

| **Potential effect on the person you were caring for** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Physical harm or death of dependent | 35% | 25% | 32% |
| Care impacted or delayed | 17% | 9% | 14% |
| Dependent would need to move | 15% | 7% | 12% |
| Demoralizing for a proud person (e.g. because they can’t manage as they used to be able to intellectually or physically) | 15% | 4% | 10% |
| **Potential effect on other family members** | | | |
| Also stressed by the situation | 55% | 43% | 50% |
| My partner/ siblings/family would have to help | 43% | 35% | 39% |
| **Potential effect on your work** | | | |
| Have to take time off, use vacation days or sick days | 26% | 36% | 31% |
| No potential to impact my work | 30% | 6% | 24% |
| **Potential consequences on employed caregiver** | | | |
| Less sleep | 36% | 10% | 24% |
| Negatively affected my health | 8% | 18% | 13% |
| **How respondent felt about these potential consequences** | | | |
| Stressed | 12% | 21% | 16% |
| At peace (acceptance) | 13% | 2% | 8% |

Men were also more likely than women to identify two ways in which the caregiving situation would negatively impact their family: their family would also be stressed and their family would have to help.

The gender differences with respect to impact of caregiving on the respondent's situation at work were also interesting with men being more likely than women to say that there was no impact and women being more likely to say that they would have to use their vacation days/call in sick to work to deal with the situation.

Also interesting are the gender differences in the perceived consequences of the situation on the employee (men more likely to say they would get less sleep, women more likely to say it would negatively impact their health) and the feelings these arouse (women more likely to say they were stressed, men more likely to say they were at peace).

### 6.2.2 Impact of Family Type on "Potential Consequences"

Data showing the impact of family type on the perceived consequences of caregiving are given in Table 28. These differences can be summarized as follows:

**Table 28: Family Type Differences: Potential Consequences**

| **Potential effect on the person you were caring for** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| Care impacted or delayed | 18% | 10% | 14% |
| Demoralizing for a proud person (e.g. because they can’t manage as they used to be able to intellectually or physically) | 6% | 15% | 10% |
| **Potential effect on other family members** | | | |
| Also stressed by the situation | 59% | 38% | 50% |
| Children/family are negatively affected (e.g. schedules had to change, lose relationship with grandparents) | 23% | 6% | 16% |
| Creates conflict among family members (siblings, partner) | 4% | 13% | 8% |
| **Potential effect on your work** | | | |
| Have to take time off, use vacation days or sick days | 36% | 25% | 31% |
| No impact/minimal impact because I separate work and personal life/ try not to think about it at work | 11% | 21% | 16% |
| **Potential consequences on employed caregiver** | | | |
| Emotional consequences (e.g. stress, anxiety, frustration) | 70% | 46% | 63% |
| Job/career implications (i.e. have to take time off, retire, will affect career progression) | 18% | 4% | 11% |
| **How respondent felt about these potential consequences** | | | |
| Frustration | 34% | 23% | 30% |
| Stressed | 12% | 22% | 16% |
| At peace (acceptance) | 12% | 2% | 8% |

Respondents with both childcare and eldercare (i.e. sandwich group) were more likely than those in the eldercare group to indicate that the situation that they were thinking of had (or would):

- Negatively impact the care recipient by causing their care to be impacted or delayed,

- Negatively impact other family members in two ways: increase their stress levels and impact schedules and relationships,
- Negatively impact the amount of time they were away from work (i.e. increase absenteeism) and limit their career progression,
- Increase their levels of anxiety, stress and frustration.

Respondents in the eldercare group, on the other hand, were more likely to indicate that the situation that they were thinking of had (or would):

- Demoralize the care recipient,
- Create conflict with other family members,
- Have little to no impact on their situation at work because they separated work and family, and
- Make them feel more stressed.

### 6.2.3 Impact of Caregiving Intensity on "Feeling Overwhelmed"

Data showing the link between caregiving intensity and the perceived consequences of caregiving are given in Table 29. While there were not many differences in the "consequences" data associated with levels of caregiving intensity, the findings do give us some insight on the factors associated with higher caregiving intensity. Key conclusions are summarized below.

**Table 29: Caregiving Intensity Differences: Feeling Overwhelmed**

| **Potential effect on the person you were caring for** | **Low** | **High** | **Total** |
|---|---|---|---|
| Demoralizing for a proud person (e.g. because they can't manage as they used to be able to intellectually or physically) | 5% | 15% | 10% |
| **Potential effect on other family members** | | | |
| Also stressed by the situation | 63% | 35% | 50% |
| No real impact on other family members | 14% | 28% | 21% |
| **Potential effect on your work** | | | |
| Less productive/ not enough time/worry about not getting job done, distracted, difficulty focusing | 28% | 40% | 37% |
| No impact/minimal impact because I separate work and personal life/ try not to think about it at work | 24% | 8% | 16% |
| **Potential consequences on employed caregiver** | | | |
| Emotional consequences (e.g. stress, anxiety) | 69% | 58% | 63% |
| Negatively affected my health | 6% | 21% | 13% |
| **How respondent felt about these potential consequences** | | | |
| Frustration | 20% | 41% | 30% |
| Stressed | 22% | 10% | 16% |
| Overwhelmed | 22% | 7% | 15% |

First, there appears to be little link between caregiving intensity and perceived/actual consequences to the caregiving recipient. Second, people with higher levels of caregiving intensity seem to be more likely to be facing the situation alone (less likely to say family members are stressed by the situation, and more likely to say that the situation has no impact on other family members), either by choice (sheltering family) or because there is no support. Third, caregiving intensity seems to be positively associated with productivity at work as those with higher levels of intensity are more likely to mention that their work is suffering (distracted, cannot focus). The comments suggest that in this case it is the intensity of the caregiving situation that is reducing productivity - not the reverse. Finally, also of note is the fact that those with lower levels of caregiving intensity were more likely to talk about how stressed and overwhelmed they were with the caregiving situation while those with higher intensity were more likely to talk about how frustrated they were and how the situation had negatively impacted their physical health.

## 6.3 Ability to deal with the situation

We asked a number of questions to determine how well prepared the respondent felt they were to were to respond to the caregiving situation they were thinking of. More specifically we asked them how confident they were that they could with the situation, how they initially thought they would deal with the situation, and to identify the single most important factor that made the situation potentially overwhelming or stressful.

Just over half (56%) of the sample indicated that they were confident that they could deal with the situation while 16% said they were not at all confident that they could handle with the situation. The rest of the respondents (28%) qualified their answer by noting that they had concerns about the situation but thought/hoped that things would be okay overall.

Respondents identified eight ways in ways that they had considered dealing with the situation (see Table 30). What was striking was that almost half the sample (45%) responded to the situation (i.e. no plans, hoped for the best, just did what had to be done) rather than took steps to deal with it proactively. One in five made a plan and got organized, 13% sought help from others, and 11% talked it through with others.

**Table 30: How did you initially think you would deal with this situation?**

| Reason | Total |
|---|---|
| Thought it would all work out/resolve itself so I just hoped for the best | 23% |
| No plans | 22% |
| Planning and organization | 19% |
| Thought I'd do what I did - which is just do what had to be done | 18% |
| Seek out/get help | 13% |
| Talk it through, communication | 11% |
| Knew it would be hard and involve personal sacrifices | 6% |
| Other | 6% |

What was it about the situation that made the situation stressful? While many respondents (17% in "other" bucket) gave idiosyncratic responses, there was some degree of consensus with respect to this issue (see Table 31). One in four mentioned that their stress arose due to concern for the wellbeing of the person they were caring for while one in five noted that the dependent themselves made the situation very stressful. Many talked about how the demands associated with caregiving made the situation overwhelming (amount of work involved, not enough time) while others attributed the stress of caregiving to the lack of control they had over the situation (it is not predictable, the situation was unexpected). Other stressors, identified by approximately one in ten included the following: caregiving had negatively impacted their relationship with their partner, challenges of caring over a distance, issues associating with balancing work, life and caregiving, and the reaction of their siblings to the situation.

**Table 31: What was the most important factor making this situation stressful?**

| Reason | Total |
|---|---|
| Concern for health/wellbeing of dependent | 25% |
| Dependent themselves (cannot understand, wants independence so much they are making poor decisions, they do not listen) | 19% |
| Other | 17% |
| The amount of work involved /I became exhausted | 16% |
| Lack of control and predictability | 13% |
| Time constraints, not enough time | 10% |
| Impacted my relationship with my partner | 9% |
| Timing, situation was unexpected | 9% |
| Distance to travel | 8% |
| Balancing work/life/care giving | 8% |
| Reaction of extended family/siblings | 8% |

### 6.3.1 Impact of Gender on Perceived Ability to Deal with the Situation

The data in Table 32 support the idea that men and women approach eldercare quite differently. More specifically, men were more likely to express confidence that they could deal with the situation they were facing while women were more likely to admit that they were not confident that they could deal with the situation.

**Table 32: Gender Differences: Ability to deal with the situation**

| Confidence they could deal with situation | Male | Female | Total |
|---|---|---|---|
| Confident | 64% | 49% | 56% |
| Not confident | 8% | 25% | 16% |
| **Initially how planned to deal with situation** | | | |
| Thought it would all work out/resolve itself/hoped for the best | 30% | 15% | 23% |
| Thought I'd do what I did - just got on with it | 26% | 10% | 18% |
| Talk it through, communication | 4% | 20% | 11% |
| **Factors making situation stressful** | | | |
| Concern for health/wellbeing of dependent | 30% | 20% | 25% |
| The amount of work involved /I became exhausted | 10% | 20% | 16% |
| Lack of control and predictability | 6% | 17% | 13% |
| Time constraints, not enough time | 14% | 6% | 10% |
| Impacted my relationship with my partner | 18% | 0% | 9% |
| Timing, situation was unexpected | 14% | 4% | 9% |

Women were more likely to deal with caregiving by talking about it and communicating with others while men were more likely to "just get on with and hope for the best". Men were more likely than women to identify four factors as making the situation stressful: concern for the wellbeing of the dependent, time constraints, timing (it was unexpected) and the fact that the situation had negatively impacted their relationship with their spouse. Women on the other hand, were more likely than their male counterparts to identify the amount of work involved, exhaustion and a lack of predictability as factors that made caregiving stressful.

### 6.3.2 Impact of Family Type on Perceived Ability to Deal with the Situation

Family type also impacts how employees approach eldercare (see Table 33). Employees in the eldercare only group were more likely than those in the sandwich group to: (1) express confidence that they could deal with the situation, (2) deal with the situation by talking to others, and (3) identify the behaviour of the person that they cared for as the most important source of stress for them.

**Table 33: Family Type Differences: Ability to Deal with the Situation**

| **Confidence they could deal with situation** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| Confident | 45% | 69% | 56% |
| Moderately/thought it would be ok/ some concerns | 38% | 16% | 28% |
| **Initially how planned to deal with situation** | | | |
| No plans | 27% | 10% | 22% |
| Planning and organization | 25% | 13% | 19% |
| Talk it through, communication | 6% | 17% | 11% |
| **Factors making situation stressful** | | | |
| Concern for health/wellbeing of dependent | 31% | 18% | 25% |
| Dependent themselves (wants independence, cannot understand, making poor decisions) | 11% | 33% | 19% |
| The amount of work involved /I became exhausted | 19% | 9% | 16% |
| Time constraints, not enough time | 15% | 6% | 10% |

Employees in the sandwich group, on the other hand, were more likely to have concerns about their ability to deal with the situation, either have no plans to deal with the situation or intend to cope through planning and organizing and identify their concern for the wellbeing of the dependent and demands on their time (not enough time, time constraints, I am exhausted) as the most important sources of stress for them.

### 6.3.3 Impact of Caregiving Intensity on Perceived Ability to Deal with the Situation

We also looked at the relationship between caregiving intensity and how employees approach eldercare (see Table 34). While the number of substantive between group differences are not as numerous as observed with respect to gender and family type, the findings do shed light on factors associated with higher levels of caregiving intensity. More specifically, respondents with higher levels of caregiving intensity were more likely to say that they were not confident that they could deal with the situation and to say that they had no real plans to deal with the situation but rather "hoped for the best". Finally, those with higher levels of caregiving intensity were more likely to identify the following factors as making the situation stressful: concern for the wellbeing of the dependent, the amount of work involved and the lack of control and predictability.

**Table 34: Caregiving Intensity Differences: Ability to Deal with the Situation**

| **Confidence they could deal with situation** | **Low** | **High** | **Total** |
|---|---|---|---|
| Not confident | 8% | 25% | 16% |
| **Initially how planned to deal with situation** | | | |
| Thought it would all work out/hoped for the best | 18% | 29% | 23% |
| **Factors making situation stressful** | | | |
| Concern for health/wellbeing of dependent | 20% | 31% | 25% |
| The amount of work involved /I became exhausted | 10% | 19% | 16% |
| Lack of control and predictability | 8% | 16% | 13% |
| Time constraints, not enough time | 16% | 4% | 10% |
| Distance to travel | 12% | 4% | 8% |

## 6.4 Coping

During the scenario section of the interview we also asked a number of questions to help us understand what the respondent did to cope with the situation they had just described . More specifically we asked them: (1) what actions they personally had taken to cope with the situation, (2) what actions others (employer, family) had taken, and (3) what they had done to deal with the emotional aspects of the situation. They were also asked to evaluate whether or not these actions had worked. Responses to these questions are discussed below.

**Table 35: How did you cope with the situation?**

| Reason | Total |
|---|---|
| Talk/vent with partner/family/friend/colleague | 26% |
| Planning and organization | 26% |
| Practically tried to solve situation - just got on with it | 23% |
| Voiced concerns/feelings/expectations to dependent/improved communication | 12% |
| Research and seek out professional resources (government, professional care etc) | 12% |
| Other | 12% |
| Ask for/accepted help from sibling/family | 9% |
| Engaged in activity to take mind off of issue | 9% |
| Step back, take a breath | 8% |
| Bit my tongue/did not verbalize feelings | 7% |
| Prioritize/put less important things on hold | 5% |
| Took time off work | 5% |

*How cope with situation?*: Respondents identified 12 coping strategies that they had used to cope with the stresses associated with an overwhelming caregiving situation. One in four coped by (1) talking/venting to a sympathetic other, (2) preparing detailed plans and getting organized, and (3) figuring out a practical solution to the problem and just "getting on it with it." Less common coping strategies, used by approximately one in ten respondents included voicing their concerns to the dependent, researching and seeking out professional resources, asking for help from their siblings and engaging in other activities to take their mind off the issue. A small number of respondents said they took at step back from the situation to try and put it in perspective, held their temper and "bit their tongue", prioritized, and took time off work.

*Why cope this way*? While many respondents (20% in "other" bucket) gave idiosyncratic reasons for coping the way they did (see Table 36), there was some consensus with respect to the motivations respondents gave for selecting the coping strategy they did. Most commonly respondents did what they did to protect the interests of the care recipient (21%), to help relieve the stress they were under (18%), to increase their sense of control over the situation (14%), and because they wanted to make sure things went according to a particularly plan. Others did what they did because they wanted to make the dependent more aware of what was going on or to give themselves some breathing space. Finally, it is interesting to note that 10% of the sample could not actually explain why they did what they did -- saying "it is just the way I do things" or "that just what I do when I am stressed." Finally, it is important to note that while the vast majority (77%) of the sample indicated that the coping strategy that they selected typically helped them solve the challenges they were facing, 23% said that the approach they took did not typically work.

**Table 36: Why did you cope this way?**

| | **Total** |
|---|---|
| In the best interest of dependent (what they would want, protecting them, etc) | 21% |
| Other | 20% |
| Helps de-stress | 18% |
| Adds rationality, control | 14% |
| To keep things simple/ make sure things get done according to plan | 14% |
| To make sure dependent was aware of situation | 11% |
| That’s just what I do | 10% |
| Gives me breathing space | 9% |
| To be accessible (to work and to dependent) | 4% |
| It was the only solution | 4% |

*What actions did others take*?: Actions taken by others to help the respondent cope with the caregiving scenario being discussed are shown in Table 37. Over a third of the sample (36%) said that no one provided help or support. One in four said that they had got emotional support from their partner (they listen, give good advice) and/or their siblings and/or their employer. One in four also mentioned that their employer also gave them time off work. Tangible help, while less common, was also mentioned with some respondents indicating that they received financial and practical help from family members (14%), friends and work colleagues (9%) and through the EAP services at work (5%). Almost all of the people who mentioned support from others noted that this support helped them deal with the caregiving situation they faced.

**Table 37: What actions did other people take to help?**

| | Total |
|---|---|
| No one provided any help or support | 36% |
| Partner gives good advice, listens or helps | 26% |
| Siblings give support (talking with siblings) | 24% |
| Employer supportive/ gives me time off | 24% |
| Practical or financial help from family members | 14% |
| Help from friends and colleagues | 9% |
| Other | 5% |
| EAP program through work | 5% |

*How cope with emotional aspects of the situation?*: Respondents used nine strategies to cope with the emotional aspects of caregiving (see Table 38). The most common approach taken by the employed caregivers in this sample was to seek emotional support from a sympathetic other (42% said they talked/vented with their partner/family/friend). The other two most common strategies used by the respondents in this sample were to ignore the emotions/do nothing (26%) and to engage in activities that would reduce their stress in a healthy manner (21% engaged in exercise, hobbies etc). One in ten used a myriad of coping strategies including: (1) introspection, (2) doing their best, (3) seeking professional help, (4) communicating with the dependent, and (5) alcohol/caffeine. While the majority (79%) said that the strategy they used had helped them cope with the emotional aspect of the situation, 21% said that the strategy they used really did not work.

**Table 38: How did you deal with the emotional aspects of the situation?**

| | Total |
|---|---|
| Talk/vent with partner/family/friend | 42% |
| Ignore it, move on (i.e. they do nothing) | 26% |
| Exercise, hobbies, relaxation | 21% |
| Introspection, thinking | 12% |
| Do my best | 11% |
| Counseling, professional help | 8% |
| Communicating with dependent other | 8% |
| Alcohol/ caffeine | 7% |
| Other | 7% |

### 6.4.1 Impact of Gender on Coping

As can be seen by looking at the data in Table 39, there are a number of gender differences with respect to how employees cope with caregiving strain. Women were more likely than men to ask others for help and cope by taking time off work - strategies that they said did not really help them cope with the situation. Women were also more likely to say that their partner supported them by listening and offering support and to say that the help offered by others did help them cope with the caregiving situation. Finally, women were more likely than men to say that they dealt with the emotional aspects of caregiving by engaging in activities (exercise, hobbies) to take their mind of the stress and by communicating with the dependent. Women were also more likely than men to claim that the strategies they used to cope with the emotional aspects of caregiver strain worked.

## Table 39: Gender Differences: Coping

| **How cope with situation?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Ask for/accepted help from sibling/family | 2% | 16% | 9% |
| Step back, take a breath | 14% | 2% | 8% |
| Took time off work | 0% | 8% | 4% |
| **Why cope this way?** | | | |
| That's just what I do | 17% | 0% | 10% |
| **Does this way of coping help?** | | | |
| Yes, typically | 82% | 74% | 77% |
| No - never works | 2% | 16% | 10% |
| **What actions did others take?** | | | |
| No one provided any help or support | 40% | 16% | 36% |
| Partner gives good advice, listens or helps | 20% | 33% | 26% |
| Employer supportive/ gives me time off | 27% | 19% | 24% |
| **Does this help?** | | | |
| Yes, typically | 44% | 62% | 75% |
| **How did you deal with the emotional aspects of the situation?** | | | |
| Ignore it, move on (i.e. they do nothing) | 36% | 15% | 26% |
| Exercise, hobbies, relaxation | 14% | 23% | 21% |
| Introspection, thinking | 16% | 8% | 12% |
| Do my best | 16% | 6% | 11% |
| Communicated with dependent other | 2% | 14% | 8% |
| **Does this way of coping help?** | | | |
| Yes | 75% | 83% | 79% |

The men in the sample, on the other hand, were more likely than their female counterparts to say they coped by stepping back from the situation because this was "just what they did." They were also more likely to claim that how they coped with caregiving was effective. Men were also more likely than women to say that no one took actions to help them cope with caregiving (probably because they did not ask for help or communicate about the issue with others) and to say that their employer helped by being supportive of the situation. Finally, men were more likely to cope with the emotional aspects of caregiving by ignoring the issue, engaging in introspection and doing their best.

### 6.4.2 Impact of Family Type on Coping

As shown in Table 40, there are also a number of interesting differences in the use of coping strategies that are associated with family type. Compared to their counterparts in the eldercare group, those in the sandwich sample were more likely to say they coped by talking and venting to their partner, a strategy they used because it helped them de-stress and gave them breathing space. Employees in the sandwich group were also more likely to claim both that no one provided them with support or help in response to their caregiving situation and to recognize that they had received support and help from their siblings and other family members. They were also more likely to mention the support they had received from the EAP program at their place of work and to say that the support they had received from others helped them cope with their caregiving situation. Those in the sandwich group were also more likely to say they coped with the emotional aspect of the situation by ignoring it, engaging in activities to take their mind of the situation/cope with the stress and by engaging in introspection.

**Table 40: Family Type Differences: Coping**

| How cope with situation? | Sandwich | Eldercare | Total |
|---|---|---|---|
| Talk/vent with partner/family/friend/colleague | 32% | 19% | 26% |
| Planning and organizing | 19% | 33% | 26% |
| Practically tried to solve situation - just got on with it | 18% | 27% | 23% |
| **Why cope this way?** | | | |
| Helps de-stress | 27% | 11% | 18% |
| To keep things simple/ make sure things get done according to plan | 6% | 21% | 14% |
| Gives me breathing space | 13% | 5% | 9% |
| To be accessible (to work and to dependent) | 0% | 9% | 4% |
| **What actions did others take?** | | | |
| No one provided any help or support | 34% | 21% | 36% |
| Support/help from/ talking with siblings | 28% | 20% | 24% |
| Practical or financial help from family members | 5% | 25% | 14% |
| EAP program through work | 10% | 0% | 5% |
| **Does this help?** | | | |
| Yes, typically | 59% | 48% | 75% |
| **How did you deal with the emotional aspects of the situation?** | | | |
| Ignore it, move on (i.e. they do nothing) | 30% | 20% | 26% |
| Exercise, hobbies, relaxation | 23% | 13% | 21% |
| Introspection, thinking | 16% | 8% | 12% |

The data indicate that those in the eldercare group, on the other hand, took a more practical approach to coping with caregiving. They were more likely to say they coped by planning and organizing, and engaging in problem solving activities, and more likely to indicate they coped the way they did because of a desire to keep things simple and get things done. Those in the eldercare group were also more likely to say that their family offered practical and financial support and less likely to claim that they were dealing with the situation on their own. Finally it should be noted that family type was not associated with the perceived effectiveness of the strategies the employee said they used to cope with either the caregiving situation or the emotions caregiving created.

### 6.4.3 Impact of Caregiving Intensity on Coping

Analysis of the data (Table 41) revealed surprisingly few differences between those with high and low levels of caregiving intensity with respect to how they coped with an overwhelming caregiving situation. Of note is the fact those with high caregiving intensity were less likely to feel that how they coped with the either the caregiving situation or the emotions it aroused was effective. Also interesting are the data showing that employees with low caregiving intensity were more able to find time to engage in activities to help them cope with the situation itself (i.e. engage in activities to take my mind off things, step back and take a breath) and the emotions attached to it (i.e. talk/vent to partner). Those with high caregiving intensity, on the other hand, were more likely to say they coped by asking for help but to also claim that such help was often not forthcoming. Those with high caregiving intensity were also more likely to cope by seeking professional help, trying to do their best and communicating with the person they were caring for. Finally, it is interesting to note that those with low caregiving intensity were more likely to say that they had received support from others and more likely to talk about the support they had received from their partners (listens and provides advice) their employer (gives time off), their family (practical and financial help) and colleagues at work and at home. Taken together these data suggest a strong link between caregiving intensity and a support for the caregiver role.

**Table 41: Caregiving Intensity Differences: Coping**

| **How cope with situation?** | **Low** | **High** | **Total** |
|---|---|---|---|
| Ask for/accepted help from sibling/family | 2% | 16% | 9% |
| Engaged in activity to take mind off of issue | 13% | 3% | 9% |
| Step back, take a breath | 13% | 3% | 8% |
| **Does this way of coping help?** | | | |
| Yes, typically | 82% | 74% | 77% |
| No - never works | 2% | 16% | 10% |
| **What actions did others take?** | | | |
| No one provided any help or support | 21% | 32% | 36% |
| Employer supportive/ gives me time off | 32% | 16% | 24% |
| Practical or financial help from family members | 22% | 8% | 14% |
| Help from friends and colleagues | 14% | 3% | 9% |
| **How did you deal with the emotional aspects of the situation?** | | | |
| Talk/vent with partner/family/friend | 55% | 30% | 42% |
| Do my best | 4% | 14% | 11% |
| Counseling, professional help | 6% | 16% | 8% |
| Communicated with dependent other | 3% | 13% | 8% |
| **Does this way of coping help?** | | | |
| Yes | 90% | 58% | 79% |
| No | 5% | 22% | 13% |

## 6.5 Resolution of the situation

We ended this section of the interview by asking the respondent how the overwhelming situation ended, how they felt when it ended (or, if the situation was on-going, how they felt about it now) and to evaluate how effective they felt they were at dealing with the situation, how overwhelming and stressful they had found the situation to be and how satisfied they were with how the situation had resolved itself.

One in three of the respondents indicated that the overwhelming caregiving situation that they spoke of was still ongoing (Table 43). In the rest of the cases the situations described by the respondents were either perceived to have been resolved successfully (38%) or to have had a less than successful resolution (19%). In 9% of the cases the dependent had passed away. While most people talked about being relieved (43%), happy and satisfied (16%), and okay/alright (10%) at the end of the situation, others talked about being overwhelmed and exhausted (17%), angry and frustrated (14%) and sad/concerned (9%) (data in Table 43).

### Table 42: How did the situation end?

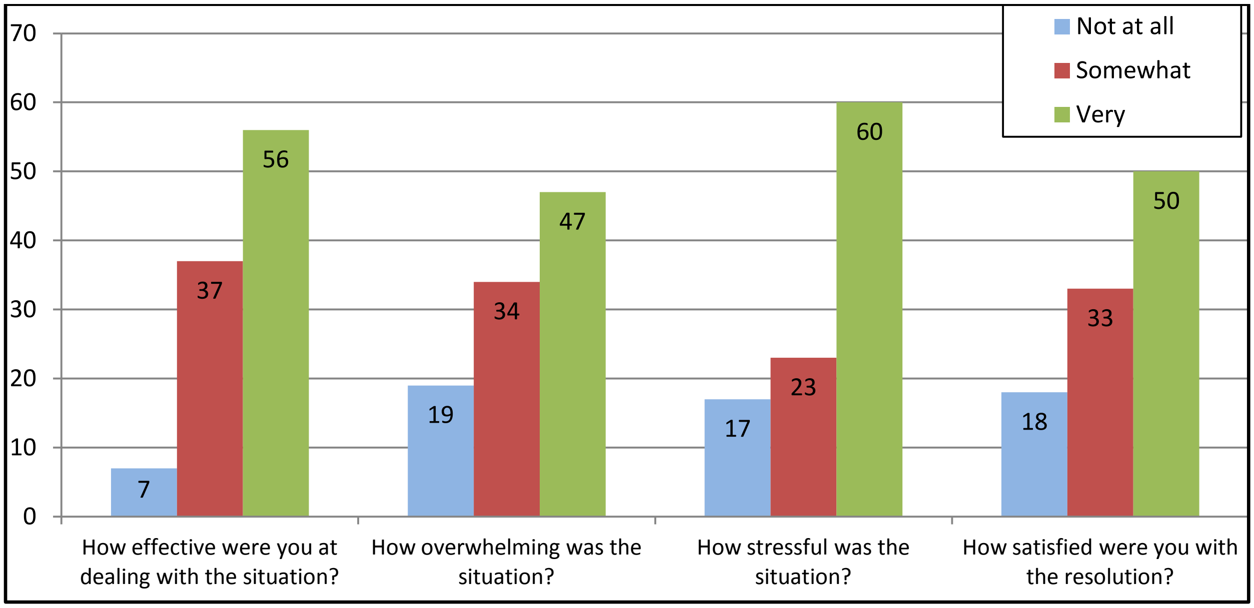
| Reason | Total |
|---|---|
| It was resolved successfully | 38% |
| It is ongoing | 32% |
| Less than successful -- but I got through it | 19% |
| Dependent passed away | 9% |
| Some improvement | 6% |

### Table 43: How do you feel about the situation now?

| Reason | Total |
|---|---|
| Relieved | 43% |
| Overwhelmed/exhausted | 17% |
| Happy, satisfied | 16% |
| Other | 14% |
| Angry/frustrated | 14% |
| Fine, ok, alright | 10% |
| Sad/concerned | 9% |
| At peace (acceptance) | 6% |

Finally, examination of the data in Figure 10 show that while the majority of the employed caregivers in this sample evaluated the caregiving situation that they had described as overwhelming (47%) and stressful (60%), they also felt that they were effective at dealing with the situation (56%) and were satisfied with how it had resolved itself in the end (50%). That being said, almost one in five did not find the situation overwhelming or stressful while one in five were not satisfied at how it resolved itself.

### Figure 10: Evaluation of the Situation: Total Sample



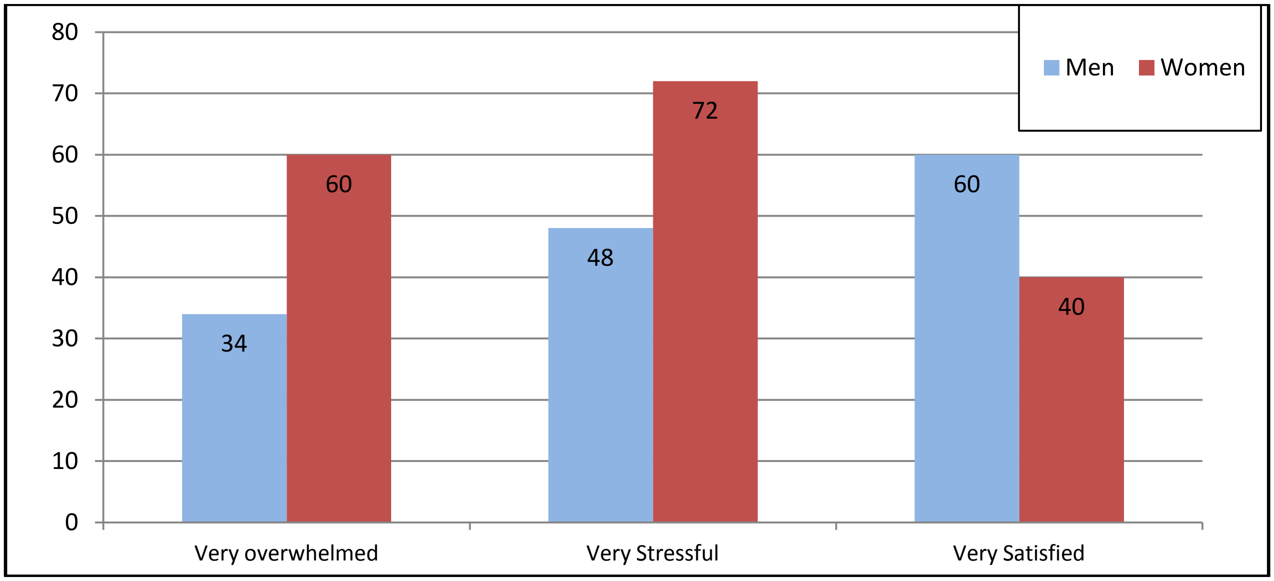
### 6.5.1 Impact of Gender on Perceived Resolution of the Situation

As can be seen by looking at the data in Table 14 and Figure 11, men and women have very different views on how their referent caregiving situation had resolved itself and their role in its resolution. Men were more likely than women to say that the situation had resolved itself successfully, to say that they felt relieved and fine/alright and to express satisfaction in how the situation was resolved. They were also less likely to say that they felt very overwhelmed and stressed by the situation. Women, on the other hand, were more likely to say that the situation was on-going, to say that they were exhausted and overwhelmed by the situation, to report that the situation was very stressful and very overwhelming for them, and were less likely to be satisfied in how it had resolved itself. Taken together these data suggest that either men and women were thinking of very different types of overwhelming caregiving situations during the interview and/or that men and women make very different attributions with respect to such situations (i.e. men display positive affectivity while women show negative affectivity).

**Table 44: Gender Differences: Resolution of the Situation**

| **How did the situation end?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| It was resolved successfully | 43% | 33% | 38% |
| It is ongoing | 27% | 37% | 32% |
| Some improvement | 10% | 2% | 6% |
| **How did you feel about the situation now?** | | | |
| Relieved | 50% | 21% | 43% |
| Overwhelmed/exhausted | 8% | 20% | 17% |
| Angry/frustrated | 16% | 5% | 14% |
| Fine, ok, alright | 12% | 5% | 10% |

**Figure 11: Gender Differences: Evaluation of the Situation**



### 6.5.2 Impact of Family Type on Perceived Resolution of the Situation

Family type is not strongly associated with how the employed caregiver evaluates the resolution of the situation (see Table 45). Key differences associated with family type include the fact that employees in the sandwich group were more likely to say that the situation they were thinking of was resolved successful where as those in the eldercare group were more likely to say that they had got through it, and those in the sandwich group were more likely to feel overwhelmed, exhausted and at peace while those in the eldercare group were more likely to say they were relieved. Family type was not associated with the degree to which the caregiver felt stressed, overwhelmed, satisfied or perceived that they had deal with the situation effectively.

