Assessing the needs of employed caregivers and employers

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EXECUTIVE SUMMARY

Care work and paid work is an increasingly pressing issue. In 2012, there were over 5.6 million employed caregivers aged 19-70 in Canada and most worked full-time. Many caregivers are in peak earning years and struggling to balance children, employment and caregiving. For some, caregiving leads to long-term, cumulative financial and personal hardship, threatening their ability to meet care and job obligations, and their financial security, both now and in the future. Understanding the challenges that organizations and individuals face in combining employment and caring is warranted to inform the development of tools and resources to help create workplace cultures that enable caregivers to continue in paid work and reduce human resource and related costs for employers.

To understand the challenges that caregivers and their employers face in combining employment and caring, we undertook a set of three 2-hour focus groups with key stakeholders:

- caregivers who were currently in the paid labour force
- caregivers who were asked to or chose to leave the labour force
- employers of caregivers.

A systematic review of the national and international literature showed that these stakeholders experience different economic costs associated with care and may have different perspectives on the topic. The Alberta Caregivers Association recruited 23 participants, aged 24 to 67 years to share their personal and organizational experiences of juggling work and caregiving. We used thematic content analysis and an iterative process to analyze verbatim transcripts.

Through our focus groups with currently and formerly employed caregivers and employers, we explored the intersection of caregiving and employment. Comparing participants' experiences, three tensions existed for both employees with care responsibilities and employers: deciding whether to disclose; trying to do it all; and managing the uncertainty of care.

The first tension revolved around deciding whether to disclose. Some caregivers knew they were family caregivers while others did not. Some caregivers disclosed

in the workplace that they had caregiving responsibilities while others made a conscious decision not to. There was consensus among employers of the importance of self-identifying and disclosing. However, conditions of both the care situation and workplace factored into caregivers' decisions. There remains a stigma around mental illness that made it difficult for some to reach out for help. Seeing how other employees with family challenges were treated in the workplace and having trusting relationships with supervisors and colleagues contributed to an environment in which caregivers felt comfortable disclosing (or not).

The second tension revolved around trying to 'do it all', but at what cost and to whom? Paid work provided caregivers with a sense of identity and normalcy outside of their caregiving role. They were committed to their jobs and needed the financial security associated with them. Yet both work and care responsibilities can be very demanding. Having workplace flexibility, such as where and when employees worked, often supported employed caregivers' ability to juggle paid and care work. However, for some caregivers, trying to do it all cost them their health or their jobs. Employers also remarked about the costs they incur, and the limits to which employees with care responsibilities can be supported to 'do it all' in the workplace. Employers spoke of the tension between supporting their employees while meeting their organization's business priorities, needs and timelines.

The third tension revolved around managing the uncertainty and unpredictability of care. Some caregivers made career decisions that enabled them to manage the uncertainty of their care situation by working part-time, taking an alternate job with less demanding responsibilities, or truncating their careers. Having workplace accommodations enabled some employed caregivers to navigate the uncertain trajectory of care without sacrificing their income. In contrast, employers had more difficulty dealing with uncertainty. It was easier for them to accommodate employees with care responsibilities if they could plan for absences and leaves in advance.

Yet the reality was that the needs of some caregivers could not be accommodated in the workplace. Formerly employed caregivers spoke about losing their jobs because of their caregiving responsibilities or seeing exit from the labour force altogether as their only solution: “trading a rigid schedule for flexible poverty.” Decisions to leave the labour force were often based on an accumulation of care receiver, family, workplace and health care system factors rather than a single tipping point.

Building on these tensions, we identified the needs of both employees with care responsibilities and employers that have the potential to ameliorate tensions.

Employees with care responsibilities need to:

- Recognize they are a caregiver
- Feel safe to disclose without risk
- Have flexible workplace arrangements and benefits
- Have access to community services

Employers need to:

- Have employees disclose that they are a family caregiver
- Understand the lived lives and demands on family caregivers’ time that lead to work-care conflict
- Have stability and predictability for work force planning
- Honor collective agreements, including benefit plans
- Understand the business case for employer supports for caregivers
- Know best-practices around supporting employees with family care responsibilities
- Know and be confident that community supports are available so that they can refer their caregiver employees accordingly

Specific strategies that will meet the expressed needs of both employees with care responsibilities and employers include:

- Building awareness of family care
- Creating a compassionate workplace culture
- Having flexible workplace policies and benefits
- Having community supports available to support caregivers’ ability to balance paid work and care, ensuring their continued labour force participation and financial security.