**Table 45: Family Type Differences: Resolution of the Situation**

| **How did the situation end?** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| It was resolved successfully | 43% | 31% | 38% |
| Less than successful - but I got through it | 15% | 24% | 19% |
| **How did you feel about the situation now?** | | | |
| Relieved | 30% | 52% | 43% |
| Overwhelmed/exhausted | 21% | 7% | 17% |
| Sad/concerned | 12% | 4% | 9% |
| At peace (acceptance) | 9% | 0% | 6% |

### 6.5.3 Impact of Caregiving Intensity on Perceived Resolution of the Situation

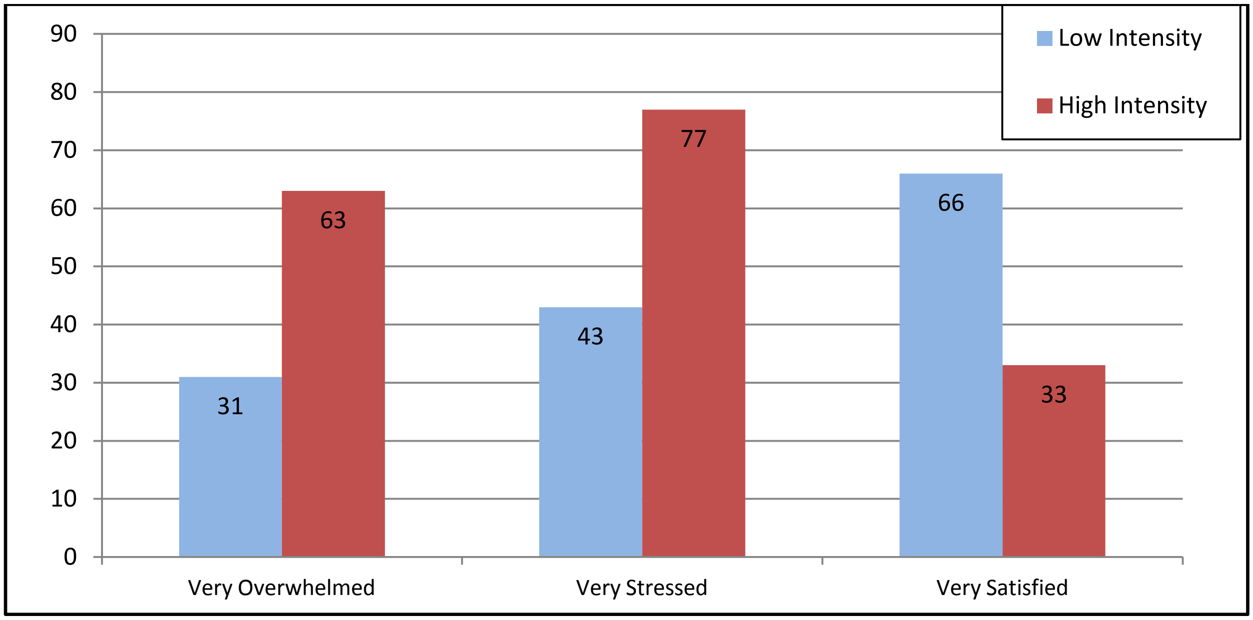
Caregiving intensity was associated in some very telling ways with how the caregiver viewed the resolution of the overwhelming situation that they were discussing (see Table 46 and Figure 12). Employees with low caregiving intensity were more likely to say that situation they were talking about had resolved itself successfully and that they felt happy, satisfied and relieved after it was over. Employees in this group were also significantly less likely to evaluate the situation as being very stressful and very overwhelming and more likely to say they were satisfied with its resolution.

**Table 46: Caregiving Intensity Differences: Resolution of the Situation**

| **How did the situation end?** | **Low** | **High** | **Total** |
|---|---|---|---|
| It was resolved successfully | 42% | 32% | 38% |
| It is ongoing | 22% | 42% | 32% |
| **How did you feel about the situation now?** | | | |
| Relieved | 42% | 28% | 43% |
| Overwhelmed/exhausted | 8% | 21% | 17% |
| Happy, satisfied | 19% | 7% | 16% |

Those with higher levels of caregiving intensity, on the other hand, were more likely to say the situation was ongoing (42% said this) and that they were overwhelmed and exhausted - findings that are consistent with how they evaluated the situation overall (63% said it was very overwhelming, 77% said it was very stressful and only 33% were satisfied with how it was resolved). These findings support the idea that caregiving intensity is positively associated with how long the situation has been viewed as overwhelming. Finally, it is interesting to note that caregiving intensity was not associated with whether or not the employee felt that they had deal with the situation effectively.

**Figure 12: Caregiving Intensity Differences: Evaluation of the Situation**



# Chapter Seven: Appraisal

In the previous chapter we used a scenario approach to help us better understand the caregiver strain appraisal process. In the next three chapters we deal more generally with the antecedents (appraisal), moderators (coping) and consequences of this phenomena. Questions used in this study to help us better understand the caregiver strain appraisal process are summarized in the box below. We begin this chapter by summarizing the responses given to each of these questions for the total sample This is followed by an examination of the relationship between gender, family type and caregiving intensity and the appraisal of strain.

**Questions: Appraisal (What makes you feel strained and overwhelmed)**

Thank you for sharing those experiences. The next few questions deal more generally with your experiences of caregiver strain. They are designed to give us a better understanding of the factors that make some people feel overwhelmed in a particular situation – while others do not.

What are the challenges (if any) you currently face with respect to providing care for your elderly dependent? More specifically:

- Are there any personal challenges?
- Are there challenges with the dependent themselves?
- Are there challenges at home?
- Are there challenges at work?
- Are there challenges within your community
- From your own personal experience, what have you found about the caregiving situation makes you feel stressed?
- What kinds of rewards do you get from caring for an elderly dependent?

## 7.1: Appraisal: Total Sample

*Personal challenges caring for an elderly dependent*: One in five of the respondents indicated that they did not currently face any challenges with respect to caring for their elderly dependent. The rest identified the challenges listed in Table 47. The most common challenge mentioned by the respondents in this sample was finding a "good" balance between work, life and their responsibilities to their elderly dependent. Sixteen percent noted that they had a pre-existing medical condition that made it difficult for them to do everything they needed to do while 13% noted challenges associated with concern for their dependent with respect to aging and their welfare ("they are a a crisis waiting to happen"). Other challenges noted by a small number of respondents included increased stress, emotional issues, being tired all the time due to a lack of sleep and the distance between themselves and the dependent they cared for.

### Table 47: What personal challenges do you currently face caring for an elderly dependent?

| | **Total** |
|---|---|
| Finding balance between my life and my responsibility to dependent (not enough time) | 37% |
| None | 20% |
| Pre-existing medical condition/health issue | 16% |
| Other | 16% |
| Concern for dependents aging and welfare (they are a crisis waiting to happen" | 13% |
| Increased stress | 7% |
| Emotional issues (feel guilty, depressed etc) | 7% |
| I get tired/don't sleep enough | 6% |
| Distance from dependent | 5% |

*Challenges with dependent themselves*: While one in five mentioned that they did not have any challenges that could be linked to the care recipient, many noted that declines in either the dependent's mental (32%) or physical (30%) health was causing them challenges (see Table 48). Another common response (28%) linked the personality of the care recipient (they are stubborn, argumentative, want to remain independent) as challenging. One in five said that they person that they cared for was emotionally needy (feels lonely and isolated) which ago increased the challenges for the caregiver.

### Table 48: What challenges do you have with the dependent themselves?

| | **Total** |
|---|---|
| Mental abilities declining ((S)he is very forgetful; personality changing for the worse) | 32% |
| Physically health declining (e.g. mobility issues ......) | 30% |
| Dependent is set in ways, stubborn, creates conflict, wants to remain independent | 28% |
| None | 20% |
| Emotionally needy/ lonely/feels isolated | 18% |
| Other | 13% |
| Dependent does not ask for help/share problems soon enough, feels guilty reaching out | 5% |

### Table 49: What challenges do you face at home?

| | **Total** |
|---|---|
| Affects my home life (e.g. less time for them, affects relationships, creates tension, routine changed, less space) | 53% |
| None | 34% |
| Hard to find time to be with my children/hard to fulfil demands associated with being mother/father | 22% |
| Other | 7% |

*Challenges at home:* While one in three indicated that they did not have any eldercare challenges that could be linked to their situation at home, this group was in the minority. Half of the sample stated that caregiving had affected their homelife (less time for family, negative impact on relationships at home, creates tension etc.) while 22% said that caregiving had decreased the amount of time and energy they had to fulfil the demands associated with being a mother, a father or a spouse (see Table 49).

*Challenges at work:* As can be seen by looking at the data in Table 50, a plurality of respondents (40%) indicated that caregiving did not present any challenges at work. The rest identified a number of ways in which these two roles conflicted, the most common of which related to the fact that they were also very busy at work (25%) which meant it was hard to balance conflicting demands. They also noted that there was a lot of conflict (especially with respect to timing) between meeting demands at work and the demands associated with caregiving (19%) and getting time off work when they needed it (policies are just not there). A minority noted that they found the fact that their productivity was negatively impacted by caregiving and the fact that their boss and/or colleagues were unsupportive and/or unaware to be challenging.

**Table 50: What challenges do you face at work?**

| | **Total** |
|---|---|
| None | 40% |
| Demanding role environment (e.g. busy time/stress at work/lots of changes) | 25% |
| Conflict between work and personal demands associated with caregiving | 19% |
| Getting time off, policies for sick days etc | 17% |
| Affects productivity (e.g. distracted, interrupted, can't focus) | 8% |
| Unsupportive/unaware colleagues/boss | 4% |
| Other | 1% |

*Challenges within their community:* Two thirds of the sample could not identify anything at the community level that made caregiving challenging (Table 51). The rest found the bureaucracy frustrating, could not find any support for caregivers in their community (lived in smaller communities) and a lack of programs within their community for seniors.

**Table 51: What challenges do you face in your community?**

| | **Total** |
|---|---|
| None | 65% |
| System/bureaucracy is frustrating – Can't find where to go to get help | 11% |
| Nature of community means little help available (e.g. aging, rural) | 10% |
| Lack of programs for seniors | 10% |
| Other | 9% |

*What is it about caregiving itself that causes you to feel stressed?:* Respondents identified ten key things associated with caregiving that made them feel stressed (see Table 52). The number one stressor mentioned by the employed caregivers in this sample (cited by a third of respondents) was all the demands on their time and their inability to balance work, life and caregiving. Other key stressors included the emotional burden attached to the caregiving role, challenges they faced dealing with the dependent and the fact that they had difficulty getting any help. Approximately one in ten identified at least one of the following stressors: dealing with the healthcare system, the quality of care their dependent was receiving in residence, the unpredictable nature of caregiving, and the fact that they have sole responsibility for the care of their dependent. Very few people were stressed by the distances involved, having their dependent living with them, or feelings of guilt because they were not doing enough.

**Table 52: What is it about care giving itself that makes you feel stressed?**

| | **Total** |
|---|---|
| All the demands on my time - hard to balance work/life/care giving | 35% |
| Emotional burden | 18% |
| Dealing with dependent (e.g. they are stubborn, can't communicate, used to being independent) | 18% |
| Difficulties getting help (e.g. bureaucracy, not knowing who to ask) | 15% |
| Other | 13% |
| Dealing with doctor/healthcare professionals | 11% |
| Quality of care in residence | 9% |
| Lack of control, unpredictable | 9% |
| Being the only caregiver, sole responsibility | 7% |
| Guilt, wanting to do more, not sure if doing the right thing | 4% |
| Distance | 4% |
| Sharing my home with dependent (sheltering kids) | 2% |

*What rewards do you get from caregiving?* As positive appraisals of the caregiving situation may somewhat mitigate the challenges faced by the employed caregivers in the sample we asked respondents to identify the rewards they received from caregiving. Findings are shown in Table 53. Of note are the following two pieces of data: (1) only 6% of the sample indicated that they did not get any rewards at all from caregiving, and (2) one in five noted that they "were not in for the rewards" but because they felt it was their moral responsibility. There was a high degree of consensus between the rest of the respondents with respect to the rewards associated with this role. More specifically, half the caregivers talked about how caregiving had improved the relationships within their family and increased family bonding. One in three talked about how they felt good just knowing the person was well cared for and safe and another 12% talked about the satisfaction one got from helping others. A minority (approximately one in ten) mentioned one or more of the following rewards: appreciation and gratitude from the dependent and a sense of personal growth and accomplishment.

**Table 53: What rewards to you get from caregiving?**

| | **Total** |
|---|---|
| Family Bonding (e.g. better relationship with person I'm caring for, better relationships with family) | 48% |
| Knowing (s)he's well cared for and safe | 32% |
| I do not expect a reward - Its right that I should do this | 21% |
| Satisfaction from helping others | 12% |
| Appreciation and gratitude from dependent | 9% |
| Personal growth, sense of accomplishment | 7% |
| Other | 7% |
| None -- nothing | 6% |
| Setting example for my children | 4% |

## 7.2 Impact of Gender on Appraisal of Strain

Gender differences in the caregiver strain appraisal process noted in this study are described in Table 54 and summarized below:

- Women were more likely than men to report that they experienced personal challenges from caregiving as well as challenges within their community (more likely than men to find the bureaucracy frustrating)

- Men were more likely than women to say that they experienced caregiving challenges that were related to the person they were caring for (their mental abilities were declining), their situation at home and the demanding environment they faced at work.

**Table 54: Gender Differences: Coping**

| **Personal challenges face caring for elderly dependent** | **Male** | **Female** | **Total** |
|---|---|---|---|
| None | 25% | 15% | 20% |
| **Challenges with the dependent themselves?** | | | |
| Mental abilities declining ( (S)he is very forgetful, personality changing for the worse) | 40% | 24% | 32% |
| None | 12% | 26% | 20% |
| **Challenges at home** | | | |
| None | 28% | 40% | 34% |
| **Challenges at work** | | | |
| Demanding role environment (e.g. busy time/stress at work/lots of changes) | 32% | 18% | 25% |
| **Challenges in community** | | | |
| None | 77% | 52% | 65% |
| System/bureaucracy is frustrating – Can't find where to go to get help | 4% | 17% | 11% |
| **What is it about care giving itself that makes you feel stressed?** | | | |
| Demands on my time - balancing work/life/care giving | 47% | 28% | 35% |
| Emotional burden | 26% | 11% | 18% |
| Difficulties getting help (e.g. bureaucracy, not knowing who to ask) | 21% | 9% | 15% |
| Dealing with doctor/healthcare professionals | 23% | 0% | 11% |
| **Rewards from caregiving** | | | |
| Knowing (s)he's well cared for and safe | 42% | 24% | 32% |
| Satisfaction from helping others | 17% | 7% | 12% |

- Men were more likely than women to say that they found the demands on their time, the emotional burden associated with caregiving, difficulties in getting help and dealing with the health care system made them feel stressed.

- Men were more likely than women to say that they were rewarded for their caregiving role by the knowledge that the person they were cared for was safe and well cared for and by the satisfaction of knowing that they were helping others

- There were no instances in which women were more likely than men to report something about the caregiving situation itself that made them feel either stressed or rewarded.

## 7.3 Impact of Family Type on Appraisal of Strain

Differences in the caregiver strain appraisal process associated with family type are noted in Table 55. Those in the sandwich group were <u>more</u> likely than those in the eldercare group to say:

- They found finding a balance between their life and their responsibilities as a caregiver challenging,
- That they found the physical decline in the health of the person they were caring for very challenging,
- That they encountered challenges and conflicts at home that they attributed to the following aspects of caregiving: less time for their family and a reduced ability to do the things that they associated with being a good mother and father,
- That they ran into challenges at combining caregiving and work due to their demanding work environment, conflict between their work and the demands associated with caregiving, their inability to get time off work for caregiving (policies not there) and the fact that caregiving had negatively impacted their productivity,
- That the demands on their time and their inability to balance work, life and caregiving made them feel stressed
- Better relationships at home were one of the rewards that they had personally realized from caregiving, and
- That they did not engage in caregiving in the expectations of a personal reward but had instead provided such care for moral reasons.

Those in the eldercare group, on the other hand, were <u>more</u> likely than those with both childcare and eldercare:

- To say that caregiving had increased their personal stress levels,
- To attribute the challenges they faced with respect to caregiving to the fact that the mental health of the dependent they cared for was in decline,
- To report that they had not experienced any challenges at either work or at home that they attributed to caregiving,
- To say that dealing with the dependent and worries about the quality of care they were receiving in residence were key stressors for them, and
- To indicate that they were rewarded for caregiving by knowing that the person they cared for was safe.

Finally, it should be noted that family type was not associated with the challenges faced within the community with respect to caregiving.

**Table 55: Family Type Differences: Coping**

| **Personal challenges face caring for elderly dependent** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| Finding balance between my life and my responsibility to dependent (e.g., not enough time) | 45% | 30% | 37% |
| Increased stress | 2% | 12% | 7% |
| **Challenges with the dependent themselves?** | | | |
| Mental abilities declining. e.g., (S)he is very forgetful, or personality changing for the worse | 27% | 36% | 32% |
| Physically health declining (e.g. mobility issues ......) | 35% | 20% | 30% |
| **Challenges at home** | | | |
| Affects my home life (e.g. less time for them, affects relationships, creates tension, routine changed, less space) | 56% | 44% | 53% |
| None | 27% | 43% | 34% |
| Hard to find time to be with my children/hard to fulfil demands associated with being mother/father | 27% | 17% | 22% |
| **Challenges at work** | | | |
| None | 28% | 53% | 40% |
| Demanding role environment (e.g. busy time/stress at work/lots of changes) | 30% | 18% | 25% |
| Conflict between work and personal demands | 23% | 14% | 19% |
| Getting time off, policies for sick days etc | 23% | 10% | 17% |
| Affects productivity (e.g. distracted, interrupted, can't focus) | 12% | 4% | 8% |
| **What is it about care giving itself that makes you feel stressed?** | | | |
| Demands on my time - balancing work/life/care giving | 39% | 30% | 35% |
| Dealing with dependent (e.g. they are stubborn, can't communicate, used to being independent) | 14% | 22% | 18% |
| Quality of care in residence | 5% | 13% | 9% |
| **Rewards from caregiving** | | | |
| Family Bonding (e.g. better relationship with person I'm caring for, better relationships with family) | 55% | 42% | 48% |
| Knowing (s)he's well cared for and safe | 26% | 40% | 32% |
| I do not expect a reward - Its right that I should do this | 28% | 13% | 21% |

## 7.4 Impact of Caregiving Intensity on Appraisal of Strain

Table 56 summarizes key findings with respect to how caregiving intensity is related to the caregiver strain appraisal process. What challenges are associated with the higher levels of caregiving strain? The data from this study indicate that people with high levels of caregiver intensity are more likely than their counterparts with lower intensity to:

- Say that they face personal challenges because of eldercare, that they face challenges associated with the person they are caring for, and that they face challenges because of their situation at work and the community in which they live,
- Indicate that they have a pre-existing health condition that makes it challenging for them to provide caregiving,
- Identify a lack of sleep and being tired as a personal challenge they face due to of caregiving,

- Say that the person they care for is experiencing mental and physical declines in their health,
- Say that caregiving negatively impacts relationships at home and creates tension,
- Say that they find balancing work and the demands associated with caregiving challenging,
- Say that the nature of the community they live in (rural) means that there is little support available for employed caregivers,
- Identify the following aspects of caregiving as stressful: conflict with the dependent (they are stubborn and used to being independent), difficulties in getting help (the bureaucracy), and dealing with health care professionals, and
- Say they cannot think of any rewards that they get from caregiving.

**Table 56: Caregiving Intensity Differences: Coping**

| **Personal challenges face caring for elderly dependent** | **Low** | **High** | **Total** |
|---|---|---|---|
| None | 26% | 14% | 20% |
| Pre-existing medical condition/health issue | 8% | 25% | 16% |
| I get tired/don't sleep enough | 2% | 14% | 6% |
| **Challenges with the dependent themselves?** | | | |
| Mental abilities declining. e.g., (S)he is very forgetful, or personality changing for the worse | 19% | 44% | 32% |
| Physically their health is declining (e.g. mobility issues) | 18% | 34% | 28% |
| None | 27% | 12% | 20% |
| **Challenges at home** | | | |
| Affects my home life (e.g. less time for them, affects relationships, creates tension, routine changed, less space) | 45% | 57% | 53% |
| Hard to find time to be with my children/hard to fulfil demands associated with being mother/father | 30% | 13% | 22% |
| **Challenges at work** | | | |
| None | 52% | 28% | 40% |
| Conflict between work and personal demands | 7% | 31% | 19% |
| **Challenges in community** | | | |
| None | 76% | 52% | 65% |
| Nature of community means little help available (e.g. aging community, rural) | 4% | 16% | 10% |
| **What is it about care giving itself that makes you feel stressed?** | | | |
| Dealing with dependent (e.g. they are stubborn, can't communicate, used to being independent) | 14% | 22% | 18% |
| Difficulties getting help (e.g. bureaucracy, not knowing who to ask) | 8% | 22% | 15% |
| Dealing with doctor/healthcare professionals | 4% | 16% | 11% |
| Distance | 8% | 0% | 4% |
| **Rewards from caregiving** | | | |
| Knowing (s)he's well cared for and safe | 40% | 25% | 32% |
| None -- nothing | 0% | 12% | 6% |

# Chapter Eight: Coping with Caregiver Strain

This chapter focuses on how employees in this sample cope with caregiver strain in general. Questions used in part of the interview (see Box below) were included to give us a better understanding of what does and does not help people cope with the strains associated with caregiver strain are. This chapter is divided into four sections which focus on the identification of: (1) the of factors which facilitate caregiving, (2) the factors which hinder caregiving, (3) strategies which prevent caregiver strain from manifesting itself, and (4) positive spillover between caregiving and work and family role performance. In all cases the section begins by presenting key findings obtained using the total sample This is followed by an examination of the relationship between gender, family type and caregiving intensity and coping with caregiver strain.

**Questions: Coping with caregiver strain**

The next few questions deal specifically with coping with caregiver strain. More specifically we want to ask you more about how you cope with the challenges you talked about earlier.
- What do you personally do to cope with caregiver strain?
- What does your family do? What else could they do?
- What does your employer currently do? What else could they do?
- What does your community currently do? What else could they do?
- How about the government (local, federal, provincial)? What do they currently do? What else could they do?

We now want to ask what sort of things make it worse or more difficult for you to cope with the challenges you face combining employment and caregiving for an elderly dependent? More specifically:
- Is there anything your dependent does that makes things worse?
- Is there anything your family does that makes things worse?
- Is there anything your employer does that makes things worse?
- Is there anything that the local/federal/provincial government does that makes things worse?
- Is there anything you personally do that makes things worse?

Do you have any strategies that you have found to be successful in PREVENTING these stressful situations from happening in the first place? If yes, what are they?

Research shows that while caregiving can be stressful and challenging it can also provide those who provide such care with a number of benefits. The next set of questions explore this side of caregiving.
- How does your role as a caregiver help you at work? (or does it?)
- (For sandwich respondents only) How does your role as parent help you manage your caregiving responsibilities? (or does it?)
- How does what you do at work help you manage your caregiving responsibilities? (or does it?)

## 8.1 Factors that facilitate coping

*Personal coping strategies:* Respondents identified ten strategies that they personally used to cope with caregiver strain (see Table 57). Many of these strategies (especially the most common ones) were mentioned previous in the scenario discussion: talk/vent with partner and exercise. In addition to these two strategies, each of which was mentioned by approximately half the sample, one in five talked about they spent time on their hobbies and in other activities that they enjoyed. They noted that this enabled them to relax and "got their mind off" the challenges they faced with respect to caregiving. One in five coped by using alcohol and "eating comfort food" - a strategy that while perhaps minimizing the symptoms of stress in the short term does nothing to reduce the stressor in the long term. Other strategies cited by approximately one in ten respondents included live a healthy lifestyle/get enough sleep, stay organized, and just focus on getting through with it.

Of note are the data showing that virtually all of the strategies used by the respondents in this study focus on alleviating the symptoms associated with higher levels of stress. Only two of the strategies mentioned, (stay organized; just do it) focus on reducing the occurrence of the stress.

**Table 57: What do you do to cope with this stress?**

| | **Total** |
|---|---|
| Talk/vent with partner/family/friends | 45% |
| Exercise, e.g., sports, walking | 44% |
| Hobbies (reading, crafts, etc) | 20% |
| Relax, (e.g. take it easy, shopping, time with pet/dog, take my mind off it) | 20% |
| Other | 18% |
| Drink alcohol, eat comfort food | 18% |
| Live a healthy lifestyle (e.g. eat healthily, get a good night’s sleep) | 13% |
| Stay organized (use calendar) | 12% |
| Just do it and get through it | 8% |
| Spend quality time with partner and/or family | 5% |
| Be positive, think of bigger picture | 3% |

*Support from Family: What do they do? What could they do?* Just over one in four of the interview respondents said that they received no support from their family that helped them cope with the stresses associated with caregiving (Table 58). Half said that their partner's was very supportive, one in four noted help from their children and one in five talked about support from their siblings. Support offered by ones immediate family (children and spouse) seemed, from the comments, to be somewhat different from support from ones siblings. More specifically, respondents talked about receiving both emotional and instrumental support from their partner and children while support from siblings more often involved listening and offering verbal support.

Half of the sample could not think of anything else that their family could do to help them cope with the stress of caregiving. The rest of the respondents (35%) asked their siblings to make more of an effort to visit with and offer more help to "mom and dad" and to increase their involvement in the problem solving process (i.e. offer more instrumental support). Only 5% felt that their immediate family (spouse, children) could do more than they already were.

**Table 58: Support from Family**

| What does your family do to help you cope with this stress? | Total |
|---|---|
| Partner very supportive (both emotional and instrumental support with tasks) | 46% |
| Nothing | 28% |
| Children are understanding (if activities canceled, do more chores etc) | 25% |
| Siblings help by listening and offering emotional support | 20% |
| Other | 12% |
| **What else could your family do to help you cope with this stress?** | |
| Nothing | 47% |
| Siblings could visit/help their Dad/Mom/ relative more | 35% |
| Other | 12% |
| Get involved, problem solve, be part of solution | 8% |
| Partner/children could visit/help more at home | 5% |

*Support from Employer: What do they do? What could they do?* Just under one in four of the interview respondents said that they received no support from their employer for the issues that they faced balancing work and caregiving (Table 59). Others noted a number of things that their employer did that they found helped them cope, including allowing the employee to take time off work/a leave of absence (35%) and use flextime and/or telework work schedules (18%). Almost one in three talked very generally about how their employer and their immediate manager were supportive, but supplied few concrete details. Finally, 8% of the respondents indicated that the EAP offered by their organization had really helped them cope with stress.

Sixty percent of the sample could not think of anything else that their employer could do to help them cope with the stress of caregiving. The rest of the respondents requested their employer allow them to take compassionate leave and/or work a 4 day work week.

**Table 59: Support from Employer**

| What does your employer do to help you cope with this stress? | Total |
|---|---|
| Allow me to take time off/a leave of absence | 38% |
| Very supportive | 29% |
| Nothing | 23% |
| Allows flextime and/or teleworking | 18% |
| Immediate manager/supervisor is supportive | 8% |
| EAP | 8% |
| I don't know, haven't asked | 5% |
| Other | 2% |
| **What else could they do?** | |
| Nothing | 59% |
| Allow time off/compassionate leave | 23% |
| Allow flextime/ 4 day weeks | 12% |
| Other | 6% |
| Be more supportive (co-workers/boss) | 5% |
| Provide more info on options | 4% |

*Support from Community: What do they do? What could they do?* The data from this study indicate that very few Canadian communities offer their citizens any form of support to help them provide care to an elderly dependent(s). Half of the respondents indicated that their community did nothing to help them cope with the stress of caregiving (Table 60). What does seem to help? Community facilities (15%), meals on weeks (4%) and para-transpo (4%). Other respondents talked about the support they received from neighbours, the church etc.

Most of the respondents had suggestions on how the community could help them cope with the demands caregiving places on them. Three of these ideas were offered by a substantial number of employees. One in four wanted the community to provide expert guidance, advice and assistance for caregiving issues ("one number to call to get advice and help"), the same proportion that requested more senior community centers. One in five felt that in-home care options (cleaning, meals etc) would be very valuable and made requests with respect to transportation options for the elderly (e.g. transportation for medical appointments, greater accessibility of public transportation).

**Table 60: Support from Community**

| **What does your community do to help you cope with this stress?** | **Total** |
|---|---|
| Nothing | 50% |
| Community facilities available (e.g. church programs, recreational events, and homecare programs) | 15% |
| Don’t know what they can do | 10% |
| Other | 9% |
| Good support network (e.g. neighbors help, visit dependent, provide food, send flowers, talk) | 8% |
| Give advice, provide information, and support me emotionally | 5% |
| Meals on wheels | 4% |
| Provide transportation | 4% |
| **What else could they do?** | |
| Provide expert guidance and advice on eldercare issues (from in home facilities, to care facilities, to palliative care planning) | 25% |
| More senior community centers | 24% |
| Nothing | 22% |
| More in-home care options (from cleaning, meals to doctors house calls) | 18% |
| Provide transportation to medical appointments | 13% |
| Other | 13% |
| Improve public transport (accessibility etc) | 8% |

*Support from Government: What do they do? What could they do?* A plurality of respondents (39%) could not identify anything that either the provincial or federal government did to support employed caregivers (Table 61). Another one in four (26%) said that they were not aware of any supports but admitted that they had not looked into the issue. In other words, almost two thirds of the employed caregivers in this sample were not aware of any policies or practices put in place by these two levels of government to support citizens who were looking after elderly dependents. This suggests that either such supports are not readily available or that governments are not doing a good of informing the public of what is available. In fact the only government support mentioned by a substantive number of respondents (20%) were services such as the CCAC, homecare etc.. The rest of the respondents (20% gave idiosyncratic answers) that seemed to be community or situation specific.

While respondents had difficulty thinking of governments supports currently available to them, they had no such problem identifying things that the government could do that they thought would help. While there were a lot of individual requests (27% "other"), other suggestions were giving by an appreciable number of respondents. Many respondents asked the government to provide more funding for programs offered by the CCAC. Others asked for tax credits/other forms of financial assistance for those providing elderly care, more high quality long-term eldercare facilities, and family care leave (replace compassionate care leave with a leave that is modeled after parental leave). One in ten requested the government streamline the bureaucracy so that people were more aware of what was available and more able to obtain help.

**Table 61: Support from Government**

| **What does the government do to help you cope with this stress?** | **Total** |
|---|---|
| Nothing | 39% |
| I don't know, haven't looking into it | 26% |
| Provides some services (e.g. Home care, CCAC, EAP) | 20% |
| Other | 20% |
| Limited coverage/access | 5% |
| **What more could they do?** | |
| Other | 27% |
| More funding and support for things such as homecare, CCAC | 21% |
| Tax credits and/or financial assistance | 17% |
| Nothing | 15% |
| More/cheaper/better long-term eldercare facilities/ nursing homes | 10% |
| Provide more information/reduce bureaucracy | 10% |
| Don't know | 9% |
| Offer family care leave (equivalent to maternity leave) | 7% |
| Provide care giving support, e.g., (i.e. for mother) when elder caregiver (i.e. father) becomes ill, | 7% |
| Provide more specialists in local area | 5% |
| Suggestions related to health care | 5% |

### 8.1.1 Impact of Gender on Factors that Facilitate Coping

Overall, there were more similarities than differences between the men and women in the sample with respect to coping and support. That being said, there were a number of gender differences with respect to these issues that are worthy of note (Table 62). The women in the sample were more likely than the men to:

- Cope with stress by making time for exercise and hobbies,
- Indicate that the help provided by their siblings helped them cope with the stress of caregiving,
- Say that the flexible work arrangements offered by their employer helped them cope with the stress of caregiving,

- Request that their employer allow them to use flexible work arrangements (4 day work week mentioned specifically), and
- Say that their community offered no supports to employed caregivers.

The men in the sample were <u>more</u> likely than the women to:

- Cope by "just getting it done",
- Say that their family and their employer offered no support to employed caregivers/them,
- Feel that there was nothing that either their family or their employer could do other than what they were currently doing,
- Request that their employer provide compassionate care leave,
- Indicate that the facilities in their community helped them balance employment and caregiving,
- Request two forms of support from the community: senior centers, and expert advice on how they could best help their dependent, and
- Ask the government provide financial assistance to caregivers in the form of a tax credit.

**Table 62: Gender Differences: Factors that Facilitate Coping**

| **What do you do to cope with this stress** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Exercise, e.g., sports, walking | 55% | 33% | 44% |
| Hobbies (reading, crafts, etc) | 8% | 32% | 20% |
| Just do it and get through it | 12% | 4% | 8% |
| **What does your family do to help you cope with this stress?** | | | |
| Nothing | 34% | 20% | 28% |
| Siblings help | 6% | 35% | 20% |
| **What else could they do?** | | | |
| Nothing | 57% | 39% | 47% |
| **What does your employer do to help you cope with this stress?** | | | |
| Nothing | 29% | 18% | 23% |
| Allow flextime and/or teleworking | 14% | 22% | 18% |
| **What else could they do?** | | | |
| Nothing | 68% | 52% | 59% |
| Allow time off/compassionate leave | 29% | 17% | 23% |
| Allow flextime/ 4 day weeks | 2% | 20% | 12% |
| **What does your community do to help you cope with this stress?** | | | |
| Community facilities available (e.g. church programs, recreational events, and homecare programs) | 21% | 11% | 15% |
| Don’t know what they can do | 17% | 6% | 10% |
| **What else could they do?** | | | |
| Offer expert guidance and advice on eldercare issues (from in home facilities, to care facilities, to palliative care planning) | 25% | 11% | 25% |
| More senior community centers | 21% | 13% | 24% |
| Nothing | 27% | 39% | 22% |
| **What else could they do?** | | | |
| Tax credits and/or financial assistance | 26% | 8% | 17% |

Finally it is important to note that very few respondents of either gender felt that the government did anything to support employed caregivers.

### 8.1.2 Impact of Family Type on Factors that Facilitate Coping

Table 63 summarizes key differences in coping strategies and perceived support associated with family type.

**Table 63: Family Type Differences: Factors that Facilitate Coping**

| **What do you do to cope with this stress** | **Sandwich** | **Elder** | **Total** |
|---|---|---|---|
| Talk/vent with partner/family/friends | 54% | 35% | 45% |
| Exercise, e.g., sports, walking | 48% | 38% | 44% |
| Hobbies (reading, crafts, etc) | 24% | 16% | 20% |
| Relax, (e.g. take it easy, shopping, time with pet/dog, take my mind off it) | 26% | 14% | 20% |
| Drink alcohol, eat comfort food | 24% | 6% | 18% |
| Stay organized (use calendar) | 7% | 16% | 12% |
| **What does your family do to help you cope with this stress?** | | | |
| Partner very supportive | 52% | 40% | 46% |
| Siblings help | 16% | 24% | 20% |
| Children help | 23% | 12% | 17% |
| **What else could they do?** | | | |
| Nothing | 55% | 38% | 47% |
| Siblings could visit/help their Dad/Mom/ relative more | 31% | 41% | 35% |
| Get involved, problem solve, be part of solution | 4% | 13% | 8% |
| **What does your employer do to help you cope with this stress?** | | | |
| Immediate manager/supervisor is supportive | 14% | 2% | 8% |
| EAP | 14% | 2% | 8% |
| **What else could they do?** | | | |
| Nothing | 51% | 70% | 59% |
| Allow time off/compassionate leave | 32% | 11% | 23% |
| Allow flextime/ 4 day weeks | 17% | 5% | 12% |
| **What does your community do to help you cope with this stress?** | | | |
| Nothing | 23% | 40% | 50% |
| Community facilities available (e.g. church programs, recreational events, and homecare programs) | 20% | 12% | 15% |
| **What else could they do?** | | | |
| More senior community centers | 12% | 21% | 24% |
| **What does the government do to help you cope with this stress?** | | | |
| Nothing | 29% | 50% | 39% |
| I don't know, haven't looking into it | 33% | 19% | 26% |
| Provides some services (e.g. Home care, CCAC, EAP) | 24% | 16% | 20% |
| **What else could they do?** | | | |
| More funding and support in general | 17% | 26% | 21% |
| Tax credits and/or financial assistance | 13% | 21% | 17% |
| Nothing | 19% | 9% | 15% |

Those in the sandwich group were more likely than their counterparts in the eldercare group to:

- Cope by engaging in activities to reduce the impact of caregiver strain (i.e. taking with their partner, their family and their friends, exercise, make time for hobbies and relaxation, and drink alcohol),
- Say that their partner and their children helped them cope with the challenges associated with caregiving,
- Say there was nothing else their family could do to support them,
- Say that their immediate manager at work was supportive of their need to balance work and caregiving and that the EAP services offered by their organization helped them cope with stress,
- Ask their employer to support employed caregivers by offering compassionate care leave and compressed work week schedules,
- Say that the availability of church programs, recreational events for seniors and homecare programs in their community helped them cope with caregiver strain, and
- Say that government programs such as Homecare and the CCAC helped them cope with caregiver strain.

Those in the eldercare group were more likely than their those in the sandwich group to:

- Cope by taking steps to reduce the stress before it occurred (i.e. organize, plan),
- Say that their siblings helped them cope with the challenges associated with caregiving,
- Say that they would like their siblings to spend more time with their parents and to participate in problem solving with respect to the care of their parents,
- Say that there is nothing that their employer, their community and the government could do in terms of helping them cope with caregiver strain
- Say that they needed more senior centers in their community, and
- Indicate that they would like the government to provide financial assistance/tax credit to support employed caregivers.

### 8.1.3 Impact of Caregiving Intensity on Factors that Facilitate Coping

Examination of the relationship between caregiving intensity and the data on coping/support (see Table 64) give us a better understand of some of the factors associated with higher and lower levels of caregiving intensity. Key observations are summarized below.

*Personal coping*: Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were more likely to say that they coped by drinking alcohol and eating comfort food and spending time in their hobbies. They were, however, less likely to cope by exercising, relaxing, getting enough sleep and concentrating on "just getting through" the situation. While it is hard to determine direction of causality from these data (those with high could have less time for coping activities or poor use of coping techniques could lead to higher strain) there does appear to be a link between effective coping and intensity/strain.

*Support from family*: The data also suggest that those in the low intensity group receive more support (instrumental and emotional) from their families. Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were less likely to say that their siblings helped with their parents care and more likely to request that their siblings make more of an effort to visit their parents.

**Table 64: Caregiving Intensity Differences: Factors that Facilitate Coping**

| **What do you do to cope with this stress** | **Low** | **High** | **Total** |
|---|---|---|---|
| Exercise, e.g., sports, walking | 50% | 37% | 44% |
| Hobbies (reading, crafts, etc) | 11% | 29% | 20% |
| Relax, (e.g. take it easy, shopping, time with pet/dog, take my mind off it) | 27% | 14% | 20% |
| Drink alcohol, eat comfort food | 10% | 22% | 18% |
| Live a healthy lifestyle (e.g. eat healthily, get a good night's sleep) | 16% | 8% | 13% |
| Just do it and get through it | 12% | 4% | 8% |
| **What does your family do to help you cope with this stress?** | | | |
| Siblings help | 25% | 16% | 20% |
| **What else could they do?** | | | |
| Nothing | 56% | 38% | 47% |
| Siblings could visit/help their Dad/Mom/ relative more | 26% | 44% | 35% |
| **What does your employer do to help you cope with this stress?** | | | |
| Very supportive | 34% | 24% | 29% |
| **What else could they do?** | | | |
| Nothing | 64% | 45% | 59% |
| Allow flextime/ 4 day weeks | 6% | 16% | 12% |
| **What does your community do to help you cope with this stress?** | | | |
| Nothing | 18% | 63% | 50% |
| **What else could they do?** | | | |
| More senior community centers | 8% | 34% | 24% |
| More in-home care options (from cleaning, meals to doctors house calls) | 8% | 27% | 18% |
| **What does the government do to help you cope with this stress?** | | | |
| Nothing | 34% | 45% | 39% |
| **What else could they do?** | | | |
| Provide more specialists in local area | 0% | 10% | 5% |
| Suggestions related to health care | 0% | 10% | 5% |

*Support from employer*: The data also indicate that employees in the low intensity group receive more support from their employers. Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were less likely to say that their employer was supportive and less likely to say that there was nothing more that their employer could do to support employees with eldercare demands. They were also more likely to say that flextime and compressed work week arrangements would help them balance work and caregiving.

*Support from community and government*: The data from this study also support the idea that employees who cannot access support from their community or the government are more likely to report high levels of caregiving intensity (half of those with higher caregiver intensity claim that neither of these bodies offer them any form of support). The findings also suggest that things such as senior community centers, in-home care options, and a focus on health care options for seniors would help this group cope with the strain they face.

## 8.2 Factors that hinder coping

What makes caregiving more difficult? What makes it harder for employed caregivers to balance caregiving, family and work? Answers to these questions are provided below.

What does the care recipient do that makes things more difficult for the caregiver? Responses to this question are shown in Table 65. While one in four said nothing, the rest of the respondents identified a number of factors that make caregiving more challenging. Many of these challenges related to personality conflicts and differences in priorities between the caregiver and the care recipient (they are stubborn, obstructive, disrespectful of my time commitments and demanding). Others relate to the fact that the physical and mental health of the care recipient is in decline and requires more of the caregivers time and energy.

**Table 65: What does the dependent you are caring for do that makes things worse?**

| | **Total** |
|---|---|
| They are stubborn or obstructive | 33% |
| Nothing | 27% |
| Disrespectful of my time commitments/time at work | 18% |
| Physical and/or mental health in decline so can’t help themselves and/or forgets things | 16% |
| They are demanding, e.g., they nag | 15% |
| They don’t get involved in solving the problem | 11% |
| Other | 8% |

While half of the respondents indicated that their family did not do anything to make matters worse (see Table 65), many said that they behaviour of their siblings made things more challenging (they don't help, they are not there for me, fight with siblings etc.). Very few people said that their partner and children made things worse.

**Table 66: What does your family do that makes things worse?**

| | **Total** |
|---|---|
| Nothing | 49% |
| Siblings can’t/don’t help/ live far away don’t realize how difficult it is/ not there for me | 28% |
| Conflict with siblings | 10% |
| Other | 8% |
| Put demands on my time | 7% |
| Partner/children could be more helpful/supportive | 5% |

Two-thirds of the employees in this sample indicated that their employer did nothing to make it harder for them to cope with eldercare demands. Approximately one in ten of the employees in the sample did, however, identify three ways (see Table 67) that their employer made things worse: (1) their employer had very high expectations with respect to workloads and deliverables that did not consider other demands on the employee's time, (2) the employer was unsupportive of time off for caregiving, and (3) there was little flexibility with respect to work hours, work location and vacation time.

**Table 67: What does your employer do that makes things worse?**

| | **Total** |
|---|---|
| Nothing | 68% |
| High expectations (workloads, deliverables) | 12% |
| Unsupportive about time off (paperwork requirements are onerous) | 9% |
| Lack of flexibility | 7% |
| Other | 6% |
| Work conflicts with care giver requirements | 5% |

Two-thirds of the employees in this sample identified things that the government did that made it more difficult for them to balance work and caregiving (see Table 68). Most commonly they felt that the services provided for the aged were inadequate and insufficient in number, that the bureaucracy made it very difficult for someone in need to find help and information, and that budget cuts had reduced the amount of support available.

**Table 68: Does the government do anything that makes things worse?**

| | **Total** |
|---|---|
| Nothing | 36% |
| Not enough/inadequate services for the aging | 26% |
| Finding help & information is difficult (e.g. too much bureaucracy, unclear what is available) | 23% |
| Not enough support/budget cuts | 17% |
| Other | 11% |
| Not enough retirement facilities/ wait times long | 4% |

Eighty percent of the sample identified things that they personally did that made their situation worse (see Table 69). More specifically, they note that they made things worse when they "hung on" to responsibility for the care of their family member (even when things got too much), got upset too easily, internalized their problems, took their stress out on the care recipient (abrupt, and fight with dependent) and/or themselves (self-guilt) and let things go that they shouldn't.

**Table 69: Is there anything that you personally do that makes things worse?**

| | **Total** |
|---|---|
| Take all the responsibility | 27% |
| Nothing | 21% |
| Get upset/stressed too easily | 16% |
| Tend to internalize problems/ don’t deal with it | 11% |
| Be short/abrupt with dependent | 8% |
| Put my own self-guilt on myself | 7% |
| No longer proactive (don't want to do this, resigned, let things go that I shouldn't) | 7% |
| Fight/argue with person I am caring for | 6% |
| Fight with siblings | 4% |

### 8.2.1 Impact of Gender on Factors that Hinder Coping

The men in the sample gave very different answers to many of these questions than the women in the sample (Table 70). Men were more likely than women to:

- Say that the dependent, their employer, the government and they themselves did not do anything that made things worse,
- Say that it made it harder to them when the person that they were caring for took no responsibility for problem solving,
- Say that conflict with their siblings and fights with the person they were caring for made things more challenging, and
- Say that government budget cuts for services to support caregivers had made things more challenging.

**Table 70: Gender Differences: Factors that Make things Worse**

| **What does the dependent you are caring for do that makes things worse?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Nothing | 32% | 22% | 27% |
| Disrespectful of my time commitments/time at work | 11% | 21% | 18% |
| Physical and/or mental health in decline so e.g. can't help themselves and/or forgets things | 11% | 21% | 16% |
| They don't get involved in solving the problem | 15% | 5% | 11% |
| **What does your family do that makes things worse?** | | | |
| Conflict with siblings | 17% | 4% | 10% |
| **What does your employer do that makes things worse?** | | | |
| Nothing | 78% | 59% | 68% |
| Unsupportive about time off | 4% | 14% | 9% |
| Lack of flexibility | 2% | 11% | 7% |
| Work conflicts with care giver requirements | 10% | 1% | 5% |
| **What does the government (local, provincial, federal) do that makes things worse?** | | | |
| Nothing | 49% | 25% | 36% |
| Not enough/inadequate services for the aging | 20% | 30% | 26% |
| Finding help and information is difficult (e.g. too much bureaucracy, unclear what is available) | 14% | 31% | 23% |
| Not enough support/budget cuts | 25% | 10% | 17% |
| **Is there anything that you personally do that makes things worse?** | | | |
| Nothing | 29% | 13% | 21% |
| Get upset/stressed too easily | 10% | 21% | 16% |
| Fight/argue with person I am caring for | 13% | 0% | 6% |
| Fight with siblings | 9% | 0% | 4% |

Women were more likely than men to:

- Say that their dependent made things worse when they were disrespectful of their time,
- Say that that decline in the physical and/or mental health of the dependent they were caring for had made things more difficult,

- Say that a lack of flexibility at work and difficulties in getting time off to care for their dependent made things more difficult,
- Say that a lack of government services to support the aged and challenges dealing with the bureaucracy had made things more problematic,
- Indicate that they made it harder on themselves when they got stressed and upset over the situation they found themselves in.

### 8.2.2 Impact of Family Type on Factors that Make things Worse

Data showing the relationship between family type and the identification of factors that hinder caregiving are shown in Table 71. Respondents in the eldercare group were more likely than those with both childcare and eldercare to:

- Say that their family, their employer, the government and they themselves did not do anything to make things worse,
- Say that the care recipient made things more challenging by nagging,
- Say that they themselves had made things worse by internalizing issues, not dealing with problems and by becoming resigned with their situation and letting things go that should be addressed.

**Table 71: Family Type Differences: Factors that Make things Worse**

| **What does the dependent you are caring for do that makes things worse?** | **Sandwich** | **Eldercare** | **Total** |
|---|---|---|---|
| Disrespectful of my time commitments/time at work | 20% | 12% | 18% |
| They are demanding, e.g., they nag | 10% | 21% | 15% |
| **What does your family do that makes things worse?** | | | |
| Nothing | 43% | 55% | 49% |
| Conflict with siblings | 14% | 6% | 10% |
| **What does your employer do that makes things worse?** | | | |
| Nothing | 64% | 72% | 68% |
| Unsupportive about time off | 14% | 4% | 9% |
| **What does the government (local, provincial, federal) do that makes things worse?** | | | |
| Nothing | 30% | 42% | 36% |
| Finding help & information is difficult (e.g. too much bureaucracy, unclear what is available) | 28% | 18% | 23% |
| **Is there anything that you personally do that makes things worse?** | | | |
| Take all the responsibility | 34% | 19% | 27% |
| Nothing | 13% | 29% | 21% |
| Tend to internalize problems/ don’t deal with it | 7% | 15% | 11% |
| No longer proactive, don't want to do this, resigned, let things go that I shouldn't with dependent | 1% | 13% | 7% |

Respondents in the sandwich group, on the other hand, were more likely than their counterparts in the eldercare group to say:

- That the care recipient made things more challenging by nagging and not respecting their time commitments at work,

- That conflict with their siblings had made things worse,
- That the fact that their employer was unsupportive about time off work made things more challenging,
- That the bureaucracy had made things more difficult as it was very hard for them to find help and relevant information, and
- That they themselves had made things worse by taking on all of the responsibility for the care of their elderly dependent.

**Table 72: Caregiving Intensity Differences: Factors that Made things Worse**

| **What does the dependent you are caring for do that makes things worse?** | **Low** | **High** | **Total** |
|---|---|---|---|
| Nothing | 40% | 14% | 27% |
| Disrespectful of my time commitments/time at work | 9% | 22% | 18% |
| Physical and/or mental health in decline so e.g. can't help themselves and/or forgets things | 10% | 22% | 16% |
| They don't get involved in solving the problem | 5% | 16% | 11% |
| **What does your family do that makes things worse?** | | | |
| Nothing | 62% | 37% | 49% |
| Siblings can't or don't help/ live far away/ don't realize how difficult it is/ not there for me | 18% | 37% | 28% |
| Conflict with siblings | 2% | 18% | 10% |
| **What does your employer do that makes things worse?** | | | |
| Nothing | 78% | 58% | 68% |
| High expectations (workloads, timelines) | 6% | 18% | 12% |
| Unsupportive about time off | 4% | 15% | 9% |
| **What does the government (local, provincial, federal) do that makes things worse?** | | | |
| Nothing | 50% | 22% | 36% |
| Not enough/inadequate services for the aging | 17% | 35% | 26% |
| Finding help & information is difficult (e.g. too much bureaucracy, unclear what is available) | 17% | 28% | 23% |
| Not enough support/budget cuts | 10% | 24% | 17% |
| **Is there anything that you personally do that makes things worse?** | | | |
| Nothing | 33% | 8% | 21% |
| Be short/abrupt with dependent | 4% | 12% | 8% |
| Put my own self-guilt on myself | 2% | 12% | 7% |
| No longer proactive, don't want to do this, resigned, let things go that I shouldn't with dependent | | | 7% |
| Fight with siblings | 8% | 0% | 4% |

### 8.2.3 Impact of Caregiving Intensity on Factors that Make things Worse

Data on the relationship between caregiving intensity and factors that make it harder for an employee to cope with the demands of caregiving are given in Table 72. Respondents in the low intensity group were more likely than those reporting high levels of caregiving intensity to say that their dependent, their family, their employer, the government and they themselves did not do anything to make caregiving more challenging. Those in the high intensity group, on the other hand were more likely to identify things in each of these areas that made caregiving more difficult. More specifically, they were more likely to identify the following factors as making it more challenging for them to provide eldercare:

- The person they were caring for did not respect their time commitments at work, and did not get involved in solving caregiving problems,
- Declines in the physical and/or mental health of the dependent they were caring for,
- Their siblings did not provide any help or support,
- Conflicts with their siblings,
- Their employer was unsupportive about time off work and expected a lot of their employees,
- A lack of government services, an opaque bureaucracy, and a lack of funding for the aged, and
- Their own sense of guilty and resignation.

## 8.3 Preventing caregiver strain

We asked respondents to identify any strategies that they had found to be effective at preventing caregiver strain in the first place. While 10% of the sample were not able to think of anything that had worked, the rest identified the strategies shown in Table 73. What prevents or minimizes strain? According to the employed caregivers in this sample, planning and organization (39%), better communication with the dependent and their family with respect to expectations (27%), being realistic about what you can and cannot do ("accept that you cannot control everything"), delegating work to others and getting help from other family members, maintaining a positive outlook and not getting angry, making time for oneself, and dealing with things as they come ("worry about what might happen in the future doesn't really help anything").

**Table 73: Do you have strategies to prevent these stressful situations from occurring?**

| | **Total** |
|---|---|
| Planning and organization | 39% |
| Better communication with everyone involved to set expectations | 27% |
| Other | 19% |
| Accept that I can’t control the situations/be realistic about what I can and can’t do | 12% |
| Delegate work /get help from other family members | 11% |
| No | 10% |
| Not getting upset/angry if it’s not worth it/maintain positive outlook/pick your battles | 9% |
| Take care of myself, take time for myself | 7% |
| Deal with it as it comes | 7% |

There were only four significant between group differences with respect to preventative strategies:

- Men (15%) were more likely that women (0%) to say that they "just deal with things as they come",
- Those in the eldercare group (33%) were more likely than those in the sandwich group (21%) to focus on setting expectations and communicating with all involved, and
- Respondents with high caregiving intensity were more likely than those with low intensity to say that they had no strategies to prevent strain from occurring (16% versus 0%) and less likely to say that they focused on communicating and setting expectations (17% versus 35%).

## 8.4 Positive Spillover

Recent research in the work-life area has recognized that combining working and family responsibilities need not always be detrimental and that the skills and insights gained in one domain can positively spillover to the other domain. We ended this section of the interview by asking respondents a number of questions to help us understand the extent to which employed caregivers experience positive spillover between the work, parent and caregiver roles. Data on positive spillover are presented in Table 74 (spillover from caregiving to work), 75 (spillover from work to caregiving), and 76 (spillover from parent role to caregiving). One in three of the employed caregivers in our sample felt that there was no positive spillover at all from work to caregiving or from caregiving to work. By comparison, 88% of the parents in the sample were able to identify ways in which the experience as a parent had helped them with respect to the provision of eldercare.

How does the role of caregiver benefit an employee at work? Respondents indicated that it helped them emphasize with their colleagues and clients who were in the same boat as they were, it had made them more diplomatic and patient, it had helped them appreciate the challenges faced by elderly Canadians, and had made them more aware of people with health issues and disabilities.

**Table 74: How does your caregiver role help you at work?**

| | **Total** |
|---|---|
| It doesn't | 34% |
| It helps me empathize with other care givers (e.g., colleagues, clients) | 30% |
| I see the bigger picture (more diplomatic, patient) | 27% |
| It helps me appreciate the difficulties the elderly face | 8% |
| I am more aware of people with health issues/disabilities | 6% |
| Other | 6% |
| Skills transfer | 5% |

How does the work role help an employee manager their caregiver responsibilities? Respondents indicated that it gave them the organizational and planning skills needed to effectively provide care, it helped them deal more effectively with crisis and stress, it helped them emphasize with other caregivers, and it gave them the technical skills they needed to find information on the web. Also of note are the data showing that for 5% of the sample, work provided an escape from the stress of caregiving.

**Table 75: How does your role at work help you manage your caregiver responsibilities?**

| | **Total** |
|---|---|
| It doesn't | 30% |
| Organizational/planning skills | 25% |
| Helps me to deal better with stressful situations/crisis | 18% |
| Helps me empathize with care givers | 12% |
| Technical expertise helped | 11% |
| Work is my escape, I enjoy it | 5% |
| Other | 4% |

**Table 75: How does your role as a parent help you in your caregiver role?**

| | Total |
|---|---|
| Parenting techniques apply to care giving | 38% |
| It doesn't | 12% |
| Makes me more patient | 12% |
| Other | 12% |
| Helps me see the big picture | 10% |
| Family bonding | 9% |
| Improves my organizational & multitasking skills | 9% |

With respect to spillover between the parent and caregiver roles, many in the sample (38%) said that the techniques and skills that they used as a parent applied to caregiving as well. One in ten indicated that parenting had taught them patience, helped them see the big picture, recognize the importance of family bonds, improved their ability to multi-task and helped them accept responsibility, all of which had high utility for caregivers.

### 8.4.1 Impact of Gender on Spillover

The perception of positive spillover varied with gender as shown in Table 76. Women were more likely than men to say that caregiving did <u>not</u> help them at work, that work did not help them with caregiving and that parenting provided no skills that helped them with caregiving. In other words, men were more likely to benefit from taking on the caregiving role than women.

**Table 76: Gender Differences: Spillover**

| How does your caregiver role help you at work? | Male | Female | Total |
|---|---|---|---|
| It doesn't | 27% | 41% | 34% |
| It helps me empathize with other care givers (colleagues, clients) | 35% | 25% | 30% |
| I see the bigger picture (more diplomatic, patient) | 31% | 23% | 27% |
| **How does your role as a parent help you in your caregiver role?** | | | |
| Parenting techniques apply to care giving | 47% | 24% | 38% |
| It doesn't | 11% | 29% | 12% |
| Helps me see the big picture | 14% | 4% | 10% |
| **How does your role at work help you manage your caregiver responsibilities?** | | | |
| It doesn't | 24% | 35% | 30% |
| Organizational/planning skills | 29% | 21% | 25% |
| Helps me to deal better with stressful situations/crisis | 33% | 3% | 18% |
| Work is my escape, I enjoy it | 0% | 10% | 5% |

More specifically, men were more likely than women to say that:

- Caregiving had helped them at work by making them more empathetic, diplomatic and patient,
- Their work role had made them a more effective caregiver by giving them planning, organizational and crisis management skills,
- That the techniques they had learnt as a parent had helped them in their caregiver role, and

- That being a parent had helped them see the big picture - a skill that helped them in their caregiver role.

### 8.4.2 Impact of Family Type on Spillover

The perception of positive spillover varied with family type as shown in Table 77. Employees in the eldercare group were more likely to say that their role as a caregiver did not help them at work. Those in the sandwich group, on the other hand, said that the caregiver role had made them more empathetic, diplomatic and patient. Respondents in the sandwich group were twice as likely as those in the eldercare group to say that parenting techniques apply to caregiving and that the organizational and planning skills that they had gained at work helped them with their caregiving responsibilities. It may be that positive spillover is more likely to occur when an individual is engaging in two roles simultaneously.

**Table 77: Family Type Differences: Factors that Prevent Stress**

| How does your caregiver role help you at work? | Sandwich | Eldercare | Total |
|---|---|---|---|
| It doesn't | 29% | 40% | 34% |
| It helps me empathize with other care givers (e.g., colleagues, clients) | 37% | 23% | 30% |
| I see the bigger picture (more diplomatic, patient) | 33% | 21% | 27% |
| **How does your role as a parent help you in your caregiver role?** | | | |
| Parenting techniques apply to care giving | 50% | 21% | 38% |
| **How does your role at work help you manage your caregiver responsibilities?** | | | |
| Organizational/planning skills | 29% | 20% | 25% |

### 8.4.3 Impact of Caregiving Intensity on Spillover

The perception of positive spillover varied with caregiving intensity as shown in Table 78. Employees with high caregiving intensity were more likely to say that their role as a caregiver did not help them at work. Those with low intensity, on the other hand, reported positive spillover from caregiving to work (I am more diplomatic, patient and aware of people with disabilities), from work to cargiving (work gave me good crisis management skills) and from parent to caregiver roles (gave me good multi-tasking and organizational skills).

**Table 78: Caregiving Intensity Differences: Factors that Prevent Stress**

| How does your caregiver role help you at work? | Low | High | Total |
|---|---|---|---|
| It doesn't | 28% | 41% | 34% |
| I see the bigger picture (more diplomatic, patient) | 34% | 20% | 27% |
| I am more aware of people with health issues/disabilities | 12% | 0% | 6% |
| **How does your role as a parent help you in your caregiver role?** | | | |
| Improves my organizational & multitasking skills | 17% | 2% | 9% |
| **How does your role at work help you manage your caregiver responsibilities?** | | | |
| Helps me to deal better with stressful situations/crisis | 22% | 13% | 18% |
| Work is my escape, I enjoy it | 0% | 10% | 5% |

These findings suggest that positive spillover offers some form of defense mechanism protecting against the strains of caregiving. The question remains, however, as to whether the perception of positive spillover is a function of the actual situation, the personality of the individual, or a combination of both.

Finally, it is interesting to note that one in ten of the women in the sample (but none of the men), and one in ten of those with high caregiving intensity (but none of those with low intensity) said that work was something they enjoyed - an opportunity for them to escape from the stress of caregiving. In these cases, work offers a haven from family strains, a situation that is seldom talked about in the work-life literature.

# Chapter Nine: Consequences of Caregiving

The final section of the interview included a number of questions designed to help us better understand how caregiving impacts the following key stakeholders: the caregiver, the recipient of care, the employer and the caregiver's family. The questions asked in this section are provided in the box below. Findings with respect to the total sample are provided first following by an examination of how gender, family type and caregiving intensity impacts the results. The last section of the chapter looks at the answers to the final question of the interview " What one piece of advice would you offer to a friend who has all of a sudden assumed care for an elderly dependent?"

**Questions: Consequences of caregiver strain**

The next few questions deal specifically with what happens to you when you are experiencing caregiver strain.

When you feel stressed or overwhelmed with the duties and responsibilities associated with caring for your elderly dependents what happens to you:
- Physically?
- Emotionally?

- Does caregiving change how you deal with others at work? If yes, how?

- Does caregiving affect your productivity at work? If yes, how?

- Does caregiving change how you deal with others at home? If yes, how?

- Does caregiving change how you deal with others the person you are caring for?

- Does caregiving change how you deal with others other family members?

We would now like you to ask you one last question to help us get an idea of what is important to YOU with respect to caregiving strain.

- What one piece of advice would you offer to a friend who has all of a sudden assumed care for an elderly dependent?

## 9.1 Consequences of Caregiver Strain

*Physical consequences to the caregiver*: The majority (83%) of the respondents experienced physical consequences of caregiver strain (see Table 79) the most common of which (44%) was exhaustion and tiredness. Other complaints mentioned by respondents included headaches, nausea, insomnia, increased in blood pressure, aches and pains and tension in the shoulder and neck. Given this list of symptoms it is not surprising that those with high levels of caregiver strain are absent from work more frequently.

**Table 79: Physical Consequences of caregiver strain**

| | **Total** |
|---|---|
| Tiredness/ exhaustion | 44% |
| Nothing | 17% |
| Headaches | 15% |
| Upset stomach, nausea | 15% |
| Other | 13% |
| Insomnia | 12% |
| Blood pressure increases | 11% |
| Aches and pains | 10% |
| Tension (shoulder/neck) | 8% |
| Poor eating habits | 5% |

*Emotional consequences to the caregiver*: Virtually all (94%) of the respondents said that high levels of caregiver strain came with emotional consequences (see Table 80). One in three said that the strain made them short tempered and grumpy. Other emotional responses to strain mentioned by respondents included becoming drained, anxiety attacks, crying, depression, sadness, anger and frustration, feeling overwhelmed, and wanting to be alone.

**Table 80: Emotional consequences of caregiver strain**

| | **Total** |
|---|---|
| Short tempered/ grumpy | 31% |
| Emotionally drained | 18% |
| Become anxious, anxiety attacks | 16% |
| Cry, get upset | 15% |
| Depressed, sad, lonely, helpless | 13% |
| Frustrated, angry | 12% |
| Overwhelmed | 11% |
| Become more introverted/want to be alone | 11% |
| Other | 6% |
| Nothing | 4% |
| Feel guilty | 4% |

*Consequences at work*: Just over half the sample indicated that the stress of caregiving negatively spilt-over into the work environment, either by having a negative impact on how they deal with their work colleagues or clients and/or by reducing their productivity (see Table 81). Examination of the data suggests that the emotional turmoil associated with caregiving for many of the employees in this sample meant that they were less patient with their colleagues at work, less social with others and inattentive to their work. The respondents also linked this lack of focus to a decline in their work productivity and increased absenteeism.

### Table 81: Consequences at work

| Impact of caregiving on how you deal with others at work | Total |
|---|---|
| No impact | 48% |
| Less patient, cranky, short with people | 32% |
| Less sociable | 12% |
| Shorter attention span, scattered | 8% |
| Other | 6% |
| **Impact of caregiving on productivity at work** | |
| No impact | 41% |
| Less focused | 34% |
| Decreases productivity | 27% |
| Other | 6% |
| Call in sick, work fewer hours | 5% |
| Wastes time | 4% |

*Consequences at home*: Virtually all of the respondents (80%) indicated that caregiving strain had a negative impact on how they deal with immediate family (see Table 82). Half said that they were more short tempered and less patient with their spouse and/or children while one in ten reported that they were more withdrawn, often in a bad mood, less engaged in family discussions and activities, tired, and argumentative.

### Table 82: Consequences at home

| | Total |
|---|---|
| Short tempered, less patient, bossy | 45% |
| It doesn't | 19% |
| More withdrawn (e.g. I avoid talking about it), less time with them | 12% |
| Grouchy, bad mood | 11% |
| Less engaged | 10% |
| Tired, less energy | 8% |
| Creates conflict with partner | 5% |

*Consequences for care recipient*: Many of the caregivers in this sample admitted that they took their stress out on the person they were caring for (66% of respondents report negative spillover to care recipient). Again we note (see Table 83) the link between caregiver strain and becoming short tempered and frustrated. One in ten noted that they managed their strain by reducing the level of care or minimizing the contact they had with the care recipient.

### Table 83: Consequences to care recipient

| | Total |
|---|---|
| Short tempered, frustrated | 42% |
| It doesn't | 33% |
| Other | 14% |
| Reduces level of care | 10% |
| Minimize contact | 10% |

*Consequences for other family members***:** Many of the caregivers in this sample also admitted that the strains of caregiving had a negative impact on how they dealt with other family members (66% of respondents reported some form of negative spillover to other family members). Again we note (see Table 84) the link between caregiver strain and becoming short tempered, frustrated, bossy, blunt, directive, and less sociable. Only one in ten respondents noted that they managed their strain by reaching out to family members and increasing communication (i.e. reported that caregiving had resulted in their family becoming closer - a positive consequence).

**Table 84: Consequences to other family members**

| | **Total** |
|---|---|
| It doesn't | 32% |
| Short tempered and frustrated | 26% |
| Other | 21% |
| I am more blunt, direct/bossy | 10% |
| Less or zero contact with (some of) them | 10% |
| I reach out more for support, more communication, we are closer | 8% |
| Less sociable, more introverted | 7% |

In summary, the data paints a pretty consistent picture of the consequences of caregiver strain. It seems from this study that the emotional aspects of strain contribute to caregivers being tired, short tempered and frustrated. A majority of our respondents then take this frustration out on others at home, at work, and on the recipient of care. Virtually no one in the sample identified any positive consequences of caregiving.

### 9.1.1 Impact of Gender on Consequences of Caregiving

As can be seen by looking at the data in Table 85, the reported consequences of caregiving strain are strongly associated with gender. The men in the sample were more likely than the women to say that caregiver strain:

- Did not affect them physically, did not impact their behaviour at work, and did not impact how they treated the person they were caring for, suggesting that men are more able than women to compartmentalize the caregiver role,
- Caused tiredness and exhaustion (physical impact),
- Caused them to be more introverted and avoid social contact (emotional impact),
- Had reduced their productivity at work, and
- Meant that they were more short tempered with the care recipient and other family members.

The women men in the sample, on the other hand, were more likely than the men to say that caregiver strain:

- Affected them physically in the following ways: headaches, nausea, insomnia, aches and pains, tension in their neck and shoulders and poor eating habits,
- Affected them emotionally in that they cried and were upset more often,
- Meant that they minimized contact with the person they cared for and reduced the level of care they gave them, and

- Caused them to be more direct and bossy with other family members.

Finally, gender was not associated with the extent to which caregiver strain impacted how respondents dealt with others at work and others at home.