Caregiving is an issue that will affect most Canadians at some point in their lives. While employees with care responsibilities are diverse, so too are their employers. There is no one-size-fits-all solution that will meet everyone's needs. Yet with commitment, flexibility and creativity, employers can play an important role in supporting caregiver employees and ensure their continued workplace participation.

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BACKGROUND AND RATIONALE

Caregiving is an increasingly pressing issue. In 2012, 8.1 M Canadians (28% of those aged 15+) were caregivers, providing help to a family member or friend living with challenges owing to illness, disability or aging (Sinha, 2013). The vast majority of care occurs in the community, and as the population ages family members are increasingly relied upon to provide care.

The impacts of caregiving are well documented: caregivers have higher rates of depression, are in poorer physical health, are more likely to be socially isolated and to be financially troubled (Turcotte, 2013). Combining care work and paid work is becoming the norm for many Canadians (Fast, Dosman, Lero & Lucas, 2013), with caregivers making up 35% of the workforce (Employer Panel for Caregivers, 2015). In fact, there are over 5.6 million employed caregivers in Canada and most work full-time. Most employed caregivers provide 10 hours of care per week or less. On average, employed women caregivers spend 9.5 hours per week while their male counterparts spend 6.9 hours per week and employed women are significantly more likely than men to provide more than 20 hours per week of care (Fast, Lero, DeMarco, Ferreira & Eales, 2014). The impact of caregiving on employment includes restricted work hours and absences, decreased productivity, career limitations, and labour force exit/preclusion (Fast et al., 2013; Fast, Lero, DeMarco et al., 2014; Keating, Fast, Lero, Lucas & Eales, 2014).

Most caregivers are aged 45 and older in peak earning years (Sinha, 2013), many of whom experience a “caregiving squeeze,” balancing children, employment, and caregiving. Missing days of paid work, working fewer hours or leaving the labour force altogether because of caregiving translates into reduced/foregone income, lost benefits and reduced pension (Keating et al., 2014). For some, caregiving leads to long-term, cumulative financial and personal hardship, threatening their ability to meet care and job obligations, their current financial security, and their ability to prepare for their own later years (Columbo, Llena-Nozal, Mercier & Tjadens, 2011).

In Canada, the 2013 Throne Speech and priorities of the Federal/ Provincial/ Territorial Ministers Responsible for Seniors demonstrated awareness of caregiver costs, noting the need to “assist older workers balancing the competing demands of work and care" (Canadian Intergovernmental Conference Secretariat, 2014; Government of Canada, 2013). The legal landscape also is shifting. The age of pension eligibility has been raised and may keep Canadians at work longer (Service Canada, 2013), and human rights cases are emerging that suggest that employers have a 'duty to accommodate' employees who are providing family care (British Columbia Law Institute and Canadian Centre for Elder Law, 2010; Canadian Human Rights Commission, 2013). The recently released report from the Canadian Employer Panel for Caregivers (2015) emphasizes the expectation that employers have a role in supporting caregivers' continued labour force participation.

A Canadian survey showed that employers view supporting work life balance for all employees as an organizational priority. However, more than half said that supporting employees with adult caregiving responsibilities was a low priority workplace issue, or not even on their radar screens (Lero, Spinks, Fast, Hilbrecht & Tremblay, 2012). Yet in 2012 caregiving resulted in over 9.7M days of absenteeism, an aggregate reduction in work hours of 4.9M hours, and a loss of 559,000 employees from the paid labour force (Fast, Lero, DeMarco et al., 2014). The Conference Board of Canada estimated (conservatively) that the annual cost of lost productivity because of care-related turnover and absenteeism alone is $1.3 billion dollars to Canadian employers (Hermus, Stonebridge, Theriault, & Bounajm, 2012). Avoidable costs for employers arise from replacing employees who quit a job or retire early to care (often at career peak), absenteeism, "presenteeism"[1], reduced work hours and foregone investments in human capital (Fast, Lero, Keating, Eales & Duncan, 2014; Hermus et al., 2012; Johns, 2010; Metlife Mature Market Institute and National Alliance for Caregiving, 2006).