**Table 85: Gender Differences: Consequences of Caregiving**

| **What happens when physically stressed by caregiving?** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Tiredness/ exhaustion | 50% | 38% | 44% |
| Nothing | 28% | 8% | 17% |
| Headaches | 4% | 25% | 15% |
| Upset stomach, nausea | 7% | 23% | 15% |
| Insomnia | 7% | 17% | 12% |
| Aches & pains | 2% | 17% | 10% |
| Poor eating habits | 0% | 10% | 5% |
| **What happens when emotionally stressed by caregiving?** | | | |
| Cry, get upset | 4% | 25% | 15% |
| Become more introverted, avoid social situations | 15% | 8% | 11% |
| **How does stress of caregiving impact your productivity at work?** | | | |
| It doesn't | 45% | 36% | 41% |
| Decreases productivity | 31% | 23% | 27% |
| **How does stress of caregiving impact how you deal with person you are caring for?** | | | |
| Short tempered, frustrated | 47% | 38% | 42% |
| It doesn't | 40% | 28% | 33% |
| Reduces level of care | 0% | 13% | 10% |
| Minimize contact | 0% | 10% | 10% |
| **How does stress of careging impact how you deal with other family members?** | | | |
| Short tempered | 36% | 16% | 26% |
| I am more blunt, direct/bossy | 4% | 15% | 10% |

### 9.1.2 Impact of Family Type on Consequences of Caregiving

As can be seen by looking at the data in Table 86, the reported consequences of caregiving strain are also linked with family type, with those in the sandwich group being more likely to be negatively impacted by caregiving strain that those in the eldercare group. Those in the eldercare group were more likely than those in the sandwich group to say that caregiver strain:

- Did not affect them physically, emotionally, in how they behaved at work, their productivity at work, how they treated the person they were caring for, and how they treated other family members,
- Caused headaches and insomnia (physical impact),
- Meant that they were more short tempered with the care recipient and other family members.

Those in the sandwich group, on the other hand, were more likely than those with eldercare to say that caregiver strain:

- Affected them physically in the following ways: tiredness, aches and pains, and tension in their neck and shoulders,
- Affected them emotionally in the following ways: short tempered, grumpy, emotionally

drained and anti-social,

- Meant that they were less patient/more short tempered with people at work, the
- Meant that they were less productive and less able to focus at work, the person they cared for, and other family members, and
- Caused them to reach out more and become closer to other family members.

**Table 86: Family Type Differences: Consequences of Caregiving**

| What happens when physically stressed by caregiving? | Sandwich | Eldercare | Total |
|---|---|---|---|
| Tiredness/ exhaustion | 48% | 40% | 44% |
| Nothing | 8% | 27% | 17% |
| Headaches | 10% | 20% | 15% |
| Insomnia | 8% | 16% | 12% |
| Aches & pains | 16% | 4% | 10% |
| Tension (shoulder/neck) | 12% | 4% | 8% |
| **What happens when emotionally stressed by caregiving?** | | | |
| Short tempered/ grumpy | 35% | 28% | 31% |
| Emotionally drained | 27% | 8% | 18% |
| Become more introverted and avoid social contact | 15% | 6% | 11% |
| Nothing | 0% | 8% | 4% |
| **How does stress of careging impact how you deal with others at work?** | | | |
| It doesn't | 40% | 57% | 48% |
| Less patient, cranky, short with people | 42% | 21% | 32% |
| **How does stress of careging impact your productivity at work?** | | | |
| It doesn't | 34% | 48% | 41% |
| Less focused | 38% | 29% | 34% |
| Decreases productivity | 36% | 16% | 27% |
| **How does stress of careging impact how you deal with others at home?** | | | |
| Short tempered, less patient, bossy | 54% | 30% | 45% |
| Less engaged | 14% | 4% | 10% |
| **How does stress of careging impact how you deal with person you are caring for?** | | | |
| Short tempered, frustrated | 50% | 33% | 42% |
| It doesn't | 25% | 42% | 33% |
| **How does stress of careging impact how you deal with other family members?** | | | |
| It doesn't | 20% | 43% | 32% |
| Short tempered | 33% | 18% | 26% |
| Less or zero contact with (some of) them | 6% | 14% | 10% |
| I reach out more for support, more communication, we are closer | 12% | 5% | 8% |

### 9.1.3 Impact of Caregiving Intensity on Consequences of Caregiving

The data from this study show a strong link between caregiving intensity and the consequences of caregiving on the employee (see Table 87). More specifically, those with lower levels of caregiving intensity were more likely than those with high levels of intensity to say that strain had not impacted them physically, at work (productivity), how they dealt with the person they cared for, and how they interacted with other family members. In other words, those with lower intensity were more able to compartmentalize the caregiver role. Those with high caregiving intensity, on the other hand, were more likely to say that caregiving had:

- Affected them physically in the following ways: tiredness, aches and pains, and headaches,
- Affected them emotionally in the following ways: emotionally drained, frustrated, angry, and overwhelmed,
- Made them less patient and short tempered with people at work and the person they cared for,
- Meant that they were less productive and less able to focus at work
- Meant that they minimized contact with the person they cared for and reduced the level of care they provided, and
- Caused them to lose contact with their extended family.

There was no link between intensity level in how the respondent dealt with others at home.

**Table 87: Caregiving Intensity Differences: Consequences of Caregiving**

| **What happens when physically stressed by caregiving?** | **Low** | **High** | **Total** |
|---|---|---|---|
| Tiredness/ exhaustion | 37% | 50% | 44% |
| Nothing | 27% | 8% | 17% |
| Headaches | 8% | 22% | 15% |
| Aches & pains | 2% | 18% | 10% |
| **What happens when emotionally stressed by caregiving?** | | | |
| Emotionally drained | 15% | 22% | 18% |
| Frustrated, angry | 8% | 16% | 12% |
| Overwhelmed | 19% | 4% | 11% |
| **How does stress of careging impact how you deal with others at work?** | | | |
| Less patient, cranky, short with people | 28% | 36% | 32% |
| Shorter attention span, scattered | 4% | 12% | 8% |
| **How does stress of careging impact your productivity at work?** | | | |
| It doesn't | 47% | 34% | 41% |
| Decreases productivity | 21% | 32% | 27% |
| Wastes time | 0% | 8% | 4% |
| **How does stress of careging impact how you deal with person you are caring for?** | | | |
| Short tempered, frustrated | 38% | 46% | 42% |
| It doesn't | 44% | 23% | 33% |
| Reduces level of care | 4% | 15% | 10% |
| Minimize contact | 2% | 16% | 10% |
| **How does stress of careging impact how you deal with other family members?** | | | |
| It doesn't | 39% | 24% | 32% |
| Less or zero contact with (some of) them | 4% | 16% | 10% |

## 9.2 One Piece of Advice

We ended the interview by asking respondents: "What one piece of advice would you give to someone assuming care for an elderly dependent?" Responses are given in Table 88.

**Table 88: One piece of advice**

| | **Total** |
|---|---|
| Get help, talk to others | 44% |
| Take care of yourself and make time for yourself | 23% |
| Other | 16% |
| Connect with other caregivers in similar situations for mutual support | 10% |
| Planning and organization/develop a plan/routine | 10% |
| Set boundaries ahead of time about what you can and can’t offer | 9% |
| Keep things in perspective | 8% |
| Research available resources in your community | 7% |
| Don't try and do it all (you can't) | 6% |
| Be patient | 5% |
| Be understanding/empathetic with dependent, try to respect their independence | 5% |
| Take time for relationship | 4% |
| Don't just react in stressful situations, take time to consider the repercussions | 2% |
| Treat it like parenting | 2% |

The most common piece of advice (mentioned by almost half the sample) was to "get help, talk to other people-- don't try to do this on your own). One in four people recommended that the person made sure that they took care of and made time for themselves as "what will they do if you get sick?". Approximately one in ten gave the following types of advice: connect with others in similar situations for mutual support, plan, organize and develop a routine, set boundaries on what you can and cannot do, keep things in perspective and do your research. Most of these pieces of advice seem to focus on the emotional aspects of caregiving rather than the logistical or physical elements of care. There were very few between group differences in these pieces of advice (see Table 89). The following differences were noted:

Men were more likely than women to advice people to make time for themselves, to connect to other caregivers for mutual support, and to plan, organize and develop a routine. The women in the sample, on the other hand, were more likely to advice others to set boundaries ahead of time.

Those in the sandwich group were more likely to advise others to plan, organize and develop a routine while those in the eldercare group were more likely to suggest patience.

Those with low caregiver intensity were more likely to advise others to get help, talk to others, take care of yourself and research was is available to help you in your community.

## Table 89: Between Group Differences: Advice

| **One piece of advice** | **Male** | **Female** | **Total** |
|---|---|---|---|
| Take care of yourself and make time for yourself | 28% | 17% | 23% |
| Connect with other caregivers in similar situations for mutual support | 16% | 3% | 10% |
| Planning and organization/develop a plan/routine | 18% | 2% | 10% |
| Set boundaries ahead of time | 4% | 14% | 9% |
| | **Sandwich** | **Eldercare** | **Total** |
| Planning and organization/develop a plan/routine | 15% | 4% | 10% |
| Be patient | 0% | 10% | 5% |
| | **Low** | **High** | **Total** |
| Get help, talk to others | 49% | 35% | 44% |
| Take care of yourself and make time for yourself | 26% | 18% | 23% |
| Research available resources in your community | 13% | 2% | 7% |

# Chapter Ten: Conclusions

This report presents the findings from a qualitative study of 111 Canadian employed caregivers. All respondents worked full time, were married/lived with a signifcant other, and spent at least one hour a week in childcare (if relevant) and eldercare. The sample was balanced with respect to three criteria: gender, family type (eldercare, sandwich) and caregiving intensity. Respondents came from across Canada and lived in a variety of sizes of communities. Sample selection and our analytic approach (look at impact of gender, family type and intensity on findings) increases generalizability of the findings.

Key conclusions and observations arising from this study are provided below.

## What do the demographic data tell us about employed caregivers?

The data supports the following conclusions with respect to employed caregivers in Canada:

- Most employed Canadians care for a family member (58% indicating that they cared for their mother and 17% their father) who is older than 75 years of age (77.9 years old on average for this sample) and lives nearby (68% of the employees in this sample care for someone who lives within 30 km of their house).

- Caregiving is not a transient activity. The employed caregivers in this sample have spent 6.3 years, on average, in caregiving.

- Eldercare is time consuming for both the employee (an average of 10.7 hours per week in caregiving) and their partner (an average of 5.6 hours per week in caregiving).

- Work demands do not appear to diminish with the addition of the caregiving role (respondents spent an average of 51 hours per week in paid employment).

- Employees in the sandwich group also spend a significant amount of time parenting (an average of 15 hours per week in childcare).

## Why do employed Canadians take on the role of caregiver?

The data from this study support the following conclusions with respect to why employed Canadians take on the caregiving role:

- In many cases the reasons for taking on this type of commitment are pragmatic (i.e. they live nearby, they are the only child, the are the oldest daughter).

- Many respondents feel that they have no choice but to provide care (the care recipient is having health issues, their siblings can't or won't provide care, no options in their community, dependent does not want to move).

- Very few employees said they wanted to take on this role.

### What activities are undertaken by employed caregivers in Canada?

The most common form of care offered is emotional support followed by activities to help the dependent with respect to health and daily living. The data from this study support the following conclusions with respect to the key components of the caregiving role:

- *Offer emotional support to dependent*: Emotional support can take many forms but most often involves the caregiver sitting and talking to the dependent. Caregivers who live at a distance provide similar support when they "touch base" with their dependent by phone. Phone calls are also done to reassure the caregiver that "everything is alright" with the dependent.

- *"Running around"*: Caregivers take the person they are caring for to appointments (mostly medical) and/or run errands for them (i.e. pick up medications, do grocery shopping). In most cases this form of support is necessary because the dependent has either lost their driver's license or is too frail (mentally or physically) to take public transit.

- Housework: Caregivers cook, clean and put out the garbage.

- Administrative support: Caregivers plan their dependent`s medical appointments and organize their meals).

- Relatively few employed caregivers in this sample helped out by doing physical tasks around the house (yardwork, cutting the lawn).

- Relatively few employed caregivers in this sample provide physical/nursing care or financial support as part of their caregiving activities.

- Many caregivers received no instrumental support from their partner for the caregiving role.

- Partners who do "help out" spend their time in essentially the same activities as those performed by the primary caregiver. What is important, however, is to note that partners were less likely to provide each of these forms of care than were the respondents.

### What are the consequences of caregiving for the employees who take on this role?

All of employed caregivers in this sample were able to identify ways in which the caregiving situation had impacted them personally. All spoke at length about how caregiving had (or could) impact them negatively. No one spontaneously discussed the benefits of taking on this role. The most common consequences of caregiving related to the emotional aspect of caregiving (stress, anxiety, frustration) and how caregiving had/could negatively impact their health (less sleep, no downtime), their family (relationship with partner negatively impacted, things in my life do not get done) or their career.

The data from this study support the following conclusions with respect to how caregiving can impact the employed caregiver:

- Very few of the Canadian employees in this sample experienced financial caregiver strain.

- Physical caregiver strain is reported more frequently than financial caregiver strain

- The data support a strong link between the caregiving and emotional strain.

- Most of the employees in this sample experienced one or more physical problems related to caregiver strain. Consequences noted by respondents included exhaustion and tiredness, headaches, nausea, insomnia, increased blood pressure, aches and pains and tension in the shoulder and neck.

- Virtually all of the employed caregivers in this sample experienced one or more of the following emotional consequences of caregiver strain: more short tempered and grumpy, drained, suffered from anxiety attacks, tearful, depressed, sad, angry, frustrated, overwhelmed and anti-social.

- Emotional strain is associated with worry about the dependent (their health, their death, the quality of care they are receiving) teamed with a lack of time for themselves and their families and the amount of work that has to be done.

- Caregiving is associated with a number of negative emotions and feelings including anger and frustration, worry and anxiety, guilt, overwhelmed, overloaded hopeless, powerless and trapped

- None of the respondents is our sample talked about positive feelings with respect to caregiving (e.g. no one said hopeful, useful).

- Many caregivers expressed concern that their caregiving demands would negatively impact their careers (i.e. have to use vacation days to care for dependent, absent more frequently from work, fear that they will lose their job).

### What makes the role of employed caregiver stressful and overwhelming?

What makes caregiving stressful? What makes the role of caregiver overwhelming? The data from this study identifies the following dimensions of the role as contributing to the caregivers feeling both stressed and overwhelmed:

- Overload: Caregivers have too many demands on their time.

- Role Conflict: Caregivers find it very difficult to balance work, life and caregiving activities.

- Time and timing: it is unexpected, it is urgent, it requires a lot of a person's time.

- The emotional burden of cargiving (concern over the wellbeing of the person they were caring for, felt powerless, the person was dying and they felt helpless).

- Emotional attachment to the person they were caring for (concern for wellbeing of the dependent),

- The nature of their interactions with the person they were caring for: frustrated that the person they were caring for would not listen to them, was angry with them and generally acted in a way that the respondent felt made it more difficult for them to provide care.

- The lack of control they had over the situation (caregiving is unpredictable).

- The amount of difficulty they had getting help or support for the role (many have sole responsibility for the care of their dependent and cannot get support from their family, their community, the government, or their employer).

- Dealing with the healthcare system is very stressful.

- Worry about the quality of care their dependent was receiving in residence,

- A lack of personal choice/control (feeling powerless, feeling trapped, only one available, it all fell on me).

What is less likely to cause stress? The distances involved, having their dependent living with them, or feelings of guilt because they were not doing enough.

**What makes caregiving more difficult?**

The following conclusions on the challenges employees in Canada face with respect to caregiving are supported by the data from this study:

- Caregiving is challenging for employed Canadians (80% reported feeling challenged).

- Challenges are often self imposed or are generated by other key stakeholders in the caregiving situation (recipient of the care, their immediate family, their extended family, their employer). These challenges are exacerbated by the fact that many caregivers could not get support for the role from their partner, their employer, their extended family or the government.

- Many caregivers admitted that they "made their caregiving situation worse" by hanging on to responsibility for the care of their family member (even when things got too much), got upset too easily, internalized their problems, took their stress out on the care recipient (abrupt, fought fight with dependent) and/or themselves (self-guilt).

- Finding a "good" balance between work, life and their responsibilities to their elderly dependent is problematic for many.

- Many caregivers have a pre-existing medical condition that makes it difficult for them to do everything they need to do.

- Declines in the dependent's mental and/or physical health makes the caregiver role more challenging (they need more of my time and energy).

- Personality conflicts and differences in priorities between the caregiver and the care recipient often make things more challenging Two main areas of conflict were identified in this study: (1) dependant wants to remain independent while the caregiver wants them in some form of structured safe environment, and (2) the dependent feels lonely and isolated while caregiver feels overwhelmed by all the demands on their time.

- Many noted that the behaviour of their siblings made things more challenging (they don't help, they are not there for me, within family conflict).

- Many caregivers found that the role of employee conflicts with the role of caregiver (competing demands on their times, timing issues, difficult to get time off work when they needed it, little flexibility with respect to work hours, work location and vacation time, the employer was unsupportive of time off for caregiving,).

- Many caregivers noted that there were no policies in place within their workforce addressing issues associated with eldercare (employer unsupportive or unaware).

- One in three caregivers (mainly those in smaller communities) noted that they could not find any support for caregivers or programs for seniors within their community.

- Many caregivers said that they found the lack of government support for the caregiving role challenging. They noted that the services provided for the aged were inadequate and insufficient in number, that the bureaucracy made it very difficult for someone in need to find help and information, and that budget cuts had reduced the amount of support available.

### What are consequences of caregiver strain on key stakeholders

The following potential consequences to key stakeholder were indentified in this study:

- *Consequences to care recipient*: Many of the caregivers in this sample admitted that they took their stress and frustration out on the person they were caring for**.** One in ten noted that they managed their strain by reducing the level of care or minimizing the contact they had with the care recipient.

- *Consequences at home***:** Many caregivers report that caregiving has negatively impacted their homelife (less time for family, negative impact on relationships at home, more tension at home, less time to spend in parenting activities). Virtually all of the respondents indicated that caregiving strain had a negative impact on how they dealt with their immediate family. They confessed that they were more short tempered and less patient with their spouse and/or children, more withdrawn a home and less engaged in family discussions and activities. Only one in ten respondents noted that they managed their strain by reaching out to family members and increasing communication (i.e. reported that caregiving had resulted in their family becoming closer - a positive consequence).

- *Consequences at work*: The data from this study supports the idea that the stress of caregiving negatively spills over into the work environment. Caregiver strain appears to impact how caregivers deal with their work colleagues (less patient with their colleagues at work, less likely to socialize with work colleagues) and negatively impact work productivity (i.e less productive, more distracted, not enough time, find it hard to focus at work).

In summary, the data paints a pretty consistent picture of the consequences of caregiver strain. It seems from this study that the emotional aspects of strain contribute to caregivers being tired, short tempered and frustrated. A majority of our respondents then take this frustration out on others at home, at work, and on the recipient of care. Virtually no one in the sample identified any positive consequences of caregiving.

### What actions can caregivers take to prevent or minimize strain?

According to the employed caregivers in this sample the following actions can either prevent caregiver strain from manifesting itself or minimize its intensity: (1) planning and organizing how you will deal with the situation, (2) constantly communicating expectations on what you will and will not do with the dependent and other family members, (3) being realistic about what you can and cannot do ("accept that you cannot control everything"), (4) delegating work to others and getting help from other family members and (5) maintaining a positive outlook and not getting angry.

### How do caregivers cope with caregiver strain?

The following conclusions on how employees cope with caregiver strain can be drawn from this study:

- The most common coping strategies used by the employed caregivers in this sample included: (1) talking/venting to a sympathetic other, (2) preparing detailed plans and getting organized, and (3) figuring out a practical solution to the problem and then just "getting on it with it."

- Less common coping strategies (used by approximately one in ten respondents) included voicing their concerns to the dependent, researching and seeking out professional resources, asking for help from their siblings, and engaging in other activities to take their mind off the issue.

- The employees in this sample coped with the emotional aspects of caregiving by seeking emotional support from a sympathetic other, just ignoring the emotions (i.e. did nothing), and engaging in activities that would reduce their stress in a healthy manner (exercise, hobbies etc).

- Other strategies used by respondents to cope with the emotional aspects of the caregiving included: (1) engaging in introspection and reflection, (2) doing their best, (3) seeking professional help, (4) communicating with the dependent, and (5) increasing their intake of alcohol, caffeine and comfort food.

- Another perspective on how to cope with caregiver strain can be gathered by looking at the advice the caregivers in this sample gave to someone taking on the caregiving role. They noted that caregivers should: (1) "get help, talk to other people-- don't try to do this on your own, (2) take care of and made time for yourselves, (3) connect with others in similar situations for mutual support, (4) plan, organize, research and develop a routine, and (5) set and communicate boundaries on what you can and cannot do.

- Respondents coped the way that they did because: (1) of a desire to protect the interests of the care recipient, (2) they wanted to relieve the stress they were under, (3) they wanted to increase their sense of control over the situation, and (4) they wanted to make sure things went according to plan.

### What can others do?

The following conclusions on other stakeholders can help employees cope with the strains and demands of caregiving are supported by the data from this study.

- One in three of the caregivers in this sample said that no one provided them with any form of help or support.

- The employees in this sample were more likely to talk about the emotional support that they received from their partners (they listen, give good advice), their friends, and their extended family than they were to receive tangible help from any of these stakeholders.

- The type of support offered to the caregiver by ones' immediate family (children and spouse) was somewhat different from the support received from ones' siblings. More specifically, respondents talked about receiving both emotional and instrumental support from their partner and children. Support from siblings more often involved listening and offering verbal support.

- Many of the caregivers in this sample would like their siblings: (1) to make more of an effort to visit with and offer concrete help to "mom and dad", and (2) to increase their involvement in the problem solving process (i.e. offer more instrumental support).

- Caregivers in this sample said that their employer helped them in the following ways: (1) made it easy for them to take time off work/take a leave of absence, (2) supported the use of flextime and/or telework work schedules, and (3) offered an EAP program.

- Many of the caregivers in this sample would like their employer to allow compassionate care leave and introduce compressed work week schedules..

- Very few Canadian communities offer their citizens any form of support to help them provide care to an elderly dependent(s).

- The following community supports were identified as being helpful in this study: community senior centers, meals on weeks and para-transpo.

- Most of the respondents had suggestions on how the community could help them cope with the demands caregiving places on them. Many spoke about how they would like their community to (1) provide expert guidance, advice and assistance for caregiving issues ("one number to call to get advice and help"), (2) build more senior community centers, (3) offer more in-home care options (cleaning, meals etc) would be very valuable, and (4) increase the number of transportation options for the elderly (e.g. transportation for medical appointments, greater accessibility of public transportation).

- Almost two thirds of the employed caregivers in this sample were either not aware of any policies or practices put in place by provincial or federal governments to support citizens who were looking after elderly dependents. This suggests that either such supports are not readily available or that governments are not doing a good of informing the public of what is available.

- The only government support mentioned as useful by a substantive number of respondents (20%) were services offered by the CCAC

- What could the government do to help support employed caregivers? Respondents offered a number of suggestions including the following: (1) provide more funding for programs offered by the CCAC, (2) give tax credits/other forms of financial assistance for those providing elderly care, (2) provide funding for more high quality long-term eldercare facilities, (4) introduce some form of family care leave (replace compassionate care leave with a leave that is modeled after parental leave), and (5) streamline the bureaucracy so that people are more aware of what support is available and more able to obtain help.

### What rewards do employees get from taking on the caregiver role?

Many caregivers in this sample noted that they "were not in for the rewards" but because they felt it was their moral responsibility. That being said, many of the employees in this sample were able to identify some rewarding aspects of the role.

- The key rewards of caregiving mentioned by the employees in this sample included: (1) the role improved relationships within their family and increased family bonding, (2) reassured because they knew the person was safe and well cared, and (3) a sense of satisfaction from helping someone else.

- Many of the employed caregivers in our sample felt that there was no positive spillover at all from the work role to the caregiving role or visa versa.

- Almost all of the parents in the sample were able to identify ways in which their experience as a parent had helped them with respect to the provision of eldercare. They noted: (1) that the techniques and skills that they used as a parent applied to caregiving as well, and (2) that parenting had provided them with a number of skills that helped them in their caregiver role such as patience, and their ability to multi-task and accept responsibility

- How does the role of caregiver benefit an employee at work? Respondents indicated that the caregiver role helped them: (1) emphasize with their colleagues and clients who were in the same boat as they were, (2) be more diplomatic and patient, and (3) appreciate the challenges faced by elderly Canadians.

- How does the work role help an employee manager their caregiver responsibilities? Respondents indicated that it: (1) gave them organizational and planning skills needed to effectively provide care, (2) helped them deal more effectively with crisis and stress, and (3) it gave them the technical skills they needed to find information on the web

## 10.1 Key gender differences

This study noted the following key gender differences in caregiving.

**Men and women have different reasons for taking on the role of caregiver**

Women were more likely than men to feel obligated to take on the caregiving role (the dependent needs help and my place in the family structure -- the daughter - means that is it up to me to provide such care). Men, on the other hand, were more likely than women to take on the role because there was no one else who could take on the role or to say that they shared the responsibility with their siblings.

**Men and women engage in a different mix of caregiving activities**

Women were more likely to say that they help out by doing errands for the dependent and by talking to them on the phone. Surprisingly, it was the men in the sample who indicated that they took physical care of the dependent (feeding, bathing).

The women in the sample were more likely than the men to say that their partner did not provide any form of eldercare support. Those women who did receive support from their husband were more likely to note that their partner helped by doing yardwork and gardening (i.e. traditional male tasks).

The men in the sample were more likely than their female counterparts to receive support from their wives with respect to caregiving. More specifically, they were more likely to note that their partner helped by providing emotional support, taking the dependent to appointments, doing housework, groceries and errands, and providing physical care. Many of these tasks (cleaning, shopping, feeding, bathing) that they women took on have traditionally been viewed as "womens work".

## Gender played a role in what made people feel overwhelmed

Men were more likely than women to say that they were overwhelmed by caregiving because they felt powerless, had little control over their caregiving situation and the role required a lot of their time. The women in the sample, on the other hand, were the only ones that talked about how distance contributed to their feeling overwhelmed.

Gender had little impact on the feelings generated by caregiving.

## Caregiving impacts men and women in very different ways

Men were more likely than women to say that caregiving had negatively impacted their family and noted that their family was also stressed by the situation and that their family had to help with caregiving.

Men were more likely than women to say that caregiving would have no impact on their situation at work while women were more likely to say that their work would be negatively impacted by caregiving as that they would have to use their vacation days/call in sick to deal with the situation.

Men were more likely to say that caregiving meant that they got less sleep, while women were more likely to say that caregiving had negatively impacted their health

Men were more likely than women to identify the following factors as ones that made caregiving situation stressful: (1) concern for the wellbeing of the dependent, (2) time constraints, (3) timing (it was unexpected) and (4) the fact that the situation had negatively impacted their relationship with their spouse.

Women were more likely than their male counterparts to identify the following factors as ones that made caregiving stressful: (1) the amount of work involved, (2) exhaustion, and (3) a lack of predictability.

## Gender impacts perceived ability to deal with caregiving

Men were more likely to express confidence that they could deal with the caregiving situation they were facing while women were more likely to admit that they were not confident that they could deal with the situation.

## Gender impacts how employees cope with caregiving strain

Women were more likely than men:

- to cope by asking others for help and taking time off work - strategies that they said did not really help them cope with the situation.
- to say that their partner supported them by listening and offering support.
- to say that they dealt with the emotional aspects of caregiving by engaging in activities (exercise, hobbies) to take their mind of the stress and by talking to the care recipient.
- to deal with caregiving by talking about it and communicating with significant others.

Men were more likely than women:

- to say they coped by stepping back from the situation because this was "just what they did."
- to cope with the emotional aspects of caregiving by ignoring the issue, engaging in introspection and doing their best.
- to say that no one took actions to help them cope with caregiving (probably because they did not ask for help or communicate about the issue with others). and
- to say that their employer helped by being supportive of the situation

### Perceived Resolution of the Situation

Men were more likely than women to say that the situation had resolved itself successfully, to say that they felt relieved and fine/alright and to express satisfaction in how the situation was resolved. They were also less likely to say that they felt very overwhelmed and stressed by the situation.

Women were more likely to say that the situation was on-going, to say that they were exhausted and overwhelmed by the situation, to report that the situation was very stressful and very overwhelming for them, and were less likely to be satisfied in how it had resolved itself.

Taken together these data suggest that either men and women were thinking of very different types of overwhelming caregiving situations during the interview and/or that men and women make very different attributions with respect to such situations (i.e. men display positive affectivity while women show negative affectivity).

### Appraisal of Strain

- Women were more likely than men to report that they experienced personal challenges from caregiving as well as challenges within their community (more likely than men to find the bureaucracy frustrating)

- Men were more likely than women to say that they experienced caregiving challenges that were related to the person they were caring for (their mental abilities were declining), their situation at home (increased conflict with their partner) and the demanding environment they faced at work.

- Men were more likely than women to say that they found the demands on their time, the emotional burden associated with caregiving, difficulties in getting help and dealing with the health care system made them feel stressed.

- Men were more likely than women to say that they were rewarded for their caregiving role by the knowledge that the person they were cared for was safe and well cared for and by the satisfaction of knowing that they were helping others

## Factors that Facilitate Coping

Overall, there were more similarities than differences between the men and women in the sample with respect to the amount of support they felt they obtained for the caregiving role.

## Factors that Hinder Coping

The men in the sample gave very different answers than women to many of these questions that dealt with this issue.

Men were more likely than women to:
- Say that the dependent, their employer, the government and they themselves did not do anything that made it harder for them to manage their caregiving situation,

Women were more likely than men to:
- Say that their dependent made things worse when they were disrespectful of their time,
- Say that that decline in the physical and/or mental health of the dependent they were caring for had made things more difficult,
- Say that a lack of flexibility at work and difficulties in getting time off to care for their dependent made things more difficult,
- Say that a lack of government services to support the aged and challenges dealing with the bureaucracy had made things more problematic,
- Indicate that they made it harder on themselves when they got stressed and upset over the situation they found themselves in.

## Spillover

The data supports the idea that men were more likely to benefit from taking on the caregiving role than women. More specifically, the men in the sample were more likely than women to say that:
- Caregiving had helped them at work by making them more empathetic, diplomatic and patient,
- Their work role had made them a more effective caregiver by giving them planning, organizational and crisis management skills,
- That the techniques they had learnt as a parent had helped them in their caregiver role, and
- That being a parent had helped them see the big picture - a skill that helped them in their caregiver role.

## Consequences of Caregiving

The reported consequences of caregiving strain are strongly associated with gender.

The men in the sample were more likely than the women to say that caregiver strain:
- Did not affect them physically, did not impact their behaviour at work, and did not impact how they treated the person they were caring for, suggesting that men are more able than women to compartmentalize the caregiver role,
- Caused them to be more introverted and avoid social contact (emotional impact),
- Had reduced their productive at work, and

- Meant that they were more short tempered with the care recipient and other family members.

The women men in the sample, on the other hand, were more likely than the men to say that caregiver strain:

- Affected them physically in the following ways: headaches, nausea, insomnia, aches and pains, tension in their neck and shoulders and poor eating habits,
- Affected them emotionally in that they cried and were upset more often,
- Meant that they minimized contact with the person they cared for and reduced the level of care they gave them, and
- Caused them to be more direct and bossy with other family members.

## 10.2 Key Differences Associated with Family Type

This study observed the following differences in caregiving associated with family type:

Compared to their counterparts in the eldercare group, respondents in the sandwich group were younger, spent more hours in paid employment per week, were more likely to be caring for 2 or more dependents and more likely to be caring for their father.

### Family type impacts reasons for taking on the role of caregiver

Employees in the sandwich group were more likely to say that they had assumed the role of caregiver because they lived near the dependent and because the dependent was experiencing health problems and needed care. Those in the eldercare group were more likely to take on the role because the dependent needed help and no one else could or would take on the responsibility (partner cannot do it, siblings can't or won't).

### Family type impacts the mix of caregiving activities performed

Employees in the sandwich group were more likely than those in the eldercare group to engage in four of the ten caregiving activities identified by the respondents: provide emotional support, take dependent to appointments, shop and run errands for the dependent and do housework for the dependent. Many of these activities are very time consuming. There were no cases where those in the eldercare group were more likely than those in the sandwich group to provide care.

Those in the eldercare group were more likely than those in the sandwich group to say that their partner did not provide any form of eldercare. Those in the sandwich group, on the other hand, were more likely to say that their partner helped them in the provision of eldercare by talking to the dependent (either in person or on the phone) or by doing shopping and errands.

### Family type associated with caregiver strain

Family type is associated with the incidence of two out of three of the forms of caregiver strain considered in this study. More specifically, respondents in the eldercare group were more likely to report that they experienced both physical and emotional strain weekly or more. The greater levels of physical strain might be due to the fact that those in the eldercare group were older than those in the sandwich group. The higher levels of emotional strain, on the other hand, might be due to the fact that they have little support for the role from either their partner or their family.

### Family type played a role in what made people feel overwhelmed

Those in the sandwich group were more likely to link the time demands and the emotional intensity of the situation with their feeling overwhelmed while those in the eldercare group were more likely to be overwhelmed by the timing of the situation (urgent, unexpected) and the fact that they had no one to help them deal with the issue.

### Family type impacts how employees approach eldercare

Employees in the eldercare only group were more likely than those in the sandwich group to: (1) express confidence that they could deal with the situation, (2) deal with the situation by talking to others, and (3) identify the behaviour of the person that they cared for as the most important source of stress for them.

Employees in the sandwich group, on the other hand, were more likely: (1) to have concerns about their ability to deal with the situation, (2) either have no plans to deal with the situation or intend to cope through planning and organizing, and (3) identify their concern for the wellbeing of the dependent and demands on their time (not enough time, time constraints, I am exhausted) as the most important sources of stress for them.

### Family type impacts the use of coping strategies

Compared to their counterparts in the eldercare group, those in the sandwich sample were more likely to say they coped by talking and venting to their partner, a strategy they used because it helped them de-stress and gave them breathing space.

Employees in the sandwich group were also more likely to claim both that no one provided them with support or help in response to their caregiving situation and to recognize that they had received support and help from their siblings and other family members. They were also more likely to mention the support they had received from the EAP program at their place of work and to say that the support they had received from others helped them cope with their caregiving situation. Those in the sandwich group were also more likely to say they coped with the emotional aspect of the situation by ignoring it, engaging in activities to take their mind of the situation/cope with the stress and by engaging in introspection.

Those in the eldercare group, on the other hand, took a more practical approach to coping with caregiving. They were more likely to say they coped by planning and organizing, and engaging in problem solving activities, and more likely to indicate they coped the way they did because of a desire to keep things simple and get things done. Those in the eldercare group were also more likely to say that their family offered practical and financial support and less likely to claim that they were dealing with the situation on their own.

## Appraisal of Strain

Those in the sandwich group were <u>more</u> likely than those in the eldercare group to say:

- They found finding a balance between their life and their responsibilities as a caregiver challenging,
- That they found the physical decline in the health of the person they were caring for very challenging,
- That they encountered challenges and conflicts at home that they attributed to the following aspects of caregiving: less time for their family and a reduced ability to do the things that they associated with being a good mother and father,
- That they ran into challenges at combining caregiving and work due to their demanding work environment, conflict between their work and the demands associated with caregiving, their inability to get time off work for caregiving (policies not there) and the fact that caregiving had negatively impacted their productivity,
- That the demands on their time and their inability to balance work, life and caregiving made them feel stressed
- Better relationships at home were one of the rewards that they had personally realized from caregiving, and
- That they did not engage in caregiving in the expectations of a personal reward but had instead provided such care for moral reasons.

Those in the eldercare group were <u>more</u> likely than those with both childcare and eldercare:

- To say that caregiving had increased their personal stress levels,
- To attribute the challenges they faced with respect to caregiving to the fact that the mental health of the dependent they cared for was in decline,
- To report that they had not experienced any challenges at either work or at home that they attributed to caregiving,
- To say that dealing with the dependent and worries about the quality of care they were receiving in residence were key stressors for them, and
- To indicate that they were rewarded for caregiving by knowing that the person they cared for was safe.

## Factors that Facilitate Coping

Those in the sandwich group were <u>more</u> likely than their counterparts in the eldercare group to:

- Cope by engaging in activities to reduce the impact of caregiver strain (i.e. taking with their partner, their family and their friends, exercise, make time for hobbies and relaxation, and drink alcohol),
- Say that their partner and their children helped them cope with the challenges associated with caregiving,
- Say there was nothing else their family could do to support them,
- Say that their immediate manager at work was supportive of their need to balance work and caregiving and that the EAP services offered by their organization helped them cope with stress,

- Ask their employer to support employed caregivers by offering compassionate care leave and compressed work week schedules,
- Say that the availability of church programs, recreational events for seniors and homecare programs in their community helped them cope with caregiver strain, and
- Say that government programs such as Homecare and the CCAC helped them cope with caregiver strain.

Those in the eldercare group were <u>more</u> likely than their those in the sandwich group to:

- Cope by taking steps to reduce the stress before it occurred (i.e. organize, plan),
- Say that their siblings helped them cope with the challenges associated with caregiving,
- Say that they would like their siblings to spend more time with their parents and to participate in problem solving with respect to the care of their parents,
- Say that there is nothing that their employer, their community and the government could do in terms of helping them cope with caregiver strain
- Say that they needed more senior centers in their community, and
- Indicate that they would like the government to provide financial assistance/tax credit to support employed caregivers.

### Factors that Make things Worse

Respondents in the eldercare group were <u>more</u> likely than those with both childcare and eldercare to say that they themselves had made things worse by internalizing issues, not dealing with problems, and by becoming resigned with their situation and letting things go that should be addressed.

Respondents in the sandwich group, on the other hand, were <u>more</u> likely than their counterparts in the eldercare group to say:

- That the care recipient made things more challenging by nagging and not respecting their time commitments at work,
- That conflict with their siblings had made things worse,
- That the fact that their employer was unsupportive about time off work made things more challenging,
- That the bureaucracy had made things more difficult as it was very hard for them to find help and relevant information, and
- That they themselves had made things worse by taking on all of the responsibility for the care of their elderly dependent.

### Consequences of Caregiving

The reported consequences of caregiving strain are linked with family type, with those in the sandwich group being more likely to be negatively impacted by caregiving strain that those in the eldercare group. Those in the eldercare group were <u>more</u> likely than those in the sandwich group to say that caregiver strain:

- Did not affect them physically, emotionally, in how they behaved at work, their productivity at work, how they treated the person they were caring for, and how they treated other family members,

- Caused headaches and insomnia (physical impact),
- Meant that they were more short tempered with the care recipient and other family members.

Those in the sandwich group, on the other hand, were more likely than those with eldercare to say that caregiver strain:

- Affected them physically in the following ways: tiredness, aches and pains, and tension in their neck and shoulders,
- Affected them emotionally in the following ways: short tempered, grumpy, emotionally drained and anti-social,
- Meant that they were less patient/more short tempered with people at work, the
- Meant that they were less productive and less able to focus at work, the person they cared for, and other family members, and
- Caused them to reach out more and become closer to other family members.

## 10.3 Differences Associated with Caregiving Intensity

To help us understand better the factors that put Canadian employees at risk with respect to caregiver strain we compared the caregiving experiences of those with low levels of intensity to those with high levels of intensity. Key conclusions for this analysis are summarized below.

Intensity was associated with almost of the demographic characteristics and outcomes considered in this analysis. More specifically, compared to their counterparts in the low caregiving intensity group, respondents reporting high caregiving intensity:

- Are less likely to live with a partner (while no one in the low intensity group did not have a partner, one in four in the high intensity group were in this situation),
- Are more likely to care for their mother (68% versus 48%) and less likely to care for their mother-in-law (20% versus 4%)
- Spent more hours per week in childcare and eldercare,
- Had a partner who spent more hours per week in childcare and eldercare, and
- Have spent a longer period of time caring for this particular elderly dependent.

These data support the idea that intensity is associated with demands on ones time, support for care, and the persistence over time of the caregiving role.

### Caregiving Situation

People with higher levels of caregiver intensity are more likely that those with lower intensity to:

- Live close to the dependent they care for,
- Feel that they had no choice but to take on the caregiver role,
- Do housework for the dependent they are caring for,
- Have a partner who does not provide any form of support (half of the individuals with high intensity are in this situation),
- Attribute their feelings of being overwhelmed to a lack of time for themselves and their family,
- Report higher levels of financial strain, and
- Report higher levels of emotional strain.

It would appear from this data that intensity is associated with having to take on the role of caregiving, financial strain, and proximity.

The fact that intensity is not associated with the incidence of physical strain suggests that intensity is more likely related to the emotional aspect of caregiving than the provision of physical care (i.e. feeding, bathing).

### "Feeling Overwhelmed"

The data from this study give us some insight into what it is about caregiving that contributes to high levels of caregiving intensity. It would appear that intensity increases when the care recipient is difficult (i.e. will not listen, angry, scolds), and the person feels powerless and very emotional about the situation. Respondents with high levels of caregiving intensity were also more likely to note that they felt hopeless, powerless and trapped by the situation. Surprisingly, urgent situations are less likely to be associated with high intensity. Taken together these data suggest that the ongoing nature of caregiving and a lack of control may contribute to higher levels of caregiving intensity.

### Feeling Overwhelmed

First, there appears to be little link between caregiving intensity and perceived/actual consequences to the caregiving recipient. Second, people with higher levels of caregiving intensity seem to be more likely to be facing the situation alone (less likely to say family members are stressed by the situation, and more likely to say that the situation has no impact on other family members), either by choice (sheltering family) or because there is no support. Third, caregiving intensity seems to be positively associated with productivity at work as those with higher levels of intensity are more likely to mention that their work is suffering (distracted, cannot focus). The comments suggest that in this case it is the intensity of the caregiving situation that is reducing productivity - not the reverse.

### Perceived Ability to Deal with the Situation

Respondents with higher levels of caregiving intensity were more likely to say that they were not confident that they could deal with the caregiving situation and to say that they had no real plans to deal with the situation but rather "hoped for the best". Those with higher levels of caregiving intensity were also more likely to identify the following factors as making the situation stressful: concern for the wellbeing of the dependent, the amount of work involved and the lack of control and predictability.

### Coping

There are a number of important differences between the two groups with respect to coping strategies that suggest a strong link between caregiving intensity and a support for the caregiver role. These differences are listed below:

- Those with high caregiving intensity were less likely to feel that how they coped with the either the caregiving situation or the emotions it aroused was effective.

- Employees with low caregiving intensity were more able to find time to engage in activities to help them cope with the situation itself (i.e. engage in activities to take my mind off things, step back and take a breath) and the emotions attached to it (i.e. talk/vent to partner) than were those employees with high intensity.

- Those with high caregiving intensity were more likely to say they coped by asking for help but to more likely to claim that such help was often not forthcoming. They were also more likely to cope by seeking professional help, trying to do their best and communicating with the person they were caring for.

- Those with low caregiving intensity were more likely to say that they had received support from others and more likely to talk about the support they had received from their partners (listens and provides advice) their employer (gives time off), their family (practical and financial help) and colleagues at work and at home.

### Perceived Resolution of the Situation

Caregiving intensity was associated in some very telling ways with how the caregiver viewed the resolution of the overwhelming situation that they were discussing. Employees with low caregiving intensity were more likely to say that situation they were talking about had resolved itself successfully and that they felt happy, satisfied and relieved after it was over. Employees in this group were also significantly less likely to evaluate the situation as being very stressful and very overwhelming and more likely to say they were satisfied with its resolution.

Those with higher levels of caregiving intensity, on the other hand, were more likely to say the situation was ongoing (42% said this) and that they were overwhelmed and exhausted - findings that are consistent with how they evaluated the situation overall (63% said it was very overwhelming, 77% said it was very stressful and only 33% were satisfied with how it was resolved).

Finally, it is interesting to note that caregiving intensity was not associated with whether or not the employee felt that they had deal with the situation effectively.

### Appraisal of Strain

What challenges are associated with the higher levels of caregiving strain? The data from this study indicate that people with high levels of caregiver intensity are <u>more</u> likely than their counterparts with lower intensity to:

- Say that they face personal challenges because of eldercare, that they face challenges associated with the person they are caring for, and that they face challenges because of their situation at work and the community in which they live,

- Indicate that they have a pre-existing health condition that makes it challenging for them to provide caregiving,
- Identify a lack of sleep and being tired as a personal challenge they face due to of caregiving,
- Say that the person they care for is experiencing mental and physical declines in their health,
- Say that caregiving negatively impacts relationships at home and creates tension,
- Say that they find balancing work and the demands associated with caregiving challenging,
- Say that the nature of the community they live in (rural) means that there is little support available for employed caregivers,
- Identify the following aspects of caregiving as stressful: conflict with the dependent (they are stubborn and used to being independent), difficulties in getting help (the bureaucracy), and dealing with health care professionals, and
- Say they cannot think of any rewards that they get from caregiving.

### Factors that Facilitate Coping

Examination of the relationship between caregiving intensity and the data on coping give us a better understand of some of the factors associated with higher and lower levels of caregiving intensity. They also reinforce the idea that the more support the employee receives for the caregiving role, the lower the levels of caregiving intensity. Consider the following:

- Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were more likely to say that they coped by drinking alcohol and eating comfort food. They were, however, less likely to cope by exercising, relaxing, getting enough sleep and concentrating on "just getting through" the situation. While it is hard to determine direction of causality from these data (those with high could have less time for coping activities or poor use of coping techniques could lead to higher strain) there does appear to be a link between effective coping and intensity/strain.

- Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were less likely to say that their siblings helped with their parents care and more likely to request that their siblings make more of an effort to visit their parents.

- Compared to their counterparts with low intensity, the respondents in this sample with high caregiving intensity were less likely to say that their employer was supportive and more likely to want their employer to do more with respect to supporting employees with eldercare demands. They were also more likely to say that flextime and compressed work week arrangements would help them balance work and caregiving.

- The data from this study support the idea that employees who cannot access support from their community or the government are more likely to report high levels of caregiving intensity (half of those with higher caregiver intensity claim that neither of these bodies offer them any form of support). The findings also suggest that things such as senior community centers, in-home care options, and a focus on health care options for seniors would help this group cope with the strain they face.

## Factors that Make things Worse

Employees in the high intensity group were more likely to identify the following factors as making it more challenging for them to provide eldercare:

- The person they were caring for did not respecting their time commitments at work, and did not get involved in solving caregiving problems,
- Declines in the physical and/or mental health of the dependent they were caring for,
- Their siblings did not provide any help or support,
- Conflicts with their siblings,
- Their employer was unsupportive about time off work and expected a lot of their employees,
- A lack of government services, an opaque bureaucracy, and a lack of funding for the aged, and
- Their own sense of guilty and resignation.

## Spillover

The perception of positive spillover varied with caregiving intensity as follows. Employees with high caregiving intensity were more likely to say that their role as a caregiver did not help them at work. Those with low intensity, on the other hand, reported positive spillover from caregiving to work (I am more diplomatic, patient and aware of people with disabilities), from work to cargiving (work gave me good crisis management skills) and from parent to caregiver roles (gave me good multi-tasking and organizational skills).

These findings suggest that positive spillover offers some form of defense mechanism protecting against the strains of caregiving. The question remains, however, as to whether the perception of positive spillover is a function of the actual situation, the personality of the individual, or a combination of both.

## Consequences of Caregiving

The data from this study show a strong link between caregiving intensity and the consequences of caregiving on the employee. More specifically, those with high caregiving intensity were more likely to say that caregiving had:

- Affected them physically in the following ways: tiredness, aches and pains, and headaches,
- Affected them emotionally in the following ways: emotionally drained, frustrated, angry, and overwhelmed,
- Made them less patient and short tempered with people at work and the person they cared for,
- Meant that they were less productive and less able to focus at work
- Meant that they minimized contact with the person they cared for and reduced the level of care they provided, and
- Caused them to lose contact with their extended family.

# References

Amatea, E. S., & Fong, M. L. (1991). The impact of role stressors and personal resources on the stress experience of professional women. Psychology of Women Quarterly, 15: 419-430.

Busch, C., De Maret, P. Flynn, T., Kellum, R. Le, S., Meyers, B., Saunders, M. White, R. & Palmquist, M. (2012). Content Analysis. Denver: Colorado State University.
Available at http://writing.colostate.edu/guides/guide.cfm?guideid=61.

Canadian Caregiver Coalition, (2001). Respite: A Challenge for Caregivers, Service Providers, and Policy Makers.
Retrieved from: www.von.ca/Doc/VON%20Canada%20Caregiving%20Program.doc

Cohen, S., Kessler, R. C. and Underwood Gordon, L. (1995). Strategies for Measuring Stress in Studies of Psychiatric and Physical Disorders. In S. Cohen, R.C. Kessler and L. Underwood Gordon (Eds.) Measuring Stress, (pp 122- 147), New York: Oxford University Press

Cooper, C. L., Dewe, P.J. and O'Driscoll, M. P. (2001) Organizational Stress, Thousand Oaks, CA: Sage Publications, Inc.

Eisenhardt, K. (1989). Building theories from case study research. Academy of Management Review, 14, 4, 532-550.

Eisenhardt, K. and Graebner, M. (2007), Theory Building From Cases: Opportunities and Challenges, Academy of Management Journal, 50, *1*, 25-32.

Fast, J., & Keating, N. (2000). *Family caregiving and consequences for carers: Toward a policy research agenda.* CPRN Discussion Paper No. F/10-5. Retrieved from http://www.cprn.org/documents/familycaregivingandconsequencesforcarers.pdf.

Fineman and Payne (1981). Role stress- a methodological trap? Journal of Occupational Behaviour, *2*, 51-64.

Gilboa, S., Shirom, A, Fried, Y. And Cooper, C. (2008). A Meta-Analysis of Work Demand Stressors and Job Performance: Examining Main and Moderating Effects. Personnel Psychology, **61,** 227-271.

Glaser, B. and Strauss, A. (1967). The discovery of grounded theory. Strategies of qualitative research. London: Wiedenfeld and Nicholson.

Lazarus, R. S. & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer.

Lepine, J. A., Podsakoff, N. P. And Lepine, M. A. A Meta-Analytic Test of the Challenge Stressor-Hindrance Framework: An Explanation for Inconsistent Relationships among Stressors and Performance. Academy of Management Journal, 48 (5), 764-775.

MacDermid, S. M. and Harvey, A. (2006). The Work-Family Construct: Methodological Implications. In M. Pitt-Catsouphes, E.E. Kossek and S. Sweet (Eds) The Work and Family Handbook (pp 567-586), New Jersey: Lawrence Erlbaum Associates, Publishers.

Monroe, S. M. and Kelley, J. M. (1995). Measurement of Stress Appraisal. In S. Cohen, R.C. Kessler and L. Underwood Gordon (Eds.) Measuring Stress, (pp 122- 147), New York: Oxford University Press

Montgomery, R., Gonyea, J., and Hooyman, N. (1985). Caregiving and the Experience of Subjective and Objective Burden, Family Relations, 34, pg. 19-26.

Morris, M., (2001*). Gender Sensitive Home and Community Care and Caregiving Research A Synthesis Paper*, Canada: Women's Health Bureau

Patton, M. (2002). Qualitative research and evaluation methods. Thousand Oaks, CA: Sage.
Ruderman, M. N., Ohlott, P. J., Panzer, K. And King, S N. (2002) Benefits of Multiple Roles for Managerial Women. Academy of Management Journal, 45, (2) 369-386.

Pavalko, E., & Artis, J. (1997). Women's caregiving and paid work: Causal relationships in late midlife. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 52B* (4), S170-S179.

Sims-Gould & Martin-Matthews, 2008;
Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory.* Thousand Oaks : Sage Publications.

Thoits, (1991) On merging identity theory and stress research, Social Psychology Quarterly, 54, 101-112.

Thompson, C. A., Poelmans, S. A. Y., Allen, T. D. And Andreassi, J. K. (2007). On the Importance of Coping: A Model and New Directions for Research on Work and Family. In P. L Perrewé and D. C. Ganster (Eds.) Research in Occupational Stress, Earlman: New York

## Appendix A: Interview

### Contact Script – Telephone Contact/E-mail

May I speak to ______________________
My name is _____________ from the Sprott School of Business, Carleton University. Earlier this year you completed a questionnaire as part of a study on work-life balance in Canada. You may recall that when you completed the questionnaire you provided your name and telephone number indicating that you would be willing to be interviewed further about work and family issues. That is why I am calling you today.

Do you have a moment to talk? If not, then when would be a better time for me to call back?
______________________Date and time for call back.

**On call back, mention the study again and then begin here/OR if they do not want a call back or if you are e-mailing them ... provide this material:**

I am working with Dr. Linda Duxbury from the Sprott School of Business at Carleton University, Dr. Chris Higgins from the Ivey School of Business at the University of Western Ontario. On the basis of your demographics, your name was selected as a possible participant in a more detailed study on the way that people manage their work, non-work and family roles. The two family roles we are particularly interested in are childcare and eldercare.

Your participation in this phase of the study will involve a telephone interview that will take approximately 30 to 60 minutes of your time. The interview asks a series of questions which were designed to help us:

- Understand the relationship between providing care for an elderly dependent and employee well being in general and caregiver strain in particular.
- Understand how caregiving affects you, your family, and your situation at work, and how people behave when they experience high levels of caregiver strain (actions as well as emotions)
- Identify effective and ineffective ways to cope or deal with caregiver strain.

Are you still interested in participating in the interview?

**If yes:** Thank you very much for agreeing to participate. We would like to schedule your interview at a time that is convenient to you for sometime in the next week. Could you suggest a few times that you would be available and willing to participate in the interview. We will contact you within the next few days with the date and time for the telephone interview (**or confirm now if you can**). How would you like to be contacted?

Telephone (at what number) ________________________

E-mail (what is your e-mail address) _______________________

**If you are calling back for an interview appointment,**

Thanks again for agreeing to take part in this follow up study. Just as a reminder, this study is a follow up to the previous study in which you participated, and looks specifically at the demands that people face when the combine eldercare with paid employment, how and why people experience high levels of caregiver strain, and what can be done to reduce caregiver strain. The interview today will be audio taped to support the analysis of the data. Audio files will be stored on a password protected PC and will be deleted once the data has been coded and analysed. Names and other identifying information will not be recorded or shared with the funder. You will only be identified by a code number assigned to you. Are you happy to go ahead?

**If they are unhappy, try to identify and allay their concerns. If you cannot, end the interview and thank them for their time.**

**Turn on the recorder and ask again.**

For the benefit of the recording can I ask you to confirm that you are happy to proceed with the interview.

## Section 1: Background Information

**The first couple of questions give us some background information on you and your caregiving situation. This information will give us the context to help us interpret the data.**

***Interviewers will have the following information on the respondent (collected from survey) before they begin the interview. Please record it on this coding sheet. If any of this information is missing, please get these data from the respondent before beginning the interview***

*Gender:* ________________

*Age:* ________________

*First three digits of their postal code:* ________________

*Marital status:* ________________

*Parental status:* ________________

*If they have children ask them:*

How many children they have ________________

The ages of each of their children ________________

Hours per week in childcare ________________

Hours per week partner spend in childcare ____________________

Grandparent: ________________

Hours per week spent caring for children ____________________

***Interview itself starts here***

**Reviewers please note: I have provided you with a number of prompts. These <u>should only be used</u> when the person being interviewed does not understand the question.**

1. How many elderly dependents are you currently caring for? ________________

Thanks. I am going to answer you a number of questions about this dependent/each of these dependents to help us appreciate the demands associated with different forms of eldercare. <u>If respondent cares for more than one dependent continue by saying</u>: Let's start with the dependent who occupies most of your time and energy.

*For **<u>each</u>** dependent ask:*

a) What is the relationship of this dependent to you? ________________

b) What is this dependent's gender? (if you cannot figure out from previous question) ________________

c) How old is this dependent? ________________

d) How long have you been caring for this dependent? ________________

e) Why have you assumed the role of caregiver for this person? (prompt: How much choice do you have in terms of your taking this role?)

f) Where does this dependent live in relation to where you live? _____________Kms

g) How many ***<u>hours</u>*** per week do <u>you</u> spend in activities with or for this dependent? (please include time spent commuting to and from where they live, talking to them on the phone) ____________

h) What kinds of activities do you engage in during this time (Prompts: help them with their groceries, drive them to medical appointments, help them with finance, just sit and talk)?

i) How many **<u>hours</u>** per week does <u>your partner</u> spend in activities with or for this dependent? (please include time spent commuting to and from where they live)

j) What kinds of activities do they engage in during this time? (Prompts: help them with their groceries, drive them to medical appointments, help them with finance, just sit and talk)?

k) ***If you judge from their response to (h) above that they provide physical care for this dependent ask the following.*** Looking after an elderly dependent can contribute to physical strain if the caregiver needs to help with feeding, bathing etc. How often does caring for this dependent cause you physical strain? (never, monthly, weekly, several times a week or daily) ______________

*If they answered several times a week or daily ask them:*
In what ways is it a physical strain (Prompt:. lifting hurt my back)?

l) ***If you judge from their response to (h) above that they provide financial care for this dependent ask the following.*** Looking after an elderly dependent can contribute to financial strain if the caregiver needs to purchase support, help pay for housing etc. How often does caring for this dependent cause you financial strain? (never, monthly, weekly, several times a week or daily)

*If they answered several times a week or daily ask them:*
In what ways is it a financial strain (Prompt: pay for cleaning service, meals)?

m) How often does providing care for this dependent leave you feeling overwhelmed (Prompt: You worry about how you will manage, you get frustrated with them, the service providers, health care system) (never, monthly, weekly, several times a week or daily)

*If they answered several times a week or daily ask them:*
In what ways is it overwhelming?

## Section 2: Eldercare Scenarios

**In this section of the interview we are going to focus on a thing called caregiver strain. Caregiver strain is defined as *"feeling overwhelmed, overloaded or stressed by the pressures associated with the duties and responsibilities associated with the caregiver role"*.**

**In order to understand how people respond and cope with caregiver strain I would like you to think about a situation where you felt strained– in other words, that the duties and responsibilities associated with the eldercare role were just overwhelming. I'm going to walk you through the experience by asking you a number of questions to help me understand the situation, how it unfolded, how you felt about the situation, what you did to try and reduce the strain, and how you now evaluate your actions.**

**So – to start. Think about a situation that occurred in the past six months where you experienced caregiver strain: Please keep this situation in your head when you are answering the following questions.**

1. What made you feel overwhelmed or stressed? What was it about the situation itself?

   ____________________________________________________

2. What was your over riding feeling about the situation? (prompt: Excited, worried, overwhelmed, guilty, fearful, annoyed…..)

   ____________________________________________________

3. The following questions focus on the potential consequences of the situation if it were not resolved successfully:

   a) How was it likely to affect the person you were caring for (Prompt: they would not get the care they needed; They would have to move out of their home)?

   ____________________________________________________

   b) How was it likely to affect other family members? (Prompt: They would have to do more for the dependent; they would be worried; No impact)

   ____________________________________________________

   c) How was it likely to affect your situation at work? (Prompt: I might have to take a leave of absence; My boss would be upset; I would worry about getting things done)

   ____________________________________________________

   d) Finally, what were the potential consequences for you? (Prompt: less sleep; would worry more about the dependent)

   ____________________________________________________

   e) How did these potential consequences make you feel? (Prompt: angry, happy, overwhelmed, frustrated).______________________________________
   Why?__________________________________________________

4. This next set of questions were included to help us determine how well prepared you were to respond to this situation.

   a) How confident were you that you could deal with the situation? (Prompt: very confident, somewhat confident, not very confident, convinced I could not deal with it)
   b) Initially how did you think you would deal with the situation?

5. What was the single most important factor that made this situation potentially overwhelming or stressful for you? (Prompt: life threatening, lose my job)

6. I now want to ask about what you did to cope with the situation you just described .

   a) What actions did you take?
      i) Why these actions?
      ii) Did they work or not?
      iii) If they didn't work, did you try something else? (i.e. did you have a back-up plan?)

b) What actions did others (your employer, other members of the family) take?
   i) Did they work or not?

c) What did you do to deal with the emotional aspects of the situation?

   i) Did this work or not?

7. a) How did the situation end?
   b) How did you <u>feel</u> at the end of the situation? (or, if the situation is on-going, how do you feel about it now) (Prompt: overwhelmed, stressed, relieved, sad)

   c) "Thank you for sharing this experience with us. I am now going to ask you four questions to help me better understand the situation you just described (Prompt: we need this to help us analyze the data accurately). In each case I am going to give you a scale and I am going to ask you to use this scale to categorize your caregiver experience. So, all thing considered:

   - how effective do you feel you were at dealing with the situation (1 = not at all effective, 3 = somewhat effective, 5 = very effective)

   - how overwhelming was this situation (1 = not at all overwhelming, 3 = somewhat overwhelming, 5 = very overwhelming)

   - how stressful with this situation (1 = not at all stressful, 3 = somewhat stressful, 5 = very stressful)

   - how satisfied were you with how this situation ended (1 = not at all satisfied, 3 = somewhat satisfied, 5 = very satisfied)

## Section 3: Appraisal, Coping and Consequences

### *3.1 What makes you feel strained and overwhelmed*

**Thank you for sharing those experiences. The next few questions deal more generally with your experiences of caregiver strain. They are designed to give us a better understanding of the factors that makes some people feel overwhelmed in a particular situation – while others do not.**

1. What are the challenges you currently face with respect to providing care for your elderly dependent? More specifically:
   a) Are there any personal challenges (i.e. health)?
   ______________________________________________

   b) Are there challenges with the dependent themselves?
   ______________________________________________

c) Are there challenges at home?

____________________________________________________________

d) Are there challenges at work?

____________________________________________________________

e) Are there challenges within your community?

____________________________________________________________

2. From your own personal experience, what have you found about the caregiving situation makes you feel stressed?

### *3.2 Coping with caregiver strain*

**The next few questions deal specifically with coping with caregiver strain.**

3. We want to ask you more about how you cope with the challenges you talked about earlier (i.e. 3.1).

   a) What do you personally do (Prompt: exercise, talk things over with friends, eat comfort food)?

   b) What does your family do? What else could they do? (Prompt: Nothing, offer emotional support)

   c) What does your employer currently do? What else could they do? (Prompt: Nothing, unpaid leave, referral service, EAP)

   d) What does your community currently do? What else could they do? (Prompt: Meal on wheels, transportation such as para-transit, nothing)

   e) How about your the government (federal or provincial)? Is there anything more they could do? (Prompt: tax credit, nothing)

4. We now want to ask what sort of things make it worse or more difficult for you to cope with the challenges you face combining employment and caregiving for an elderly dependent? More specifically:

   a) Is there anything your dependent does that makes things worse? (Prompt: they refuse to move, they get angry with me)

   b) Is there anything your family does that makes things worse? (Prompt: they are just not there for me; they complain)

   c) Is there anything your employer does that makes things worse? (Prompt: they just do not understand what I am going through and do not offer any support)

d) Is there anything that the local/federal/provincial government does that makes things worse? (Prompt: too much red tape, not enough services)

e) Is there anything you personally do that makes things worse? (Prompt: I get upset, I fight with the person I am caring for)

**5.** Do you have any strategies that you have found to be successful in PREVENTING these stressful situations from happening in the first place? If yes, what are they? (Prompt: I make sure I phone my parents once a week to see that everything is all right; I have hired a person to go in once a week; I am really organized)

Research shows that while caregiving can be stressful and challenging it can also provide those who provide such care with a number of benefits. The next set of questions explore this side of caregiving.

6. What kinds of rewards do you get from caring for an elderly dependent? (Prompt: self fulfillment; feel good knowing that they are happy)

7. How does your role as a caregiver help you at work? (or does it?) (Prompt: Taught me how to be more patient)

8. (For sandwich respondents only) How does your role as parent help you manage your caregiving responsibilities? (or does it?) (Prompt: Taught me how to be more patient)

9. How does what you do at work help you manage your caregiving responsibilities? (or does it?) (Prompt: Given me the organizational skills to deal with different situations)

### *3.3 Consequences of caregiver strain*

**The next few questions deal specifically with what happens to you when you are experiencing caregiver strain.**

10. When you feel stressed or overwhelmed with the duties and responsibilities associated with caring for your elderly dependents what happens to you:

a) Physically? ________________________________________________

b) Emotionally? ________________________________

11. Does it change how you deal with others at:

a) work? If yes, how? ______________________________________________

b) Does it affect your productivity at work? If yes, how?_______________________

c) At home? If yes, how? ____________________________________________

d) The person you are caring for? ________________________________________

e) Other family members? ____________________________________________

## Section 4: End of the Interview

**The last brief set of questions are included to help us get an idea of what is important to YOU with respect to caregiving strain.**

1. What one piece of advice would you offer to a friend who has all of a sudden assumed care for an elderly dependent?
   ____________________________________________________________________
2. Is there anything else that you would like to add that I did not cover?
   ____________________________________________________________________
3. Could we contact you again in a year, year and a half so that we can see how this situation resolved? If yes, please ask for how best to contact them.
   ____________________________________________________________________

# Appendix B: Selected Quotes

## Section B: Background Information

***Why did you assume care?***

For my mum because she was a single mum and she raised us and I always said when she got older and stuff like that, I would be here.

Well, we're just here, right? We're the closest ones so when he had the stroke we were the ones that were here when the ambulance came. We're just here, so my husband would take him to our RCH when he needed to because he wasn't allowed to drive for the longest time. His kids live out of the Lower Mainland

To give my dad a break, I guess.

She had injuries. She had a fall and sustained injuries.

That'd be probably… I think we always have choice, but I think of my siblings and myself I'm closer to my parents, and because I'm the female out of two brothers I think that fell more to me, and it's probably more of my nature to be more caring and concerned.

No. He's not an only child, but no-one else in the family wanted to take care of the uncle in question, and my boyfriend decided that he didn't want him to be placed in a home, or in a facility somewhere, so he decided to take care of him. It was following an accident he had, which left him partially impaired in one arm, and there was a trauma to the head as well, so it left him with some difficulties. He cannot take care of a home, or pay bills or stuff like that.

Because I'm the only kid that cares, and they started to need it.

They were no longer capable of caring for themselves because, well, my father-in-law had bone cancer which ended up being terminal and my mother-in-law is a chronic alcoholic and I pulled [?] her. She just couldn't keep her house. Her house was going to go into receivership, so she lost her house and moved in with us.

My mum is not very old, but she had a stroke last year, so I'm taking care of her… we were living in different cities last year and now she's moved in with me in Ottawa

I lived the closest and I was the baby.

It's very simple. We are three cousins, and I was the closest to him. I believe he didn't trust the other ones, for certain reasons, and he asked me to look after them, because he couldn't look after his wife who had severe Alzheimer's, so it was a complex situation. I never thought that I would get into this type of thing, and it came as a total surprise, especially that I lived in Ottawa and they are near Osprey, so it's quite a distance. At the beginning it was quite demanding, travelling every weekend, and then extended weekends, and I finally made an arrangement with my employer whereby I was able to do tele [?] work.

(participant takes care of mother) My dad had a massive stroke and he's in a long-term care facility, so they're apart now. She suffers from anxiety and arthritis, and things like that.

I think it's because she trusts me.

...it’s my own choice. I certainly want to help out how I can and I’m fortunate that I have four other siblings who, well, some live a little bit closer and so they certainly do a lot, but I certainly try to take some of their burden as well, doing anything I can from a distance. So it has been my choice and I’ve been, just because I’ve wanted to.

You can check that box, for sure (absentee siblings). Very boldly, the other siblings ran away from there, ran away from the responsibility, so my wife was left with it.

***What activities do you engage in?***

Never a day goes by that I don’t talk to my mother, unless I’m on vacation far away, or something.

It’s usually helping her run errand, driving her around. What else do we do? I do all the maintenance of their place. They do the cleaning of their place but I do all the outside stuff. And then running her around when she has to do errands or anything because we don’t like her to drive. She still thinks she can drive but, you now. So, it’s just more giving her the independence to go where she wants to go.
Mostly just talking to her on the phone, helping her make decisions, that sort of thing.

Just support

Let me think. They’re still quite proficient on their own. It’s really more medical things and providing some support around questions to ask the doctors, so I phone doctors…

It’s more emotional support as opposed to physical stuff. I don’t provide any physical support that way. Really, it’s just finding out how their day’s been, what’s been going on for them, what types of calls they’re getting. They had a call a while back and I said, mom, that’s a fraud person – they’re just trying to defraud you; don’t call them back, don’t set up an appointment to meet with them because they’re just going to rip you off. So providing some of that feedback and…

Taking him to his doctor’s appointments; visiting with him; helping with his meds; helping with meals; helping him at his residence; talking to him every day; going to do his errands, because he can’t drive right now; and taking him to the hospital.

I would usually phone her before I come over. I would pick up something at the store for her if she would like that. When I got there I would make her a sandwich, a cup of tea. She’s gotten now to the point where she wears a diaper, so I don’t toilet her anymore. When I did that it was when she was able to transfer herself from her wheelchair to the toilet, but now she gets a catheter every day that my dad gives to her and an enema, but I don’t do that part anymore. So, it’s mostly visiting and making a sandwich and a cup of tea is really what I do now

I’ll pop over there for lunch. We’ll go to the bank, go to a lawyer’s or things like that. But generally she doesn’t need me to do any of that. It’s more of a confidence thing. She feels more comfortable if I come along.

Some pleasure, some going to movies, plays. Some going out for lunch, which they consider pleasure. We go to the Swiss Chalet. One can get tired of the Swiss Chalet. The service is very nice, and I think that helps. And then the rest of the time would be help fixing things.

Company, to visit with him, and company as in I call him on the phone most evenings. I do all of, I've helped him with all of his business affairs, the banking, the legal things, Mum's taxes. Now we're dealing with Mum's investments, like her retirement fund, and legal issues, we still have to have his will updated, and I'm cleaning the house too. Last weekend my sister helped with this, but we had to go through Mum's clothes, and we still have to go through all the other things she had in the house, and things from her parents. He calls me when anything comes up. Oh, paying bills. Yes.

We visit. They call Doug whenever anything breaks. If they get ill, they call us. You know, it luckily doesn't happen often, but any time they have gotten ill, we get the call because we're close. We have to drive them some places sometimes, and food, we bring food down. We have family gatherings that used to be held at Doug's parents' place, we have a lot of those now at our house because they can't do them
I did the housework and cooking. I would drive them around and do errands. I wasn't necessarily giving medical care. There was a lot of emotional counselling going on especially with my mother-in-law, so the housework and the stuff, and also we would talk with them. I often had to calm them down and stuff like that; sort of talk them off the ledge. You know what I mean?

Yes, like putting… What did we do? Last weekend, it would have been, I just did little things, like putting the lawnmower away, or arranging things in the house. Like, we'll probably, in the wintertime, she needs to have some kind of railing, because she's got a really bad knee; she's got osteoarthritis in her knee, so we'll have to make some phone calls to some home care places to see if we can get a railing put in, so she can walk from her garage to her house by holding on to the railing. Things like that. Like, we had the tub…when we had worked to get her house renovated, the renovator, we talked to him about what kind of bathtub to get for her, and all of that sort of thing. So we just made, mostly, arrangements. We didn't actually do… We don't do a lot

Grocery shopping, just being the go-to person for everything, whenever my mother would have an episode or a bad moment or would wander off or anything of that nature, I was the one my Dad called. Your mum's been missing for six hours; do you think you can go look for her. What do you mean; she's missing for six hours? Ann the hunt would be on. At that time I really pretty much ignored my own family; my husband and my kids because I was forever… I'd be going to work, coming home and running over to my mum and dad's to see what the latest fiasco was. And they were getting to the point where you couldn't really talk to them on the phone because it was a very confusing situation, talking on the phone. [Overtalking] understand who they were talking to

Let's see, I talk on the phone at least an hour a day if I'm not in the city, and what I can say is that I know I spend an average of 200-250 days a year with my mum, that's depending on what city. And I started keeping track of that just because everything was so busy all the time. So, those are the numbers, and I guess you can do the math. She also has been able, more recently, to come to me, but there's a lot of back and forth and planning and stuff.

I do banking for her; I get groceries for her. I take her for clothes, clothes-shopping; I take her for appointments. I clean up her apartment; I take her out for lunch or that kind of a thing the odd time. Or bring something in for her, like a supper or a lunch or something. I help her with her laundry, making her bed and things like that because that's hard for her to do. The odd time I'll do laundry for her but not on a regular basis and just keeping her company and that's what the phone calls are at night. And when I go there, sit down and have a cup of tea with her and that sort of thing, just being a daughter.

I do pay all their bills. I have powers of attorney, so everything – like if there's a problem where they live – they contact me. I take care of all their banking and their investments – all that stuff.

Well, a lot of it is caring for my sister or coming over and just being around and alleviating things they have to deal with. So now I'll help do the laundry or help cook or I'll do little things around the house, just to make life a little easier. Or even running errands too sometimes; actually, I tend to do... I'll do shopping

for them too or things like that. (My husband) takes on more of the role of the larger house things, house maintenance things because he is a guy; so he takes on that traditional role.
Discussing various approaches (with siblings) and that kind of thing. And then it would also be speaking to my parents on the phone and hearing for myself, although you don't always get all the details on the phone. But they're pretty good at being honest.

Again, it would be just support, sometimes with her, I guess well with both of them I guess, but more giving, helping her realise a little bit more what supports are available, both for her and her mum, she's still, the fact that her mum… Well, her mum lives independence still too – she's 105.

***In what ways does it cause you physical strain?***

Well, I do... this ties in with what I do. I have a bad back and neck, so certainly, when I'm busy and I'm stressed out, that definitely does get worse, and I'm sure part of the busyness or any time I experience stress will definitely frustrate that or...

***In which way was it overwhelming?***

Mostly emotional. It's mostly what was causing me problems, or not problems but issues. It was difficult to see this happening and every time you went forward it seemed it would never get better from one time to the other, so you were always going downhill and it's difficult. It's your parent.

He can take care of himself in... He does activities on his own around the house: he cleans a little bit; he takes out the garbage and stuff like that; he goes to pick up the mail. So he does some activities on his own - takes walks - but when you have to drive him places, it's strenuous, on top of all the other activities you have to do. You say, okay, I've got to drive him to the doctor's appointment. But he needs to be taken care of, he needs his Medicare. So we do it, and he's a nice person. He's never aggressive; he doesn't have temper tantrums. He's always very nice. So you look at him, you say, poor him. And then you go and you drive him, but it's still strenuous to drive him.

It gets tiring. It leaves me feeling that I can't do as much as I want. I can't care for her as much as I want because it takes me away from my work, and it takes me away from my child. And I have to try to find other resources for her, or I have to leave her to cope on her own

I'm worried about him. I'm worried that he's not going to get well. Elderly parents are stubborn. They don't want to live with you. They want to remain independent, and they don't see themselves as slowing down or not being healthy. They want their life back too, so it's challenging.

Depression would be the primary thing, watching them decline; knowing that there was nothing I could do other than spend time. And Alzheimer's is a horrible disease; it robs you of who they were. I'm sorry.

Time wise. Also, a strain on the family because she relies on me so heavily compared to anyone else, and my spouse doesn't get that, so it strains the relationship.

Well, like getting up in the morning, for example, and you're trying to get ready for work and you need to get there on time obviously. But if you're getting your mom up and she has literally shit the bed, even though she has Depends, you've got to clean her up and that's not always time that you have in the morning. It's not a great way to start your day. So that impacts your life. When my little boy is able to come up here to visit, you're almost managing two children at that time. How else does it impact? It's the frustration of making sure... because I feel that everybody… I don't think it's real but my perception is that everybody's watching, because I have a lot of control over what my mom is doing and stuff. But it's the perception of going to the nth degree to make sure that everything is clear and transparent in her finances so that people know that I'm not stealing her money and any of that kind of stuff. Dealing with Revenue Canada because she was behind on Revenue Canada. The whole motion of when I go down to the States to try to visit my son, I was able… At first my brother was willing… When her dementia was just in its early stages, he would just come and check on her and then he said he would stay here, and then he really wasn't and so I ended up having to get her an enhanced driver's license so that she could travel with me to the States.

It's very frustrating for me because my…, her mobility is very, very impaired; it just takes her forever to do things. When I have to take her out for groceries or I take her out for an appointment or whatever, by the time she shuffles down to the car and I get her into the car and buckle her up and then take apart her walker and put it in the back of the trunk and that sort of thing. That's very, that's frustrating for me because I have got so many other things to do. But it's also, she's very stubborn in trying to be independent and services have been offered to her which she has refused. They've offered to do laundry for her at no cost; they've offered to do housekeeping for her at no cost and she is refusing that. Then the burden falls on me usually; I do have a brother but she does not burden him with those kinds of things because he's busy. But even when they came to do the assessment she wasn't making sense. And she'll tell a story that's completely not true, and make up things. And the health minister even noticed that. But nobody does anything about it. I've wrote to the minister of seniors over that. And they've basically said, well, that's the system, and she's been on a waiting list. She has to stay on the waiting list. Why don't you get her to a community that's an hour away from you instead of three hours away from you? But at her age, I mean, I'm going to keep moving around for the next two or three years until she finally gets here. I said, that's not going to work.

Just the fact that she's not remembering things. I mean, I gave her a book to write down things in, like a daytimer, and she doesn't remember to use it. I've told her, okay, if you don't want to use that, use your calendar, and she doesn't remember to use that. She went to the doctor and she got new pills, and so she thought they were the same as her old pills and she was taking them twice a day, and all of a sudden she was unable to walk because these pills were only supposed to be once a day. She finally read that on the side of the container. Stuff like that. It's difficult. She really doesn't remember things and sometimes it's like if you told her something an hour ago, she asks the same question again in an hour and sometimes it's… I don't know that she's got Alzheimer's, but certainly there's some dementia going on, plus she's got congestive heart failure, so she's not… I don't think she's getting enough oxygen to her brain. She does have a pacemaker, as well, which they're checking all the time, but I don't know.

It definitely defines the boundaries of my schedule and my personal ambitions, and life and social life, which gets overwhelming when you're trying to plan. There's also… You could make a movie about it, I think. It's sort of like Harold and Maude, where there is a sense that when you spend a lot of time with an older person it's like being with kids that you're living in the moment more, and in the present, and you're sort of responding to their schedule, which in a way is probably good. I think monks are always telling us to do that more. But it also means that I get some cognitive dissonance I think, because I'm going back and forth between someone whose sense of time is a little bit different and wants me to be with her for two weeks at a time, and then when I try to come back and get my own stuff done, there's a sense both of time passing me by and just of being overwhelmed that I'm trying to be in too many places at once, and it's not really organising things properly if I actually want to get everything done. So, it's like that.

A lack of resources

That feeling that you're not caring for your mom; you're not providing enough care for her. No one should have to sit in their own filth, even if it's for three hours. At worst I think it would be three and a half hours; it's the longest she's alone. But it's that she needs more care than I can provide. I'm jumping a little bit ahead, I think, but she doesn't want to go into a home which is… and I'm trying to keep her happy but she needs to be cared for and I can’t do it. It’s just that it can’t be done anymore.

I think the lack of understanding on my wife’s side of it; she wouldn’t consider my feelings, if you will, or my attachment. And just her attitude that somehow because of that I was a mamma’s boy or something like that. But the issues there were what I saw to be jealousy and maybe some controlling… control issues, definitely control issues between the two of them, wife and mother. Who controls what and close to us, the less attention people get, the more they want and the more they [unclear] out for it. And may be and the caretaker of both of them and you’re caught in the middle. They’re both need you in certain ways and you’re not able to keep up on both sides. And my mother’s had tough years [?] in life between this and that she certainly needy and she’s not going to get less so. But at the same time she seems to understand her, clearly understand me a little better. And I don’t know, call it my wife’s lack of compassion and not seeing it, being able to see other’s needs. But that’s my shortfall too that I don’t see her needs, maybe, as much as I should. So, there the guilt comes in, maybe. Does that make any sense? Sometimes it’s easier to keep busy than to think too much about things

### *Section C: Eldercare Scenarios*

### *What made you feel overwhelmed or stressed?*

I have limited time off from work, so that’s a consideration. That one probably does play financially, depending upon the cost involved with taking the time off, going, getting a flight and all that kind of stuff.

I think for me, basically the strain has to do with the balance of everything, so we’ve got young kids, I work in Toronto half the week, and in Kitchener half the week, so I can be going to downtown Toronto. My husband has a very busy career where he manages his own practice as a trustee in bankruptcy, so for us Jack doesn’t really want for anything other than we feel guilty that he’s sitting off at a nursing home. So it’s our inability, because of all the other demands, to spend as much time with him as we’d like.

Never knowing when. Is it today I’m going to go there and he’s going to be down and I’m going to have to take care of all this and it’s the uncertainty. You can’t say Monday he’s going to fall. You don’t know when. And that was mostly what was really stressful.

Because I guess of the conflict with my three children being there and they interfere with the raising of my children, so there’s that dynamic as well. They provide their unwanted opinions, unsolicited opinions quite frequently.

It’s just too much. There’s just too much going on. There are things that we have to do on a Sunday and this impeded our being able to get things that we wanted to accomplish done. And then it was also getting my son to do his homework and then you have…

she was quite emotionally… what’s the word? It’s hard, my mind is going blank here – really hopeless, couldn’t see any positives, wouldn’t hear any positives; it was very hard to even… hearing it day after day just sucked the life out of me, I have to say. And that got overwhelming because I wanted to provide support, but really felt like that was very difficult at times with her because she was so hopeless or despondent in a way, but eventually we passed that. But those were the hardest times when she was just really, really low and there was no pulling her up.

I guess it’s the feeling that I didn’t have a choice. I couldn’t say no, I’m not going to come up for the weekend and being already really tired and stressed with work and everything else, and just feeling like I have no control over what I do.

Most of the time it’s okay, it’s manageable and it’s doable, but when everything all comes together, like I was saying before, like when work is really busy and there’s stuff going on at home – when everything all comes at the same point, it’s really, really hard. I think the work pressure combined with helping out my mum, when they hit at the same time, it’s overloading.

He had hurt himself while doing an activity outside, so he had a cut on his hand and I had to drive him to the clinic to get some stitches. But at the same time I had the kids to drive to other activities, so I felt a little bit overwhelmed. I had to separate myself in three. I was alone. My boyfriend was working at the time, so this was a situation where I felt really overwhelmed

I think a few things. I think number one is distance. Number two is my own family. Number three would definitely be my work situation. And I guess from my way of thinking is that elderly people do better when they’re in their own home. And so being able to access resources and all that kind of stuff that you need if you want to make that happen when you’re not there, is quite difficult as well.

And taking my parents to all their appointments, to doctor appointments, dentist appointments, eye doctors, you name it, every appointment that was me. And it was, that I was exhausting all of my time; be it vacation time, sick time, family-related time, everything time, taking leave without pay time. It was a very trying time.

this just goes on and on and on and on and on. So, you don’t ever get that; I'll just take three months off and it’ll be over. It’s a very difficult thing to deal with.

it’s like having a gorilla or a 500 lb weight on your shoulders; it’s just there.

I felt stressed because I was worried about losing my parent, and I was stressed because I hadn’t seen the signs and the symptoms that led up to what was happening. I wasn’t able to be there as much as I wanted to be.

Sometimes it’s timing too. It was one of those weeks where I had a huge project on the go. I almost lost my dad. I had a huge project on the go and at the end of the week I was leaving for a trip to Europe as well. So it was all or nothing and, again, I just kept thinking, at least he’s still here, otherwise we could lose someone, and I was grateful. I know something good came out of it. A lot of good came out of it, actually. I’m still stressed that he’s not coming back as fast as I wanted him to, but what doesn’t kill you…
I suppose it was the lack of control that made me feel very stressed
Yes, and so it’s more about conflicting time demands. That’s what the bottom line is that you know you have something else to get done. And in her world, what she wanted to talk about of course is a priority, but in my world it could wait another six weeks and it would be fine.

The fact that my mother was hospitalised and she broke her hip, and I was pretty much the main person to go visit her, the main person to provide her with any outside…, whether it be a cup of coffee, whether it be a visit, whatever it was, everything was put on me because of the fact that my mum does weight so heavily on me. There’s been a strain on my family, which means my immediate family as in my brothers and sisters, as they believe that I am a favourite, so they have all stepped back and allowed me to take on the responsibility of my mother because they feel that I’m the one that’s getting the credit anyways, so I might as well do it all.

it’s just that, when you’re in the middle, and the kids want one thing, and the parents want another

Well, I guess, the worst was worrying about my mum, of course. What's wrong with her, how do we get to the bottom of it, how do we manage, what's to come? How to make her comfortable and spend as much time with her and happy, so Mum, of course, was the main focus, but beyond that, just not being able to dedicate myself to that 100%. There were still things happening at home that I had to - one foot was still with my own little family, but I guess I'd have to say my bigger worry was work, and how do I not - because I didn't know how long Mum would be sick. I knew she was dying, but I didn't know how long it would take, and I couldn't just leave work, so I had an arrangement set up where I could work from a local office.

Probably the drinking was the main thing, but it was also because they were both preparing to go off on trips and I didn't feel that they were, ultimately, capable of doing these trips and in fact they weren't. My father-in-law ended up dying on this trip, but because they're relatively independent and they're grown adults, I didn't feel like I had a say in the matter, and so I was very, very frustrated and stressed out and resentful, you could say, about it. My mother-in-law was going off to a resort vacation and I resented that because I wasn't going, and that ended up contributing to the end of the relationship, actually.

Let's just call it a hopeless situation of lose/lose. A situation where my wife was basically upset that my mum is too needy, too demanding of my time. And that I'm not caring for the immediate family as much as I should. And she just figured I was dealing with it totally wrong and should somehow ship mum off to an infirmary or something crazy like that.

Oh, you tell the person not to pee on the floor, and just to hold it for a minute. Then the person does it, and it's unbelievable, so you have to control yourself. It's not the fault of the person, so you have to mop and clean up the whole thing, and it's not only that you have to clean where it's happened, but you have to undress the person, wash the person, and dress the person. When that happens once it's okay, but when that happens several times a day it's a problem.

My father was very delusional in… after my mum died my father's Alzheimer's or dementia kicked in and kicked in at high gear. He would hallucinate that he was in the war or that he… they once thought it was post-traumatic stress disorder. He would hallucinate that there were German soldiers because they grew up in wartime Holland so the war actually was going on and they were in occupied villages and he had some run-ins as such with German soldiers. And he would have – I don't know if these were flashbacks – and he had then, in his mind, turned into his actions that he would have done something different. When you go to the care-home and you see that he is in one of these states it was very hard to witness; hard to… you can understand if you're having heard the stories as we grew up. Then he would add colour to it and sound and light and motion and everything to it and give you a full picture of what actually had happened then. They don't know if that was reality or imagination. … I would experience stress and strain and frustration and… but I knew there was nothing that could be done with him or for him to make that better. We would go along with the hallucination and you had no idea how long that would last, be it five minutes, 15 minutes, the whole three-hour visit and he'd already been that way all day, or whether seeing me and confusing me for someone else, be it my mum, be it his sisters, whatever. Time had a very weird continuum so I never knew who he thought I was. It was very stressful to be forgotten but I didn't exist then. When he was in his 20s and he was a kid going through going this, I didn't exist. His siblings did and then as he was 20, in his early 20s, my mum existed. So, he would call me by my mum's name or by his sister's name and he would call me mum, but I don't know if that was what… he'd always called my mum, Mum. So I didn't know whether he was referring to his mother or mine. I was just trying to find the place where I could make him less agitated, to go along with it and whether it would be better for me to speak in his language than in English; if it would be easier for him, more calming to him. Those were the challenges of trying to keep him calm or more relaxed or able to sleep; or feeding him foods that were from Holland that would… Was that better or worse?

It was conflicting demands on my time. So, not enough time to look after my kids, work, and help this person.

It’s more feeling a bit frustrated, of not wanting to open the door of saying, mum, I’m working, because I know that leads to another conversation. And so I think the strain is more blowing it off and not really talking about it, because the real strain is the fact that I can’t be there all the time, and the fact that she’s lonely. That’s the problem. And I don’t want to get into that conversation because I know I can’t really fix it. And so then you sort of have this little conversation going on in your own head and you say, well, you know, you should fix it. You should be working.

I would say having to race back and forth, so wanting to be in Toronto at the same time as having a meeting in Ottawa, and then needing to be in London because my mum, let’s say, had an appointment with a… or a follow-up with a, say, cancer clinic related to her previous surgery.
The main thing is, of course, my mom wants me to move back to Ottawa, which is something my spouse and I don’t want to do because we’re near retirement. Almost every time I speak with her it’s guilt I feel because she says, I have no one. I would love for you to be here. Can’t you move here? That kind of thing. It’s constant. It’s every time. And then I second-guess what we really want, so that puts a strain on my relationship with my husband

The fact that my brother-in-law and sister took advantage of her financially and are still taking advantage financially.

Yes, just the fact that over the previous weeks since I’ve been off work there was plenty opportunities to get these things done but she leaves them till the last minute. And she won’t ask my brother to do those things; it has to be me all the time. It’s just annoying that and, of course, I can't say no because she is my mother and she did want to look nice for the wedding. But this could have been done weeks ago and she just leaves it till the last minute and in my opinion that’s just a way of being in control and being the centre of attention.

Well, see, five years ago, I said to the health authorities and to the housing authority here where I live, that she is not capable and she’s not making sense, and she doesn’t understand what’s going on half the time. And they said in order to bump her up the waiting list to get her in, the doctor would have to sign off that she is not competent. And he’s never done that, because she keeps switching doctors. I don’t know if she’s her own worst enemy. A few times I’ve taken the day off to go down there, made an appointment with whatever doctor she’s seeing at the time, and then I get there and she won’t go to the doctor.

We’re an hour away. We’re the sibling that is the farthest away from her and nobody took care of her yard, her property for, I want to say, six weeks and she called and just very nicely said, can you come and whipper snip? I’m like, okay, no problem. And of course, my husband’s like, what? Where’s so and so? Where’s so and so? And she’s like, no, never mind. No, no, no, it’s okay, mom. We’re on our way. We had to drop everything and go and find out what the heck’s been going on because someone didn’t hold their end of the bargain. So, sure enough, there we are getting all that done and then making sure everything inside was up to snuff and realising that two of the other three members dropped the ball. So it was like, you’ve got to be kidding me. This is bullshit. So anyway, actually just on Sunday we all got together again and we’re back on the same track. So that would have been three weeks ago.

I’m in the middle of a work case that’s taking my attention out of the province and we’re in the middle of selling and moving our own place. And then we get that call. So we had to drop everything. And part of that frustration is I was out west; there’s nothing I can do for part of it until I got back and then of course the call and then we’re dropping everything again. I don’t think I was even unpacked and we were in the car. An hour drive. Let’s go see what’s going on.

I guess the fact that she had fallen, she’s elderly. I figured she probably broke something. The actual fact of leaving work, going and checking on her dog, and then going to emerg; just seeing what was going on with her, that wasn’t particularly stressful, just when you think of the long-term stuff. She ended up with a couple of fractures of her pelvis, so that’s eight to 12 weeks of rehab and pain and not being too mobile. So the long-term stuff of that. Now, because she’s my aunt as opposed to my parent, I don’t have to detail that through, although I have provided suggestions to my cousin who’s now here.

I think, hmm, I think it was, well, part of it I think was the distance that I was at, but also maybe part of it too was my parents’ reluctance to let us get involved and so they were trying to deal with it on their own and getting very frustrated. And they have very strong Dutch accents and so communicating for them on the phone is sometimes a challenge and so they’re not always understood, and they never want to be a bother so they don’t try and make themselves understood and so they hang up the phone thinking that person didn’t understand what I was trying to say at all. And so they never want to be a squeaky wheel, and so I think that was part of my frustration that we were wanting to help them but they wanted to be independent and didn’t really want us to step in until it, kind of, became a fair bit of a crisis that I think could have been alleviated if we’d been able to be involved earlier.

I guess the most stressful is my mother still believes every word that my brother tells her because he is the male heir apparent. She is European from German background, and men just apparently are smarter. So that’s part of the problem.

I think that there’s… it used to be the idea of someone losing their mind or part of the mind was really scary but once you get it’s in and out, or it appears, or disappears or sometimes it’s worse than other times. How would I describe that? Like a feeling of loss, you’re going to… you’re losing the person who they were, and a feeling of anxiety that you don’t know what’s within your power and that you’re powerless over the ultimate end.

***What was your overriding feeling?***

Annoyed and frustrated, and it was the fact that they were able, they had the possibility to go into a residence, but they didn’t want to hear anything about it. In the end, when matters became worse, he accepted, thank God, that I placed her in the residence. And we both cried, you know, it was a drama, and when he had this cardiovascular arrest he accepted, against his will, to be placed, and when I visit him every day he barks [?] against it, but I thought many times I have to make a decision, and this was the right move.

Guilty, annoyed, I thought it was just a no-win situation; how I am I going to cut off my mum who’s been very good to me all my life and trying to keep my wife happy too; that I’m not spending too much time over there and neglecting her somehow. Yes, I don’t know.

Just, I guess, the feeling of helplessness

So that’s frustrating ... just the lack of medical care.

Powerlessness or that even though I'm the head of my household and they're our dependants, because they're adults, I couldn't say no like I would with my own children. So it was a situation of, I guess, agency

It was just, I guess, frustration. I was frustrated because I had tried to figure out situation and have a plan and then it didn't work out. And so mostly frustration and a little worry too, that I would get sick or something.

I felt sorry that my mum was subjected to some things that I think would have been unnecessary if the communication had been able to be there.

***What were the consequences for the dependent***

It could have been fatal, had it been a very long time laying on the floor. For an elderly person it's very serious.

Well, it would have been fairly catastrophic. She would have been unable to live on her own.

Well, I guess if I had gotten frustrated with her, that would have not been positive; this is a close friend and someone whom I just call Nanna, so I could have lost a friend, I guess, so, you don't ever want to get to that level where you are that frustrated. But for me really it was about recognising really, this is not you, this is not permanent, you've got to just let it go and realise you can't fix it right and she's got to find her way through this. All you can do is be there and listen and that may get exhausting and you may limit that time a little bit more maybe – that's really the only control I had around that.

I think he looks forward to our visits, and so on, so I think the less time we spend with him, the quality of his life is diminished.

If I didn't address it she would have felt very, very bad and that we didn't, that I didn't care enough about her to come and do what needed to be done in her eyes.

I think it would have been emotional. Like now she's being just left there and forgotten about. I think just eventually it would be that now she feels like she's a burden and she shouldn't. And I think emotionally that, okay, now nobody's helping me. So it's more of an emotional, I think, for her. And then what if she's decided, I'm going to try and do it myself? And then, heaven forbid, she's taken a fall, breaks a hip or… Then what?

she lives on her own and has a dog, and will she be able to live on her own and care for herself and that dog long-term while she recuperates.

She would have not been able to... she would have been very upset, she would have... her nervous state was precarious, she might have... it might have contributed to melancholy, depression... yes, it would have contributed to a depressive state.

It requires expense, resources, and time and effort because otherwise she's not going to be able to live there anymore. She's going to have to go and live in some sort of senior centre, and I don't expect that would be a good thing for the long term. It's much better that she lives in her own house.

It caused more of a strain on my marriage than it did anything else. Just the demands of my job that I had at the time, like I said, I was working on the road, so I was away from home three, sometimes five, nights a week. So, it left the burden of my wife caring for my mother with two kids at home. That caused a significant impact; in fact, it caused to the point where I had to go and put in an emergency order to find a spot for her.

They're not too bad but you worry about not being able to make good transitions from their own home to assisted living, to whatever they need, right? So, you worry more about staying too long in the family home.

The other worry would be if something happens to my mom, my dad's in big trouble. He needs 24-hour supervision, so if the primary caregiver goes down, it's red-alert time.

***What were the consequences for you?***

Well, you're always dealing with stress and anxiety so you become a bit… it has an impact on your health. You become hypertensive, you become… difficulty sleeping and regular consequences of stress. You don't eat as well, you don't sleep as well; you don't always take care of yourself as you should because you're involved with something that is very stressful.

They're younger kids. They're eight and four and one is very… how would you put it? Has a lot of energy, so for somebody who is 74, that is very stressful for her, so it ends up being me helping her out and what not. So, she gets stressed and then I get stressed. Her taking on what I think is too much and then it spilling over here, and then you have the stress that the weekend is supposed to be when you recharge and it doesn't allow you to do that. So, at the end of the weekend you're feeling more drained.

I would say lots, actually, because I mean, there's all kinds of things that you go through, and you worry about. If I take the time then I'm worried about my job, of course. If I don't take the time, then I'm worried about what's happening with my parents. And so it causes stress no matter what, really.

From a work perspective I think it hurts my career. It means I'm not there for my daughter and my husband when they need me. It makes it so there's just that much extra stress in my life and I'm just that much more tired and that much more irritable, so it's just a big snowball.
My personal wellbeing will be extremely affected – there's no question. I've had anxiety. I've actually ended up in the hospital due to anxiety and stress.

For me? Well, there's the not feeling successful in my job, so there's some emotional strain. There's also just the physical stress on my body, of the running around, and there's that feeling of failure, like you can't keep up with everything. Guilt.

***What were the consequences for your work?***

During peak times, when I have to say sorry, I have to take some time off, then I get the looks and I get the, how come she's allowed to take time off and I'm not. It causes bad feelings at work.

Yes, feeling tired, feeling like I was not as able to look after my own affairs. My own house, my own things, because I was busy looking after hers.

Well, I definitely felt higher levels of stress, and I also felt like, because of her drinking, that I couldn't really drink, myself, around her because I felt that would be a bad example even though I wanted to relax a bit. I ended up doing Affirmative Yoga [?]. I found that that helped.

Yes, frustration and worry. Yes. I mean, in the end, I could…I would just take a personal day, right, but then that would result in financial loss, because when you take a personal day, you have to pay for a substitute teacher. So yes, in that case, it would result in financial. But it's never happened.

First of all it raises my blood pressure so that's not good; secondly it makes me angry and thirdly it makes me want to avoid her for a while. Because I'm not going to yell at her and I'm just going to remove myself from the situation until I get some rest and put it in a different perspective and then I'm good to go again, so…

I've already had a consequence. I had a heart attack in May, but I'm okay.

I find those ethical things, even something like a memory. Say she thinks that book A is book B and I know that it's really A. Do I tell her that and she becomes more aware of her frailty, or her memory loss or do I just let it pass and am I doing that, am I being a coward or am I doing essentially the same? I don't know how to describe those ways… weights.

The consequences, definitely a little more worn out if you are getting sick because then it's just like compounding on top of it; then you do get sick and then you have trouble, more trouble functioning at work and in your personal life, and trying to get everything done. So I think it can just, perhaps at time be a vicious cycle if you run yourself down, because it just compounds everything. And then I would just say too, just stress in life too can just make life a little less fun at times. And so I always try to put a lot of focus on making sure you enjoy life as well and don't stress too much. But I think that can definitely be an impact as well, and the lack of sleep too if you're... or being tightly wound up too.

I'm in a position where it's only myself that does this job, so there's a lot of stress and pressure there, but the current employer, like bosses that I have, like in the Calgary Police Service people change all the time, the bosses. So I presently have understanding bosses that know that I make up my time if I have to leave during the day.

In my case, I have shaped my work around my situation with my mum. My mum's the priority and my work sort of fits in around it. As a freelancer it actually does mean that I can do that, but on the other hand, if I wasn't a freelancer then I wouldn't be expected to do that. Then other arrangements would be made. My mum would probably move to one of my cities, rather than the idea of dragging it out. It makes me feel frustrated, but also grateful that I'm able to help and that I'm fortunate enough to be in this situation, because it also reminds me that if I couldn't help it would be devastating as well emotionally. Not being able to help would be very difficult, but being able to balance it more would be better.

As a teacher it's not easy for me to take time off, but I did and I do have… That's something that I was able to have covered; I didn't lose my pay for it. But as a regular classroom teacher I had to arrange a substitute, which was difficult, and I'm the one here that looks after the dog and the kids, and I'm primarily responsible for grocery shopping, so that was an extra task my husband had to take charge of while I was busy with my mum and dad.

Well, it's distracting. You go back to work, but you're thinking about it in the back of your mind. So it definitely does impact your work.

Oh, it was horrible. I was more reclusive; I was not nearly as productive as I had been in my work history. My attendance was horrible; my frustration came out in really the wrong places. I would literally yell and swear at my boss, which… that's not the right thing to be doing. And I couldn't even see what was happening

I got, essentially, taken out of my position for a year and when I did come back to work I was – and I will say punished because they had, six months ago, tried to do this to someone else. And instead of having my office I got a little corner [?] in the library to work out of for eight months. And I had someone replace me in my duties who got paid literally over 20,000 a year more than me and couldn't even do 25% of the job. I fell apart in a year and I'm still trying to pick the pieces back up. It cost me a lot of credibility; I know my boss shared my performance issues with the rest of the management team. It will take a long time to feel better if that will ever even change.

I think, actually, in my situation it was pretty good because I had an understanding… my boss was quite understanding about the whole scenario. In one way work was good because it took my mind off what was going on and gave me a place to get away from those other things, to focus on something else for a few hours.

***What did you do to cope with the situation?***

Good time management, you know, being prepared.

Well, I actually saw a therapist earlier in the year for a few sessions just to help me process some things. I journal a lot; I have great colleagues that work here so we tend to have morning meetings to just debrief where we're at and stuff, and if things come up – we're victims services, so when there were issues that came up… we sometimes have elderly clients that we deal with, and so to ask some questions like what can we do here, what are our options, that kind of thing. So talking about it with my colleagues here and friends as well, just really help me to process stuff and put it into perspective at times when your frustration level or your overwhelming level goes up, and recognising that there are other people that you can share with and process exactly what you're feeling.

I drank just a bit more than usual. I would relax with a couple of glasses of wine or something, more than usual. It relaxed. For me, I could just sit and take a deep breather and just… not every day but after events like that it would really relax me. It would just make it, okay, take a breather and do something I enjoyed. So it was enjoyable. It was not like, I'm going to fix myself with a drink.

I asked for the help of a neighbour. A neighbour helped me in the situation, to drive my kid to his activity, which was very, very nice of that person. And then, when it was over, at the end of the day, I took a long walk to take out the strain and the stress of the day.

No, I would be who he wanted me to be with a few lies, of course. I was, if he thought I was my mum, okay, I can be your wife, but I'm not your wife when you're 25 years' old and you just got married. I'm not your hooker and literally when he's sitting there buck naked saying, where's my prostitute none of us knew what the hell to do. And then the nurse came in and said, how old are you? And he said, I'm 18, well, that made sense then. But I wasn't going to be his prostitute. And I could be my mum and I could have coffee with him or play cards with him but I was not his wife. It would confuse him too much to say that I was anything but his…

I give her choices that are going to fit in better with my schedule; I limit the amount of time that I will give to her in those kinds of situations, like she wants to go for coffee afterwards and those kinds of things. And she's lonely but just at this time I just didn't have the time for it. There are times when I will not answer the phone; I'll put it on voice-mail or whatever and then I'll call her when I have the time.

I probably made extra phone calls and did some research about things that my mum could do, services she could use without me being there. I would've tried to find out about background information about the tests that she was doing and how… where it was and what it involved, and looking up the map on the hospital to try to plan out where she would have to go and where the elevators were, so that I could tell her ahead of time to make her less frustrated and be like a scout. Ahead of time I would have researched and pre-planned and thought about all… talked through planning to do something with… Like going with someone who's autistic or high-functioning autistic; it's scouting everything out and going through a scenario with that person, in order to help them prepare for it.

Talk about what our plan was going to be on the way. Talk about – this is with my husband which is, of course, it's his mom – how we're going to deal with his brother-in-law and his sister. But more importantly, how are we going to approach mom so she doesn't feel guilty calling us? So to deal with it we had a plan and then once we got there and made sure everything was good with her inside and then got her set up outside. Okay, we're going to cut the lawn; we're going to fix this; we're going to set up blah, blah, blah. And then took her out for supper and then we dealt with the other two. So it was having a plan and it was just thinking about it and just, okay, let's just think about this and deal with it.

Get your shit together, buddy. We're more of a straight shooter [overtalking] the four of us. So we just, look, that's the way it is. Get out of the frikking… Get on board here again. So really it was just dealing with it head on, instead of not discussing it and letting it fester. So it's just talking about it and resolving it before it became a worse problem than it needed to be.

Well, I just tried to come up with new plans how to best make things work or the best thing to do. I even called my father to see what he thought I should do if that helps. And then eventually we waited around a while too and then eventually I had gotten to a point where I decided we were just going to do what we were going to do as well. So that was part of it too. I had my timeline and I was going to wait only so long and I was just going to head somewhere or do something.

Well, a big thing is I do try to get my sleep and so I do try to make sure that I am being healthy. That's been one thing which reduces the stress but, as I said to you, make sure that you can still function decently to do all the things that you need to do, which I think also helps decrease the stress. Another thing is just trying to put things in perspective when they do get stressful and just being appreciative for situations in life and what you have in life and what they are; so trying to take that positive spin and being thankful for... thankful also for the other situations that there are. For me, that definitely does help a lot, putting things in perspective

I belong to a club and every now and then my escape was to go to the social club, and we would have supper together, or hike together, or do something, so that was my release. I don't know what I would have… I think I would have gone crazy. I would have gone crazy if I had not had been a member of that club. I'm not a drinker, I'm not a drug addict, or any of those things, but the social life was what I missed the most, and it was a real relief when I was able to have supper with them. I'd get a call from them, or an email, saying, we are going to meet for this or that, so you are welcome to join us.

I worked hard at work, worked hard at home, did, took on some projects, like, more than you can choose. Took on some big projects from somewhere and got really busy; spent as much time as I could with the kids and made a lot of excuses why I can't be with either of them (in reference to wife and dependent).

***How did you deal with the emotional aspects?***

Usually I get to talk with my husband and with friends, just to be able to vent a little bit.

I think you generally put it on hold until you have a chance to deal with it. I think at the time you just kick into what you need to do and then you just do it. And then afterwards, sometimes you can get emotional. But I think when you're dealing with situations… because really right now in my life, anything that happens tends to be a crisis. So you just deal with it. And then emotionally afterwards, when you have a chance to relax and think about it. And drinking wine and talking with people works really wonders.

The emotional aspects, I guess, were exhaustion and frustration, and... just... you drive through and you come out the other end with a big sigh of relief and go home and go to bed. That's... and then... get up the next day and face it again and keep at it until we'd finally finished it, but... I think it might have been... I think we were very fortunate in... well, I think it was essential that there were the two of us working at it. I think it would have been... I'm not sure that I would have wanted to take it all on my own. It was a big job. And dealing then with... and, of course, at the same time while we're doing all that we have to go to hospital to visit my mother-in-law, who can't understand why she's there, and etc, so, anyway.

Let's see; I found resources for her, I helped her activate those resources, I showed her how to do things, I cooked for her, brought her food to make sure she wasn't going to starve and get sick. Spoke with her family. And also pointed out that I wasn't going to be carrying the load, that she would have to do this on her own. So tried to wean her from a dependence and create some capacity; get her to be more independent, autonomous.

Yes, that’s what I have to do and I just have to forget about it; I can’t stew about it, it isn’t going to change things. And I just… but I do make sure that she doesn’t… I don’t let her manipulate me whenever it’s possible. I will just say, Mom, I only have this much time and then I have to do this and I have to do that. When it’s time for her to get groceries, I'll phone her the day before and I'll say, okay, I’m coming tomorrow morning; get your grocery list ready and I'll phone you before I come. That’s what I do to give her time to process things because she doesn’t process things as quickly as she used to.
I probably went for… tried to go for a long walk. Or actually I would talk with a friend – probably not a relative. Maybe this is for another question. I actually noticed that relatives actually don’t want to be involved in the day-to-day. I feel that friends, maybe because they're one step removed… That’s another thing; there actually aren’t… The relatives that I do know don’t want to hear about that kind of thing because then they either feel that they're being asked to be drawn in, or they have enough of their own trouble. So, I would say talk to a non-related friend about it.

***How did you feel at the end?***

(Dependent had died) I felt relief and I don’t think it would be unkind to suggest that my wife felt the same way. I think that she... her mother had struggled from... healthwise, for some years, maybe for up to about ten years, so I think maybe it was maybe a bit of a blessing for her and, at the same time, I think we all saw it that way. We all felt relief and said okay, that’s... it’s a good thing that it’s over.

I was very confident I could deal with it, but I didn't realise how far along my mother was as far as her dementia and health issues that my sister had been dealing with for years

Yes. It's more manageable now because we have a bit of a contingency plan and also they're more inclined to consider assisted living than they were before. You know how some people cling like grim death to the family home and stay too long, especially if they're getting lots of support. So now, I think she's a little more inclined to be open to checking out a few places. You don't want to boot them out, right? But it's nice if it's their decision and not driven by a crisis or someone getting a bit heavy handed. So, we're there now; that's good.

## *Section D: Appraisal, Coping and Consequences*

***What is it about the caregiving situation that makes it stressful?***

Having to always be the one. Even my brothers and me have to work full-time. If we’re able to have other people that we could count on to go and check on our parents during the day – that sort of thing – because that would take away a lot of the guilt a lot of the time, driving and doing errands, and spending our time and our worry. If we could alleviate some of that, that would be [soundslip]. There’s a service here in Barrie, like a nurse that goes and visits seniors, but there’s a huge waiting list. I looked into it last year, for my mom. That’s one of the big holes where we just don’t have enough people. That’s one of the issues that’s really made things worse.

Well, time management and things like the emotional investment too. Because you have to stay really positive for long periods of time, even when you're not feeling positive, that's hard sometimes.

Just that I can’t make it better. And I wish that I could. I just wish it were different, I guess, and that’s probably the most stressful part.

Endlessness of it. That’s terrible actually, because I know it’s not going to be endless, but that’s…the constant demands, the demands that just keep growing. You sort one thing out, and then there’s another one. Exponentially growing demands. And it’s probably not going to get any fewer, as they get older, because they’re not losing their wits, thank goodness.

The time. I don't have enough time to do everything.

I think the need to be sensitive made me feel stressed. Again, when you're caregiving for kids, that's one thing, but you know that you're the boss, but when you have two people who are 60; they're not even old. They were mildly demented, but it wasn't necessarily apparent

Just the whole, not being able to control, that it’s like having a child but you can tell them over and over again, don’t do that but you know it’ll never sink in. So, there’s just no point in saying that. It was an exercise in futility, really and it was just all more for the moment; you were there for the moment. It was entirely, what it was.

Sometimes, back in the day, where there were more resources and people spent more time in the hospital. We found it very frustrating when the decision was finally made to put him into a nursing home, and he agreed with it. And completely with it. It wasn’t like he couldn’t make decisions on his own or anything like that. He was completely in favour of that. But we couldn’t get him into one. To be frank, some of the places we went and looked at were absolute dumps, and some very nice places. The very nice places had ages long waiting lists. And part of that was my mother kind of dragged her heels thinking that she could look after him at home, and then it got to be too much for her. And so maybe waited a little bit too long, but still, being on a waiting list for three different fairly large nursing homes for almost a year. So that was very frustrating. And CACC… They were very helpful, but they had one caseworker dealing with a bazillion people, and she couldn’t get back on the phone or leave messages. And she is a very competent, very good, but every time you speak to her she would not express it, but she had too much to do. And one person doing probably what ten years ago was three or four people doing. And so there was quite a bit of frustration around that, that you’ve come to terms with the fact that you need to make another step and you can’t make the other step because there’s nothing there for you. And I’m sure this is something that other people would share or would experience is that once you made that decision that they need to go into some kind of long-term care or move somewhere, and I wouldn’t be surprised if it’s very common that that’s sort of… okay, the straw that’s breaking the camel’s back is about to land on the camel’s back any minute. So you would kind of hope that there was a little bit more expeditious way to get that dealt with. And that in itself was very frustrating for everybody.

The time, of course, that it takes, just the fact that other agencies, whether it’s the hospital or the rehabilitation or whatever, aren’t able to be forceful enough to say that she is no longer able to manage on her own, that she needs additional care. And we’ve been, my brother and I have been trying for a few years to say, look, Mom, we can’t look after you so we have deliberately let her do her own cleaning and let her do own laundry and everything else to help her, that hopefully she’ll understand that we just can’t do it. A lot of the time she’ll expect us to just drop whatever we’re doing and go to do whatever she needs to do and it’s tough love in a way but that’s the way it goes.

It’s the uncertainty, the catastrophic thinking about how things progress towards the end of a person’s life, the feeling of tiredness, the obvious things like joy or how life is moving on. So it’s a darkness that’s like a feeling that where does all this sit and then how you fit it in and then where do you fit.

I would say the biggest thing is just trying to juggle it all and make sure you have time for everyone and feeling like you have time for everyone, and that you do... you are able to accomplish it all. So I would say that's definitely the biggest stressors, exactly juggling busy work day, juggling all the people in your life, all the caregiving, trying to still make sure you have your personal life, and then even just looking after the house too; trying to juggle it all and feel good about the... what you are doing and what you are able to give to each people [sic] or each part, I guess.

I think if it's... if one can schedule it and you know that okay, on Tuesday night and Thursday night... this is the... these are... we're going to give three hours or whatever it is, I think one can manage that. But it's the... when suddenly you have to drop everything and go off and rush off and do something, it... that I find... I think we all find that a bit stressful. I say we all, that's my wife and I. If we could include it in the plans for our day or our week well, then, that just becomes part of what one does. But it's the phone call or that kind of thing that just adds to the agenda of what one's trying to get done in the day, and then suddenly you've got to drop everything and go do something totally different. That's pretty stressful and tiresome.

Just lack of time. There was just not enough time to be able to do what needed doing. So you just feel not able to recoup.

***Are there any personal challenges?***

Well, other competing obligations that I have. I have young children and a full-time job that I support my family of five with.

Time management, sometimes not having as much time as I would have liked, that was a challenge with everything else going on in our lives. It's a challenge.

The fact of always having someone around. I don't have a lot of time just alone with my boyfriend. When the kids are at some activities, sometimes you can find some time alone, but the uncle is always there. And during the day, when we're not there, he has no-one to talk to, so when we come home at night, well, he's there and he wants to talk about anything, just to talk to someone because he's alone during the day. So sometimes I feel that there's always a presence. He's always there, always around. It's a challenge for me to not have my boyfriend to myself for a few minutes, aside from when we're in bed at night. So, just trying to watch TV alone, no, he's a little bit there, so that's a challenge for me.

Waiting for the phone to ring is the single hardest thing; you're afraid to look at Call-display, at any time of day or night. Because if you saw the care-home on the Call-display was it that they were calling to tell you the latest misbehaviour he had. Or was it that he hit somebody? Or is it that he's dead? Or he fell on his head again. I was getting called literally every day for something.

In terms of friendships, I haven't had a lot of time for friendships in the last year and a half, again. So I'm not as much in touch with my friends as I used to be.

Well, one of the issues that… It's the constant trying to keep them happy, that is stressful. My mom has some guilt about the way we were brought up, and she keeps apologising for it. And I mean, this was 40 years ago, and I said to her, it's time your forgave yourself, mom. I can't keep forgiving you. It's over. So there's a sort of frustration at not being able to…of having to constantly take into the fact that they're older, and therefore, more likely to be hurt, more easily hurt. I think that's a constant, trying to not treat them as children, but continuing the respect and the love that they deserve, but it's a bit onerous at times. Yes, so I find that… I guess I get tired. It's more emotionally tired. It's easy to get…it's easy to fall into a sadness yourself, over the fact that they're not…that they're aging. Yes, that's it.

Yes. There are huge personal challenges. It takes time away from my leisure and from building relationships with other people. It takes time away from me building a career, and it takes time away from my son, having grandparents. Those are big personal challenges, and I worry about them. They're my parents. It’s hard to see your parents like this.

Conflict within that’s challenging for me, and not to feel bad and to restrain how I make her feel bad.

The distance. It means I can’t be there in ten minutes. Sometimes my work takes me around Ontario so if there’s a problem, I have to download that to my husband to do it all if I’m out of town at work. So that’s a challenge.

I have two step children and I also have a husband as well. And then... well, we even have other family members that are close by. So I would say definitely just trying to fit all the people, friends as well, into the time that is available, is definitely a challenge and definitely a difficulty. It can be a stressor as well too, just trying to find time for everyone. And then also, to definitely... house fits in too; anything that has to get done and like even just making sure that, when you have the time in the day to also look after the house, cook dinner in the [unclear] with working. Yes, so definitely the house as well, and then even just finding time for yourself to make sure that you have time to de-stress and not get too stressed, I find, can be a challenge too.
I have three jobs at the moment, so yes, and it's... there's like that time of the year. So that's it definitely, and I can tell it's had impacts on my personal life, just even how de-stressed [?] I am, but also bringing it home – I've been bringing work home. So I would definitely say on work [?], for sure; and partly why I... I joined the government and partly why I did is because of my family situation and I wanted less stress and more of that work life balance. So that's often been a stressor having the work environment change to be somewhat less than... somewhat different than how I had expected it to be or planned it to be.

Oh, no, it’s just the selfish stuff, my own wanting to watch a certain TV show, or sit at home and do nothing, so it’s just personal time, I guess.
I think our biggest challenge is the distance and figuring out how often to go. Because when you do go it requires taking vacation; do just I go, does my husband and I go, do we take our kids out of school? We certainly want to go more often, but it’s kind of juggling life here with, when you go it has to be for a chunk of time, so that’s probably our biggest challenge.

***Are there any challenges dealing with the dependent?***

Well, my mother’s very independent and doesn’t like to give up control and so she’s very stubborn about staying in the house. My father has trouble negotiating the stairs and they use all three levels of their large home. So at some point I have this feeling I’m going to be left, they’re going to leave it too late to move out, and I’m going to be the one that has to negotiate with them about what they can move to a retirement home and what, so I’ll end up doing everything, do you know what I mean? So and I’m taking a considerable amount of time off from work to do it. So that’s again forward thinking.

Yes, they don’t like my spouse so whenever they want me to visit they don’t want me to bring him which I find, my spouse has some health issues himself so I find this rather unfair on their part.

Personality conflict. We’re very different people so we don’t see things the same way so that makes it challenging.

Just having new people around, that’s a challenge for him. Me, and my two kids, it’s a little bit new for him. Sometimes the rules have changed, because we’re there, so the family doesn’t do things the way they used to do. Some of the things have changed. The routine has changed a little bit. So that could be a challenge for him. Another challenge is that, where we live, there are not many activities for elders, as well. So, he’s mostly in the house. If there were some community activities more, an organization or something, where he could go during the day and meet other people... But in that part of the city it’s not very well organized. So that’s a challenge for him as well, not having a lot of people to talk to. There are not a lot of elders in the street, neighbourly, as well.

I think yes, because often they’re emotional, and so being able to, I think, help them put things in perspective as well as provide them with the support that they need, and know that they may be irrational as well. And often medication and stuff plays a large impact on how they’re feeling and reacting as well, so being aware of some of the implications and I guess the result of what happens when they’re on medication as well.

Yes, sometimes she's depressed. She's pretty negative and that affects me as well.

Oh, I know what they do that drives me crazy. They call us 20 times a day.

Physically that she can’t go where other people are able to go, so everything’s always restricted to either her home, or if she comes out to us that’s a great deal of work for my dad to get her somewhere else. Going to a restaurant is not easy and she also needs to be fed, which is sometimes off-putting for other people in restaurants. I’ve noticed that they don’t like that, so that’s an extra challenge.

My mother-in-law is very stubborn and won't do things that we recommend, that we believe. They're all stubborn, really. We'll suggest things, like, you really need, we can get this person in to help you, meals on wheels, all this stuff. A lot of times, she especially will refuse, but I know I'll probably be doing the same thing. She's hanging onto her independence and she doesn't want to come to the end of her… I don't think she wants to accept this end of life stuff, you know, it's approaching, and in a way it's great that she still has that spark of personality and challenge, but it does made it harder, for sure, when you've researched things and you think you have a great solution to make their life more comfortable or their health better and they won't do it. But I wouldn't change that, I don't want them to be little followers. We respect that they still can make their own choices

when my father-in-law became immobile, and he couldn't really walk, they were living in a room in our basement, and we literally bought a house with space for them. We had to move houses. We moved to a different neighbourhood and everything. And so to buy a house with extra space on the main level is... every house that we looked at that we could afford had basement rooms. So what ended up happening is they moved into the basement, but when my father-in-law could no longer manage the stairs we had to move down to the basement, and they moved up into the master bedroom.

Well, she’s not a very independent person. She never has been. She’s the baby of the family, so I would say, yes, she’s very frustrating because there are things she could do on her own that she chooses not to, or she just is not willing to do.

Yes. I think there are big limitations there. They’re both single. My dad actually went through a bad break-up this summer and that’s what precipitated his bad health. She drinks, and that’s a challenge. He’s been depressed and that’s part of why he stopped eating. I think a lot of what we bring to our health is whether we’re happy, and I want them to be happy. Luckily, they’re both good, strong people. It means a lot that they can work and see themselves through some of their limitations too, but I know that they will always want to be independent. Getting them into a community living scenario is going to be very difficult. My mother is bipolar, so that’s a huge challenge, with regards to her health as well. So, yes, there’s definitely issues there.
Yes. His lack of mobility. I don’t know what you’re looking for with challenges. Where he absolutely gave up and didn’t want to do anything anymore because he was getting frail and couldn’t move around and lost interest in doing anything, and lost interest in communicating with people.

Challenges for me are that both parents have left me in charge of their finances, and it's a lot of money. It makes me a little anxious to make those decisions for them, just because I want to do whatever they want. I'm in the middle because I'm dealing with financial advisors and I'm dealing with my mom, and it seems that if I make a decision, and I tell Mom, sometimes she doesn't know what the type of investment we're using is, and she gets really anxious about all that. So it's that kind of thing. It's hard to be that person making those decisions, when there's a lot of money in there.

It would be – and it sounds so selfish, and I don't want it to sound that way – it would be easier if she went into retirement facilities, not a nursing home, not anything like that because she's still okay there but somewhere where she can have companionship, like people amongst her that are in the same boat and she has someone to talk to or same interests. But I'll tell you right now, that it'll never happen. She won't leave that house but that's not just her. I think it's anybody that's in her shoes; they want to stay in their home as long as they can. It's a challenge because now we have to make sure we're looking after her and the house and make sure that as she ages, we're recognising now she needs grip bars, or now she needs certain things in the home, or now we need to touch out to CCAC to see what they can do. We're not there yet on some of that but that's going to pose challenges soon that we're going to have to recognise that because there's no way she could go into a retirement home.

Probably not disclose everything, you know just over the phone. I have to ask mum have you had any falls lately? Oh, no. And then my dad might say oh you almost fell that time, or you know things like that but I'm not really sure if I don't ask the right questions are they telling me what's actually happening. But then sometimes they'll tell one sibling one thing and they won't mention it to another sibling, but we all communicate a lot by email and stuff and so I think we have a pretty good picture of what's happening. But that kind off thing makes it a bit more challenging.

With my father – he's slower. Well, the fact that I have to… Well, not that I have to, but I took the responsibility of bringing him to golf once in a while and I don't like golf very much. It takes a long time; it's expensive; I have three children. But he'll pay for it though most of the time. Do you think I could include the golf as a challenge? Because it takes time and I have a family to look after, so it's a bit challenging for me to go golfing and I don't especially like it.
she felt that we were interfering and that she was okay. I would say she was in denial of these things. She was very strong, very strong Dutch lady and very independent, fiercely independent. Didn't like to think that she was going to depend on anybody for anything, but the reality was she had to. And so that was a constant challenge and that perhaps was part of the result of her never being grateful for anything because she resented... not resented, perhaps, us doing it, but resented the fact that we had to do it. And so that manifested itself in resentment towards... particularly towards my wife.

Again, like some things, I could find myself getting very frustrated with him, because… simple things. He could count out his medication. He had to take all these other medications and stuff like that, and he refused to do it. So my mother would be very frustrated with him, saying, I shouldn't have to count out in these receptacles all these things that he's got to do. He could do that. He tells the nurse that they're going to and the doctor when he'd see him that he's doing all this, and he was lying to them. Not a liar, he would never tell a lie on purpose. He would mislead them. Because he didn't have any interest in doing it. So I would go over and I'd kind of lay the law down to him. You've got to do this, mum's too busy to be dicking around with your pills. You do it yourself. All right, I'll do it… Three days later she'd say, yes, he did it for about two days after you talked to him, and he won't do it anymore. And there were lots of things like that that I would become very frustrated with him. And I never lost my patience with him, ever before that. But I don't know what's going on with him inside his mind about why he won't do these things or why he won't help out, because prior to having this stroke, he was one of the most helpful people you'd ever meet. Like, go out of his way to help people.

***Are there any challenges stemming from home?***

Yes, we've been balancing that aspect of my life with work and childcare and all the activities. For my son, for example, he had to miss a lot of that, as I was going back and forth to Montreal, like karate and things like that… his karate, yes. He didn't have to give it up, but he missed many classes, because of... it's just finding enough time in the week, to do all the things I have to do.

My wife likes to… she has been helping out a little bit the last little while but she makes it known that she's doing it and I somehow owe her for doing that. It's, like, you're walking on egg shells a lot of the time if you bring up anything to do with her. And you've got to be always second-guessing myself about whether I can mention this or that or even being over there sometimes. Yes, it's very hard to make your… prior-rise things. Whether you're supposed to… what's your priority and [unclear] the priorities, give them wife and friends are far down the scale and I'm a big believer in taking care of number one. You have to and that certainly suffers. You don't, just don't find time for myself at all, getting round to do things I enjoy, with all the housework and stuff they you have to do.

I'm empty nesting. Both my children have moved away. I had my children quite late in my life, so they're still quite young, but yes, they just moved away. So I'm alone and I don't have a lot of people that I hang out with, so it's basically work and the little bit of friendships I have. Thank goodness, I am the queen of our chapter of the Red Hats, so that has its own issues. I do belong to the Port Hardy Hospital Auxiliary, and I've tried to get out of that, but it's hard because people say, no, you can't leave. So, yes, I don't know what to say.

Well, separation was a definite possibility, but oh, yes, for sure, close to being separated if not, I mean divorce is a long way off that but not that far off. Yes, that was a definite possibility and I'd certainly not, not ever care for my kids but my wife was definitely getting out of the picture.

***Are there any challenges stemming from work?***

Well, the challenge is more trying to establish a schedule where I can take care of the uncle-in-law and the kids, try to combine the two. Sometimes I have to take a lot of hours off from the day. And I try to do my job as well. That's a big challenge, trying to find the right schedule.

I'm in a job right now that's temporary. It's a temporary assignment and I'll possibly be moving back to another position in uniform shortly, so that puts a change in schedules. Going back to night shift and day shift will be a difficult transition, but that's the life in our job. It's always changing. You don't have control over it. At least I have a job. I can't complain about that. It's just something you have to roll with, that's all. And day-care – I'm always after the next person that's going to help me out.

Obviously it limits the amount of money that you can make. Also, I really can't take jobs. The last time I did a contract that involved working in someone else's office was 2008 and I really am limited in that way, so I'm not circulating. I'm not fully participating in my sector, I would say, because I really can't take jobs that are either quick turnaround or long-term, so it has to be something that's quite… a certain type of work. In order for me to be able to do it, it has to be so flexible, and as we know, there isn't a great variety. I guess it also means I'm not either networking or branching out a much. I'm working for some of the same clients that I have for quite a while because they know me and they're helpful, but they're jobs that I probably would have moved on from if there had been fewer constraints on the type of work. I'm holding myself back in that way.

***Are there any challenges stemming from the community?***

We live in a rural area so there would be no supports here or anything for her
Lack of medical services. I just finally got a doctor after my doctor actually went back to South Africa. So that's a big challenge right there and, of course, any medical stuff that you have to do.

Probably there's a feeling of invisibility associated with this that's sort of an overall social… It really is. Elder care really feels like the tip of an iceberg that people don't want to see, and there are good reasons why people don't want to think about it. But on the other hand, it could represent one third of people's existence and… There's a feeling that I'm going through. I feel a bit like a single parent, and yet… Now, people with kids and single parents I have utmost respect for because they have 100% responsibility to look after someone else, where in my case it's… Fortunately, my mum is still very much strong-willed and able to do… I don't have to do the physical caregiving at this point. She can still decide what to wear and what to eat and things like that, but it still feels like everything is my responsibility, and I can see… In a sense, people with kids are allowed to talk about it, and people who are dealing with older people, there's no, or there's less public discussion than I would think, now having reached this stage of life. But of course I didn't think about it much until it happened to me either. But it definitely feels like it's almost a gap. As soon as you start talking to people about it, it's like – oh well, that's the way it is, or that's what you have to do, or – oh well, you had a wonderful childhood, so now you have to help more. It was like a vacuum or a black hole that didn't actually have work attached to it. I guess kind of like women's labour too is the way it's thought of. Everyone takes for granted the infrastructure until suddenly they have to help

***What do you do to cope with caregiver strain?***

Co-ordinate with other family members

Yes. Another thing that I've been doing and it's actually helping a lot is when things aren't as busy at work and things are fairly settled at home, I've taken some time off work and I've driven up there and we've just gone out and done something together, just the two of us, my mum and I. We've gone out for lunch or we've gone to the spa. Just something that is totally unrelated, just to spend time, the two of us, in a zero stress situation.

I read novels and I watch movies. Yes, absolutely. That's my sanity. I come from a…our whole family reads, so it's a sanity thing to read, whether I'm reading Jane Austen, or some other 19th century novel, preferably, because they're calming, versus modern novels which are not so calming. They're good escapes. So I just watched The Best Exotic Marigold Hotel, which is the greatest movie of the last 12 months. It's about old folks and how they look after themselves, and it's a very positive movie. So looking at positive…other people's positive results, sharing… I have a girlfriend who's also one of the prime caregivers for her mother, and so we share our irritations, periodically, knowing that we both love our mommies very much. So that helps, sharing the experience with other friends in the same situation

I do exercise, and I'm trying to make that a priority. I think I might be a little bit easier on myself. Sometimes instead of switching right into work mode when I go home from work, for example, start cleaning my house or making supper, if I'm really tired now I will give myself a break. I don't know if that's the caregiver role, or just realising that life's short and I'm getting older and why work all the time. I allow myself more time to relax than I used to. It's still not much but when I have those moments I will grab them, whereas in the past I'd probably say, no, I can force myself to clean the kitchen or make a meal, if I'm really tired I just say, no, I'm not going to. I'm going to sit here and read or exercise or do something I want

I distract myself. I do more work. I try to stay happy and be a good mom. I have a network of support with my friends. I try to enjoy a good bottle of Italian white wine.

Walks and yoga

I try to minimise the amount of the number of trips and those kinds of things. I do make a point of talking to her every night; if she doesn't phone me which is rare I do make sure that I call her to make sure that she's all right. I limit the number of times that I go there, I will limit to once or twice a week. I, some of the times I will do things that – with her banking and things like that – if she gets a cheque, rather than take it to her to show it to her, I'll just deposit it for her and say, oh, by the way, Mom, I did this. But sometimes that annoys her because she wants to go and deposit it herself. Just to make it easier for myself I'll just do it ahead of time and then just tell her after the fact. And I'm not doing her laundry because I've just put my foot down and said to myself and to my husband and my family; I've got grandchildren now I can't do it all. And I want to be an effective teacher; I want to be a partner to my husband and a helper to my children and grandchildren whenever they need it. There's only so much you can do.

I just keep busy. I've got lots to do between work and home, and I like to golf.

I guess I talk a lot. My husband and I certainly talk about it a lot, and I don't exercise as much as I wish I could but I do do that - so not very much but maybe go for a bike ride or something. I love music and so that's something that's an important part of my life. And also our faith, you know we certainly believe that God is in control and so there's certainly a peace that brings that, you know, I don't have to figure it all out on my own

My wife and I both like to try and keep physically fit, we watch what we eat, so... I don't know, whether... did I go out for a run? Maybe. No, we don't turn to the bottle, that's for sure. Although I'm sure once or twice we went home and had a beer and said oh, goody good. How did we cope with it? I don't... stoicism? Oh, I know, there is something that we would tell ourselves, that... what is it, pay forward? The concept?

this might just be a phenomenon of our generation – even just reaching out and getting support virtually, on things like Facebook. When you're just frustrated and you need an outlet, you just post something like, I'm having a rough mommy-day. Within half an hour or 45 minutes you end up with 35 people saying, I hear you. Yes, doesn't it suck? So you don't feel alone that way. It's funny how much I've relied on that, because I wouldn't have been able to pick up the phone 35 times. Utilising things like that just make me…sometimes the posts make me laugh because some of my friends will know where I'm at and throw a funny comment, and something witty or clever, or offer to come over with some wine.

Well, I guess the fact that I don't live with her probably helps, because I remove myself from the situation.

Probably the two biggest things for me was exercise, was physical, doing something physical to burn off that anxiety or whatever. And I did spend a lot of time, or maybe more than normal with friends, like good friends, and family. It was more of a time… That was a relaxed time because we could talk about the situation a bit, but it was also, we would talk about other things, and have fun and laugh. I tried to keep a regular life aside from that.

with elderly care, eventually they will have to move… most of them, they will. Hopefully, they don't, but a lot of them, they go through this where they come to a point where they need full assistance from somebody, and that's when their life changes and they get depressed, and they always hope that the next day, they won't be alive, and that, and then you as a child or as a daughter-in-law or son-in-law, you have to have to cheer them up and give them hope and making sure that they're positive because that plays in the fact on the way they heal, too, and that. So it's definitely tough.

***What does your employer do to help?***

Well, we have a really family-oriented department; the whole police department's very family-oriented. I've only been here five years, but they've always talked about if your child has a sports event or a school event, you go; make a go, we want you to be connected to your family because balance is so key here, right. And so I'm able to change my hours around as long as I'm not messing up my work here or anything, to be flexible to meet the needs of my family and friends. And if I needed to go out, let's say, to go out for an emergence or something they would just say go. So I don't even know if they knew about any of this stuff going on, but I know that the underlying subculture of the department is that family is important and you take care of that.

My employer, on top of my holidays that I get annually, they give me up to five days per year to assist either my kids, my wife or my parents, to help them out. I usually take this type of holiday when my kids are sick, like if they have a cold and they have to stay at home and I can't get the nanny, or I can't get my parents to help out, then I'll have to take a couple of hours to stay with them at home, or to drive them to an appointment, a doctor appointment

I get reasonable holidays and as well as that we've got, what we call approved time because we work 12-hour shifts, we get an extra day every six weeks or something like that. As well as that, I never take all my time off anyway and I've never had a big problem getting time off when I need it, if it's a medical appointment or something, they pretty well bend over backwards. And I am middle management so I'm in a good place anyway. I don't really expect my employers to do any more for that.

Yes, that's right. We do have, through our board… It's a big board; we have 2,500 teachers or whatever it is. They do have guidance services and that kind of thing which I've never… I've never felt the need to tap into that. I do get a regular massage which is helpful. I have a frozen shoulder and when I'm stressed it freezes, and so I get massage therapy which is paid for by my plan, through my employer. So, that's something I do for myself.

Employer is tolerant of the time that it takes to deal with that. I would put that in the sense of it's a local manager, who's very tolerant of that. I don't know how the organization is in general, but our local manager is very tolerant.

Well, they have all kinds of leaves. We've got a great employee services system if you need to take advantage of it; very good supportive management, so it's pretty good, as good as you can hope for. It's a public service so red carpet at work.

***Was there anything your family does to help you cope?***

Oh, my husband just listens; my sister-in-law in Toronto, I phone her and I vent. And I talk to some of my friends who have elderly parents and we share our stories and sometimes your burdens aren't as much as somebody else's so that helps things. My brother, I have, I've just told him. I said you've got to carry your share of it; I know Mom doesn't ask you to do some of these things but he got a taste of it when he had to look after her for the wedding. He said, now I know what you do! Now I know what you mean! Anyway, I said, well, it's… I've just put my foot down and said, no, he can share some of that responsibility too and I just don't do it.

***Was there anything the community did to help out?***

My mother got a fair bit of support from… and I don't know who it is, but they were very much involved in the Legion, for instance, so people from the Legion would drive them around when he needed to. And these day away things that he went to, they had a core group of volunteer drivers and things like that, so they did rely on that a fair bit, again, going back to my mother not liking to drive, especially if there was a cloud in the sky or it's too sunny or it's too rainy or it's too windy. She doesn't like to drive, so they had a fair bit of support that way at the community level.

The Alzheimer Society of Manitoba had a two-day or two three-hour sessions on understanding dementia and I thought that that was really good. And they do have an upcoming caregivers' session to tell you how to cope with being the caregiver of someone with Alzheimer's and dementia. So I think that that's good and I'd like to see people put more money into stuff like that.

***What could your employer do?***

… what I'm thinking is there's a part that's perceptions and the perceptions of it's bring your kid to work; imagine that was bring your mother to work. ... the amount of time in terms of what is family-related leave is one day ... they need to rethink this

All that energy around leave as a cost is getting tighter and tighter and at the same time that need for a caring network or… what was the word they… we used to have in Canada called? That in a social safety net for vulnerable people is shrinking, and that attitude of isolation and sometimes making them the other is… it sneaks in and there's no… That's where the idea of any employee assistance… how they might have a workshop on getting enough sleep, or they could have a workshop on caring for people with dementia or what your role is as executor. That might be a bit far out but the point is that the more visible and the more activity there is you might change perceptions and attitudes.

***What could the community do?***

They live in small town, too, so there's really not much there at all. But yes, if there were community services that could come and help her out, that would be nice.

I would sure like to see… part of the problem is there aren't enough spaces for these elderly people who are semi-independent. What I would like to see is that there are more supports in place through either the healthcare system or whatever, to allow these people to stay in their home. So that we don't have to worry about it, for example, the apartment that she's in is a senior's apartment and she fell the other day, the other night and she tripped on the rug and fell and she has one of those Medic-alert bracelets. She pushed the button; security came up and they handed her the phone to call my brother. Now if there was somebody in that facility who could have just picked her up or helped her get up, that would have been a whole lot less of a strain. But, I guess, I don't know if that's health regulations or liability issues or whatever it is.

It reminds me of an anecdote, but I don't know if it's good for this section; it might be…. it was a really big deal to plan it, but it was good psychologically – is that whenever I go on a business trip, usually I have to plan for my mum as well. She doesn't always come with me, but sometimes she does which isn't common, but that's usually… Because I'm trying to combine her schedule with mine, and if I go away for a long time then she's on her own for a long time. So, anyway, I went to one that involved going to Newfoundland and turned it into a mini vacation for me, but brought my mum with me so I stayed longer, and it really went well for my mum. This was the first thing… I think she also… Just being older and being on her own she stopped believing that she can do things and this gave her energy that she could actually go on a trip. And what really made a difference, we knew some people there, but we weren't with them all the time. The culture is different. It's still an island community and it's not that everyone gets along, and of course there's new money there because the oil industry is there. But the sense of people living together in a small place has really affected the day-to-day culture. Everyone was talking to everyone. My mum grew up in a small town and I think it reminded her of that, that even you've got skate punks on skateboards and rings and tattoos, and looking different than the way that lot seniors dress, but they'd be coming up and saying hello to her and people would see her. She was able to walk up and down the hills a little bit, and people would say hello. And we met people through the place that we stayed and they totally got the elder care. The one person we were staying with said, anytime if you want to go out, I'm going to stay with your mum and, you want me to fly out to Ontario, anytime I'll do it. And that was the sense of social structure that Ontario doesn't have. I'm sure there are in pockets, but it's not part of the general way that people…

I won't say that they should advertise more. I guess have more tailored services. In my mum's case we have looked into things like that. They don't represent either what she's eligible for or what she needs, so it's more having services in the community that focus on, I would say, the transition time of life, and that will just evolve if there are more people like her. In a sense she is the kind of person who… When it comes to homecare for example, you can certainly spend money and buy even nursing time for someone to come in and do specific things, but we've actually had interviews a couple of times and her doctor even got the community care access centre reps involved, but everyone deemed that it was… My mum was sort of inappropriate – in a good way. She falls between the cracks because she doesn't need help getting dressed; she doesn't need help bathing. Again, I'm knocking on wood when I say this. You get sort of superstitious. But up until now anyway, that's not what… there haven't been crisis items to help. The problem is that she's living in a big house by herself; she doesn't drive. It's in an area that's not exactly suburban, but it's designed for people who are mobile and mostly it feels like people who are older, especially in the city where she lives, spend too long living in their houses in single family homes, because the option which is sort of senior apartment and retirement homes represent too much care. And it's that middle sort of graduated care step that's missing. And it's the same even with, I would say… What would it be? Sort of, ordering individual services one by one. If you do live independently and you just want to buy a little help here and there, what's available still doesn't feel like what she needs. What she needs is a daughter and no matter how much time… And a daughter who's willing and available to help her live her life the way she wants to, to some extent. And you just can't spend enough money or buy that kind of help, at least unless you will compromise which a lot of older people won't, which is another question. Plus it's really expensive.

We don't do anything that's targeted around our aging population; we might do park lunches for kids in the summer but we never do anything that would be about providing some caring in a broad sense to seniors. Our communities are… and there isn't enough accommodation and affordable accommodation. Even though in the situation this woman is considering giving up her home but her preference is to be alone and I think that the number of older aging, on their own women is increasing. Their housing is either extended care, or institutional care or there isn't much of a range and I doubt very much its Saskatoon; and it's hopping in terms of a boom but that nobody's thinking about the housing, or the pathways, or the accessibility in terms of design of our community or communities or even something as accessible as groceries. As a public sector, I don't think you'd see anything that would be akin to what you might see in terms of other social justice action or in terms of public health education.

***What could the government do?***

I think federal government is... It's pretty clear that it would be in the provincial. For the most part, I mean, the federal government does offer some EI if your parent is, essentially, dying. I suppose the federal government could expand the coverage of EI to cover situations where you're providing ongoing support over a long period of time. Provincially, I think a co-ordinating body would help. A co-ordinating service would really help.

I do think that they need to look more at how they can support people to be supportive to their elderly parents to still be on their own. I mean, it's going to be less strain on the system if they're able to do that. But they also need to be able to, like I said, is there ways that they can support then taking an extended time or whatever in order to provide the support. And maybe it's just me, just knowing more what is out there, what resources are available, how to access them, and the cost of them, that kind of thing.

Well, I think for people who don't have employers as generous as the federal government I think that it would be nice if they recognised, if they could do something to recognise the need for eldercare, taking leave without risking losing your job sort of thing

I think the early intervention on care. One of the things that they're doing is the nurse practitioners in B.C. where the nurse can do a lot of the doctor's work, so it's taking a lot of the load off of the doctors, because they see a lot of the people go to the doctors for social reasons. Now they're really lonely and they worry about things. I hear stories of people going twice a week to the doctor. And any programme that keeps them out of the healthcare and more into the… if you look that the importance of the social aspect and provide those outlets, I think it would cut the drain on our healthcare system. And it's much cheaper to do it at the front end than it is… but a lot of what has been cut back, unfortunately, right now, is those social programmes, because they're deemed to be unnecessary. And I think we're going to see it at the back end, where we have alienated people because they're not funding some of the stuff that is seemingly unnecessary. And the community support mechanisms, I think, that's what our seniors need, is those sort of programmes. And it really troubles me that those are being eroded.

from a provincial level, if our health care system would allow - if they could help provide these seniors with support, that would be wonderful, to take some of the pressure off the adult children of these folks. I don't know how people without children do it, really. Like if my dad didn't have me to help, I don't know how they cope, these elderly people that don't have adult children.

The reduction in resources in health care, which both levels of government are to blame for, they're significant. Like the fact that there are not more family doctors available, but yes, they could do more. They could have more family resources and family doctors available.

We, I think it's a joke that because she has a house and she has resources and she has whatever, enough money that she can't get into an old folks' home because she doesn't… She'll never get in because somebody poor will always be on the list before her. So, she doesn't qualify for a standard old folks' home. She does, she's on a list for – I don't know what you call it – a minimal care-home where they… but the only reason she qualifies is that because she needs help bathing so she automatically qualifies. But most people in there are in walkers, so I mean my mum will never be in a walker because she's that stubborn and she would fall down the stairs, whatever, before she gets into a walker or use a cane. So, she's always getting backed up on that waiting list because there're people in walkers that will be ahead of her on the waiting list. So the community as far as I'm concerned has really fallen down on caring for their elderly that are healthy. Like I said, she doesn't apply because she'll never get into the old folks' home, which we've probably got half-a-dozen in Dryden. And she'll never get in because the people either hide their money, get in or they… the people that are – I don't know, don't hit that benchmark – are always ahead of her on the waiting list. So, she'll never get in there so…

Having a social safety net and more services available, and more flexibility, well-funded services, definitely makes for a healthier environment in general.

I guess, just because you know financially we certainly, we feel it if we have to make more trips or whatever to Saskatoon, but like any financial assistance I guess would also be a valuable thing – that plays into our decisions as to how often we can go, certainly, and we never feel like we go often enough. So, I guess, you know, dreaming...

***Is there anything the dependent does to make things worse?***

The fact that she kind of assumes that I can just drop everything and go is definitely part of it. I think that, based on the fact that they're retired, they don't see things the same way anymore. She didn't work, so she doesn't know what it's like to work full-time and have a family, so I think there's a perception difference there. This is not going to make any sense, probably, but there's a language barrier, which is crazy because she's my mum. She's French-Canadian and I'm perfectly bilingual but I'm still more English-Canadian and there's a cultural difference.

Well, they don't get anymore flexible as people age. My folks are pretty agreeable but change is hard and I think moving is a big stress. Even some sort of downsizing kind of program, there are private services out there to help you reduce your clutter and get it out of your house, but it's really the psychological hurdle that elderly people face. Mine are pretty good, but I know lots of other relatives who stayed five and ten years too long in their family home and it was really hard on all of their family members, so our motto is don't be like and then insert name here, right? So, it could be way worse.

The fact that she doesn't understand that I only get so many holidays a year, and she thinks that I could actually go and help her go to one of her medical appointments. She doesn't understand that it's four-and-a-half hours to drive down and then four and a half to drive back. She doesn't get that. She's losing it.

***Is there anything your work does to make it worse?***

Yes, the culture in the office and the lack of flexibility. If I could work from home then it wouldn't be a big deal, I could go up there and I could work from their place and still help her go to her appointments and make sure things are getting done and what not, but we're not allowed.

Yes; there's huge pressure to not take any time off, like, to not be ill.

***Is there anything your family does to make it worse?***

I think not offering help but just waiting for me to ask for it. You don't want always to ask, but maybe if they offer it would be much better.

They don't help my mother at all. My brother goes down sometimes, but when he's there, he's only basically there to stay at her house like it was a hotel. It's not really there to help her. But he has two little children and they are both very involved in hockey, ballet and all that kind of stuff.

Well, sometimes I have to attend my father or my mother and other demands. The kids are demanding sometimes and I have to cope with that. There's piano lessons I have to take the kids to, there's art school or whatever it may be. And there's a conflict there sometimes, so I have to tell my parents, look, I'll do it, but I'll do it tomorrow or later this afternoon.

***Is there anything the community does to make it worse?***

We had some problems at the beginning getting him into a nursing home, so there was that whole navigating, he was in the hospital for a while, and he's on lists, and that whole navigating the elder care system was not particularly a good experience.

Well, this whole elder care thing, there's so much… like my girlfriend, the one that was so ill, she actually got so ill that she had to come live with us, but it was because she was caring for her elderly demented husband. And so she ended up in the hospital which is what precipitated in finally being permanently placed in a home. But the nightmare that she has had to go through since that happened, all the paperwork and filing for legal separations and the amount of money that the government is then taking from couples for some of these services when elderly people are on pensions. And even just my parents… Oh, you're just getting old; these are complacent insulting ways to speak to seniors, and then they're: well, just go online. Well, not every senior is online and my parents of course aren't and so they feel like they're treated like they're most incapable. And so more of the processes and all the paperwork involved in some of those things has just been overwhelming, really, for my girlfriend especially and for my parents too. Simple things like Sharp [?] putting in their new digital boxes and then I would have to go out there and I said, this isn't working. Well, of course it is, it's working fine. And I went, okay, well, you come here then. I said, I'm sitting here right now, and so he had me unplug everything and he was, oh, I guess it's not working. But when you're talking to… they just assume the senior is stupid and that they're wrong, right. And I know my girlfriend has had the same thing; she keeps calling them repeatedly saying, this is not working. Well, what have you pressed, it's something you've done, and it isn't always, but that to me is I think what's frustrating about the community. They tend to treat seniors like they're stupid and that's sad

***Is there anything the government does to make it worse?***

Yes, it's the lack of availability of caregivers, doctors, some medical professionals.

The support programs are a bureaucratic nightmare, but that's everywhere.

Bureaucracy. Yes, I think that that's the big thing… when you need help in a hurry, it's very difficult to organise it.

Yes. What would have been really great would be actually Health Insurance for a bit more seamless. We had to get them transferred from Nova Scotia Health to OHIP and there's a three month wait you have to do or something like that. I don't know what's [unclear] but we had to get them their ID and their OHIP cards and stuff and especially in the case of my mother-in-law because she was so feckless [?]. She didn't have the proper ID, so we had to back to Newfoundland and get her wedding certificate mailed off, and that was also when she was suppose to get the passport because of this trip to Mexico. So just the bureaucratic stuff that the insurance [unclear]. That could have been, I think, a little bit more seamless across provinces. If she's got Nova Scotia Health Insurance then why does she have to... why can't she just show that she lives in Ontario now and get a transfer to Ontario as opposed to having to prove her identity and stuff like that?

I think that the big frustration is I don't think that the Health Care System is really set up to help or they're overwhelmed with the amount of requests for help because, again, I really hated when the Home Care case coordinator said it's not a babysitting service, because I'm not asking anybody to babysit my mom but I am asking for help, because it is far more economical for someone to stay in the community under the care of a relative as opposed to putting them in a home. I didn't understand… The other thing that, I guess, this case coordinator maybe did – and she didn't mean anything by it by I took great exception to it – is, what happens if I were to say, you know what? Screw it. You guys can't come in and help me at all, then I'm not caring for her anymore. And so essentially my mom would be homeless. And so I think that part gets lost. And then the other part is her Dr Hoffman [?]. I firmly believe that he's there to make money – we're all there to make money and that's why we do our jobs – but every time we go it's, we want another blood test and the last time I got into it with him. I was like, she just did the kidney dialysis thing at St. Boniface Hospital [?]. They sent you the tests and you asked me to get the tests done again even though everything looks fine. And now here it is. So for three months in a row we're getting her blood tests and you're telling me that there's nothing wrong. Let's stop poking her. And then he got mad at me saying, who's the doctor here? Do you want my help or not? And because, where do you go to get a new doctor for a 75 year old Alzheimer patient? There's no places to turn. I don't know if that answers your question.

I do think that it is a bit of a bureaucracy and I don't think that there's a clear path to know what your resources are. I think that – and the Alzheimer Society told us this as well – if the case coordinator comes in and sees that your house is clean and that there’s food on the shelves, you’re the less likely to get the help and so you almost need to put up a front. You’re better off to mess up your house before they come and I think that that’s wrong. I wouldn’t be asking for help unless I needed it and so I find that to be frustrating. On a related note, and it goes back to money unfortunately, is the amount of paperwork that we’ve had to do, in terms of… there’s a provincial grant you can get, and then a federal caregiver tax credit. These things aren’t coordinated and you don’t really know about it unless you know to ask. And every time you go back to the doctor, your doctor charges $125 to fill out one of those forms and so I wish that it was easier to... and again, it’s not really about the money but if they’re offering those kinds of things, make it easier for us to access it. And I don’t think doctors should be allowed to charge $125 to fill out a form. I think that that’s just wrong.

Well, in one way, when this happened with mom, when she had to go to the hospital – she was in the hospital till we could find a place for her to go into. The process in our case, it seemed long, but it was only a couple… In the big picture it was about a month and a half and we found a place for her. At that point I thought it was long, but when I compare it afterwards to other people’s scenarios, it was pretty quick. So initially, I think, it would have been good to have either more facilities or, again, an easier way of placing people in these situations into homes that they don’t have to wait in the hospitals and do that for a very long time.

And my mom was basically in, I guess they call it kind of like a transference ward where you’re either waiting to go somewhere else or you’re waiting to die. That’s basically the two types of people who are in this ward. So that’s not the greatest, obviously, place for somebody who’s waiting to go somewhere. People all around them are dying all the time. So that would have been nice to have a… In a perfect world, it would have been great if that process could be faster. And that’s a government thing, right? Because, I mean, they’ve got to provide the facilities.

“I feel that the Health Ontario needs a complete revamp when it comes to the elderly care….to change and making sure that they’ll get help, proper help, because for my parents, for example, we need a desperate care of home care, for example, somebody to come and help us out, an hour in the morning, an hour at night, or something like that. And because of the doctor – my parents lost their doctor a couple years ago – they were never able to get a doctor, and they’re still looking for a doctor. They were never able to ask, and I didn’t know that you could ask that way. They were never able… I called the federal government, provincial government, the city of Ottawa, to see how can I get that care, and I was unable to do that. “

Looking after my grandmother came about very suddenly, and it was unexpected. And I had no idea how to even begin to undertake that, and it is virtually impossible to get any kind of assistance or even sympathetic understanding and… or guidance or a booklet or something that points you in the right direction or tells you what call to make, and it’s just a series of websites with dead links and forms that have nothing to do with your particular case. And, like I say, when you talk to somebody on the phone, if they decide to be gracious at that particular moment, they’re unlikely to have a clue how to help you and generally shuffle you off to somebody else.

It’s a horrible system, and God bless the odd person there who’s conscientious and really is trying to make a difference. As I said, I did access a couple of those, and I was very grateful, but I know other people who have gone through a similar process and just thrown up their hands, having no idea what to do. And even though I have some experience, I don’t even know how to advise them. So I think the governments fail miserably in those areas.”

***Is there anything you do to make it worse?***

Put too much on myself

I get very impatient.

Yes, probably when I get too pissed off! It doesn't help me, it doesn't me sleep, it doesn't help me cope, it doesn't help my blood pressure; they are not good things. So usually that doesn't last long thankfully, but there are certainly… when I get overly-aggravated by situations or processes that I just don't get, like why do you have to make it so complicated, like that… yes

The only thing is, I'm very quick to offer, which does make it hard for me, rather than expect or leave it for someone else to do. I mentioned my brother doesn't help, but I don't ask him either, I offer a lot, so I am in a way my own worst enemy. I offer too quickly.

Well, you cause stress by worrying. And there's ways you can worry… I always find that worrying doesn't make it any better, so I mean, you always cause your own stress, right?

taking on too much; as teachers, we tend to be perfectionists, and I think it's a female thing, too, for sure, as we tend to be the nurturers. So most women I know take on more than they need to. They cook and they… But I'm not doing as… I try not to do as much of that. I've got a really good partner. I'm lucky. We try and balance things out amongst ourselves with the chores and that sort of thing, so I'm not falling into that category of, I know most women still do most of the housework, most of the cooking, and so on. So I tend to take on more than I need to, like most people

I think what I do, I probably don't ask for enough help. I don't take enough time for myself and by that I mean because I don't take myself out of the situation – remove myself from my mom for any period of time – that all I'm doing is increasing my anxiety and frustration and it strains my relationship with my mom, in my mind anyways. She doesn't understand what's going on but I need to ask for more help and I just need to get stuff done and that's probably just...

I did too much for too long. Initially, I did... I had to do a lot because she was in a really bad state, but I could have pulled back more and eventually I did, I learned, I think. Not that things got that much better for her, but they didn't get worse, certainly, and they got better for me.

***Do you have any strategies to prevent stressful situations from happening?***

Often, yes, you would just get your mind around it and say, okay, I'm going to go there and this is going to be the situation and I'm going to do A, B, C. So if I was prepared mentally and I had a plan then it wouldn't be so bad. Often we'd get there and I knew exactly what I wanted to do or what I had to do or who I have to call and that worked out well. That really helped.

When everyone gets involved in elder care, the kids, and we all do activities, all of us together during the day, that's a good strategy. When everyone is there, we can all chip in and we can all find some laughter and some good humour in doing everything all together during the day and involving him, teaching him to do stuff as well. You have to be patient, but you have to teach him to do stuff, so he can help himself as well. When everyone gets involved, it's helpful this way. It's a good strategy.

Well, I think communication is important; talking to my sisters. We have a lot of plans – if this happens, then… which helps us try to have some control over if my father keels over, what would we do with mum? If my mother dies first, what will we do to support my dad? – that kind of thing. So we do have those in mind.

Not overloading myself. Being more realistic about what can be achieved in a day we all care about our family members, both my husband and my children and myself, we all want the best for our parents and the children's grandparents. We're all supportive of each other. Anything that any of us do to help these elderly people in our lives, we value. We always would respect that time that any of us spent helping my dad and his parents, including the kids. We care about each other, we can communicate well, we're in a healthy place to be able to deal with these family crises that come up, because we all care about each other and about them, and that becomes the priority, making this work well. So being in that place, when we have a crisis, we can work through it.

Just try to maintain a positive outlook and if I'm tired and I can't do things, I just won't do them where it's concerning Mom. I always make sure; I don't worry about her not having enough food because she can always go downstairs to eat. But just to make sure that she's clean and has enough clothes and things like that. So I always check and remind her, Mom, did you do this? Mom, did you do that? And, I mean, that's about all I can do other than being there all the time, which I won't do.

Oh there's no prevention. They're going to happen no matter what. It's almost a given.

### *Personal rewards from eldercare*

I get to spend more time with her. Otherwise, I probably wouldn't make the time because life is so busy. And through that I get to know her a little bit better as an adult because normally as a kid, you see them very differently, so I am getting to know her a little bit better as an adult.

Well, I think it's a feeling of pay-back, looking after her in the way she looked after us.

I really enjoy finding out what her life was like in its totality, so when she was younger, because it helps explain a lot of the things the way she is now. And it makes you really admire what she's been through. And it gives context to the person that you know as an adult and the person that you thought you knew as a child. It really gives a more broader context and understanding. And I find that really enjoyable. My kids do too. They really like to hear stories about her youth.

Yes, a feeling of being totally loved, which is hard to beat.

I actually have time to talk to her and spend time with her, that's good. Because before that and before she got sick last year, I didn't spend that much time with her. I wasn't going to visit very often and I was busy. And once, after that, I actually started seeing her more often.

Benefits, I mean, certainly, she is my mother and giving her, allowing her that time to express herself and ask her about the old days and family history and sharing recipes with my granddaughter and things like that, or with my daughter rather. Making her feel good and positive and at least once a week I try to make it so that I, even though I do set a time limit it isn't where I've got other things pressing to do; just scheduling it so that it's going to work for all of us. And be a positive experience, that I don't feel that I'm obligated to go and that I have to go and that here she is taking up my time again, that kind of a thing. I just put into perspective that someday I may need that assistance from… and just go with it

I spend a lot of time with her, so I'm very privileged as I said. I know her very well and I learn from her experiences. And I guess one of the greatest is actually her knowing my kids and the relationship my kids have with their grandmother is unbelievable. I've never had a relationship like that with my grandparents. And even though she's been living with us for two years, but she's been very close to us in the last eight years, the kids still think she's a novelty. They just love her, and even my eldest who's 11, and even the nine-year-old, they go to her just to talk and to chat, and she helps... She was a teacher before, so she helps them out with their homework. She’s also available once in a while to… It’s getting more and more difficult because I have three boys, but she’s able to babysit them once in a while. She gives back to us a lot.

What are the benefits? There’s a lot. She brings another point of view … Like this week we had a problem with my elder son. He’s 11 and my husband… my husband called her and asked for her advice at how she would deal with this, so we're very close.

I would say definitely the personal connection; so the personal connection that you get back. We also cared for my grandmother when I was younger; she lived with us, and it was a similar thing too; we all, the entire family got a lot out of it, and we have these ridiculous stories we still talk about to this day and share about those experiences. So that's the bond, the family experiences, the connection and even when you’re being a caregiver, you can get those positive benefits which then also do help support you. So in ways they do help support you back in certain ways

I guess that sense of validation that you’re around and you’re helpful. I think... I don’t know if it’s from the caregiving so much, it’s the pleasure of having them around at such an age, that you still have that interaction. My mother died when she was 72. And then as a parent, my kids get to interact with their grandparents as adults as opposed to... my kids were three and six when my mother died, just that knowing that historical ancestral kind of thing. I don’t know if that really answers the question.

just, I think the satisfaction of hopefully giving back to them. We see how much they’ve given to us and sacrificed for us, and so it feels like the least we can do and so that’s satisfaction. I know with my mother-in-law, she’s just so appreciative of just knowing things that, like she just hadn’t thought of as far as caring for her mother, and so she’s just very appreciative. And my parents are appreciative of it as well, sometimes it just takes a little longer for them to get there, but they are appreciative

I enjoyed having my mother live with me and, like I said, I felt guilty every day she was in the long-term care facility. But just being able to have them there with you, I think it's, that's the way it should be if you can. But at the same time, like I said, I explained to my kids the medical issues that their grandmother had and, you know, where she is, was the safest place we could have her. As much, as hard as it was for us to put her there, that's where she needed to be. We couldn't care for her at home.

### ***Does your work help your caregiving?***

I think probably my negotiation skills that I use at work carry over. I use it in the hospitals and all the medical-type stuff. There’s a lot of negotiation that goes along with that. The language, because I work in French, so it’s made it a lot easier with what I’m dealing with, with the hospitals in Montreal, because most of them are Francophone, so that helps, just to keep me in practice. It’s not a direct relation but it’s a definite benefit. And just my management skills that I’m learning at work. The big one is coaching. I’m working really hard on coaching my employees instead of giving them answers and I’m able to do the same thing with my mum and she gets less impatient because she doesn’t feel like she’s being told what to do all the time.

All life experience helps me in my job, as far as being able to understand different types of people and being compassionate is concerned, but I don’t really need my caregiving role with my parents for that. I’d rather just have them as parents and enjoy them, rather than having to care for them.

If you don’t have children and you don’t have elderly parents you can’t possibly understand as a manager, why somebody would need to leave in the middle of the day and be able to give them that freedom to do that without making them go through hoops

I would say, yes. It helps me, perhaps, think things through before acting, and consult with stakeholders, take into account the different opinions.

I think it broadens one's perspective. Especially when you do it for the first time, you suddenly realise, oh, there's more to this world than I had realised and it broadens one's perspective. I think it makes, perhaps, one a little more tolerant of other people

***How does caregiving affect your productivity?***

You just can't do the work. You can't get to be in the field and you can't be writing reports at the same level when you're thinking about your family. You're just not as strong. You're not as focussed. You're not eating. You're not sleeping. And you're taking phone calls at work about personal matters. Instead of multi-tasking about work issues, because we're all multi-tasking about work, you're now working, and multi-tasking, about all those work issues plus personal issues. That's when mistakes get made and, at the level that we all work, sometimes you can't afford mistakes.

I couldn't focus. I would have two pieces of paper to move off my desk; I would be literally staring at them and I could not decide which one to do first. One could be a one-minute task, one could be one-hour task and I couldn't decide. It was lack of attention; I had no attention span; I would jump from one thing to another, to another, to another, to another. And never really finish anything. I wasn't able to do any follow-through; you do something then you email someone back and you tell them what you're going to do and then when you're done, okay, it's done, can you now test it? Now it's working; good, now I can close that. Couldn't do it, I would either do it and not say anything or not do it or hide from it or I would miss meetings; I would deliberately be away sick the day of an important meeting. I just, I couldn't do it. I didn't want to attend training; I didn't want to do anything. I didn't have an extra grain, an extra ounce of energy to do anything.

I would say in general I just don't work as well, as fast, and what I'm doing is… Probably my work in general isn't as sharp or quick as it would be when I'm doing a lot of extra with my mum and for my mum.

***How does parenting benefit your caregiving?***

Oh, yes, there is a connection there, because sometimes people who depend on you, it's almost like a child and you've got to treat them... well, not like a child, but there are some similar strategies you can use. To calm them down and things like that. It's interesting how, just talking to them and explaining things and all that. And again, patience.

***Emotional/Physical effects of caregiving***

Physically, when I get all stressed out then I don't eat properly and then I gain weight and then I get stressed and it's a vicious cycle. And I don't get the chance to go the gym and stuff because I'm busy running around the whole country and I don't have time for anything. So, that all contributes to gaining weight and getting depressed. From the emotional side, I just get frustrated, I get irritable, I end up crying on the couch talking to my husband and then he has to support me. So yes, it gets overwhelming at times.

Pressure in my chest, sleeplessness, irritability, just all over not feeling great.

Well, I certainly get very… I can get very testy. I suppose that's probably the big thing is that I'm more irritable, regardless of where the stress stems from. I don't think I have any physical ailments that are a result of it.

I feel tired. I find emotional strain makes me exhausted. I don't do well with that. And I don't eat. Those are things that… I'm a beast for regularity so I like my life to be nice and easy and peaceful. When I have too much on the go, then those are the first things that usually go.

I think my blood pressure goes up. It's always... yes, and I might get a headache and might get a bit dizzy, might be shaking a bit. That's in extreme situations.

Especially sleeping less, certainly stressed and maybe a little depressed that it was a hopeless situation to be in. Maybe a little bit of self-medicating with the drinking, no drugs, but certainly…

Frustration, and feeling lonely. I remember when I got here I was calling my friends in Ottawa often, and now I don't call them that often any more. Yes, being by yourself in the middle of nowhere.

Physically I can definitely feel when blood pressure goes up; I can, yes, that's for sure. And it's stressful for a bit and then I've just got to let it go and… but sometimes I just get a knot in my stomach and I'm… I'll be frustrated by the time my husband gets home from work and he'll say, what happened. And just talk about it and then it's just over and done with and you just move on.

Yes, sometimes angry, frustrated and angry and worried, of course, because I don't know, we're just waiting every time the phone rings late at night. What's happened? Has she fallen? Has she, is she in the hospital? Is she…? How long is she going to be able to stay where she's at? She refused to look at any other alternative living situations, when the time would come that she needed them because she's not moving. And the time will come when her living situation is not independent enough and she will have to move. Then we'll deal with that when that comes.

### *Section E: Advice to others*

Have a network of people that you can rely on, whether it's family or friends or whatever. But it's good to have others. You're not bearing the burden on your own.

Find a way to make time for yourself and learn to say no.

Do a lot of research on it, see if there's any help that you can get through the community or whatever, and try to avoid it if you can because I think it's very difficult if you have a family

Probably to find out what their resources are, because I think you all think you can do it yourself in the beginning and you can't. So, start finding out what's out there, and use it right away, instead of waiting until somebody in the family crashes and can't do it any more.

Really start searching for help, either in the community, or family members, or friends. Not to deal with this alone. Try to find other people who are already giving elder care. Ask questions: how they go through it, how they live with this. That would be my first advice.

I think make sure that you have a good support system, connections, people.

Something that I haven't done but I've found in other areas of my life, was if you can friends in the same situation or maybe even a group that you can associate with, talking things through can be very helpful with other people and you find out that you're not isolated and it does happen to other people.

Find some ways to incorporate your own self care, like the physical fitness and the wellness, and make that time as important as cleaning their house and doing their grocery shopping, whether that means getting a babysitter for the kids, or just telling your husband, no, you're not going golfing, you're going to stay home because I have to do stuff. Don't be a doormat.

Set the parameters. Let them know that you are not available at certain times.

Wow. I guess my advice would be that you have to want to do that, like your heart has to be in it.

Oh gosh. Just ask for more help and insist more help, and you have to be a real advocate. When I was asking for this personal support worker and getting told, no, you have to change this living situation, I think I should have just put my foot down a lot harder and insisted a lot earlier that something has to be done about this. I just thought... Because everybody said, oh, you know what, when the time comes you can get a personal support worker, and that will all be fine, and it just didn't happen. It didn't materialise. I thought it was just something that would work through the system and that CCAC would eventually call me back, but they actually did. They called me back about six weeks after my father-in-law had died.

Get some help. Don't bury yourself in the entire care of an elderly parent.

It's very important to find time for yourself. Sometimes, when it seems like you're too busy, you've got to stop and try to balance yourself out and find a bit of time to just do something you normally do, or did before you ended up in this situation, like read a book

I think they need to have things planned out a lot better than we did, like what are your next steps? What are you going to do? You need to make sure that you have a really good inventory of what resources are available to you, and start looking for this right away. And again, unlike my mother, don't be afraid of depending on what resources there are. Like our church could have been a lot more helpful, but my mother wouldn't let them. So maybe it's a personality thing, but you need to be able to rely on people that you wouldn't have relied on in ordinary circumstances.

Let's see. Don't deny what's happening and definitely… Don't pretend it isn't happening, and everyone make as many jokes as they possibly can along the way. Because don't forget – best case, everyone's going to get older

My advice would be to make sure you take care of yourself first, because you can't help them if you're upset or you're… I would say, probably, don't call until you know… What I do now is, I call when I want to, not when I feel I should, when I'm in the right frame of mind to deal with whatever happens. So that's what I do, and that's what I would tell them.

Well, I guess it would be, I think I said that earlier, but really clarifying at first the expectations of each party. Yes, that I think would be the most important thing, because otherwise situations can arise and then if you would have said so in the first place, maybe those problems wouldn't have arrived. You know, what you're willing to do and what you're… Well, not willing not to do, but basically, yes, expectations and maybe even how to resolve different situations. But I guess sometimes you can't think about all the situations until they happen, but yes, I would say really sitting down and talking about it. It might not be as easy, I guess, when somebody's really sick, but in my case it's kind of the beginning of a relationship, but I see it maybe becoming more… She'll become more and more dependent of me, but right now she's not, so it's hard to say. But basically yes, I'd say communication at first, expectations and talking to others too, like for myself, talking to my sister and not just taking everything on your shoulders.

If at all possible to maybe not let it consume a person. Keep perspective and keep balance in your life.

Get help. Do research, talk to people who are... if you can, talk to people who are in that business and go looking for government resources to help you. Look after yourself first.