There is growing evidence from the UK that supporting caregivers at work makes good business sense (Byrne, 2011; Dex, 2003; Yeandle, Bennet, Buckner, Shipton & Suokas, 2006). Yeandle and her colleagues (2006) found that flexible working arrangements and family-friendly employment practices benefited businesses by increasing productivity, reducing recruitment and retention costs, reducing sick

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[1] being at work but not fully engaged or performing below standard due to ill health or care-related distractions

leave, and lowering staff turnover while meeting client needs. In addition, employees of 'carer-friendly' organizations were happier and had a high level of trust in relationships at work.

In Canada, access to flexible work arrangements varies considerably. Even among employed caregivers who had flex work options in their workplaces, almost half felt that they could not use them without negatively impacting their careers (Fast, Lero, DeMarco et al., 2014). Canadian research shows that flexible work schedules and leave options are effective at easing work-care conflict and reducing the incidence of absenteeism and reduced labour force engagement (Fast, Lero, DeMarco et al., 2014). Understanding the challenges that organizations and individuals face in combining employment and caring is warranted to inform the development of tools and resources to help create workplace cultures that enable caregivers to continue in paid work and reduce human resource and related costs for employers.

METHODOLOGY

To understand the challenges that caregivers and their employers face in combining employment and caring, we undertook a set of three focus groups with key stakeholders: caregivers who are currently in the paid labour force; caregivers who left the labour force; and employers of caregivers. A systematic review of the national and international literature showed that these stakeholders experienced different economic costs associated with care (Keating et al., 2014; Fast, Lero, Keating, Eales, & Duncan, 2014) and may have different perspectives on the topic. Understanding the needs of caregivers with varying attachments to the labour force forms the foundation on which tools and resources that employers need can subsequently be developed. While national survey data are available to examine the incidence and predictors of care-related employment impacts, focus groups allow us to investigate complex behavior and motivations (Casey & Krueger, 2000) for issues such as how caregivers juggle care and employment and the personal, family and workplace factors that enable them to manage well. In this section we describe focus group recruitment, participants, data collection and analysis (Casey & Krueger, 2000).

Recruitment

This study is part of a larger project, *Increasing Economic Opportunities for Women,* being conducted by the Alberta Caregivers Association (ACGA) with funding from the Status of Women Canada. ACGA recruited potential participants through broadcast emails to their members, announcements at programs conducted by ACGA, and networking events for employers. The names and contact information of potential participants who were available for the scheduled focus groups were forwarded to the study coordinator. The study coordinator confirmed via telephone or email that each participant met the inclusion criteria. Employed and formerly employed caregivers were included if they provided care to one or more adults with a long term health problem, physical or mental disability or problems related to aging in the last three years, had provided care for at least one year, spent at least two hours per week providing care, and were currently in the labour force or had left paid employment to provide care. Human resource advisors, disability managers and supervisors were included who had personal experience managing or supervising one or more employees who faced challenges combining paid work and caregiving roles.

Participants

The full sample consisted of 23 participants, aged 24 to 67 years. The majority (n=22) were women. Table 1 summarizes participants in each focus group.

Table 1. Focus group participants

	Currently Employed Caregivers	Formerly Employed Caregivers	HR Advisors and Supervisors
Number of Participants	11	8	4
Age Range	27 to 63 years	24 to 67 years	39 to 63 years

Currently and formerly employed caregivers (caregivers) reported caring for between 1 and 4 persons during the last 3 years; most had been providing care for an average of 10 years. Currently employed caregivers spent on average 22 hours per week providing care[2] to all of the adults they supported, while formerly employed caregivers spent 58 hours per week on average providing care. The amount of time spent providing care varied widely from 2 to 70 hours per week for employed caregivers and even higher for formerly employed caregivers (20 to 147 hours per week), often dependent on the care receiver's condition and need for assistance. Most caregivers were caring for parents or parents-in-law, although some were caring for spouses or siblings. Most currently employed caregivers worked full-time (two worked part-time) for government (federal, provincial, territorial or municipal) or broader public sector (education, colleges/universities, hospitals/healthcare) organizations. Many caregivers were married and had children (some of whom lived with them in the same household).

HR and employee relations advisors, disability managers and supervisors (employers) were primarily from large, broader public sector or government organizations. They reported that during the last 3 years, they were aware of up to 25 employees who faced challenges combining work and caregiving for an adult or elderly family member, and most of these employees reportedly still worked for their organization. Compared to five years ago, requests for support by employees with caregiving responsibilities had increased in 3 of the 4 organizations represented, but all participants expected requests for caregiver support to increase over the next five years. Three of four participants had personal experience with family caregiving, likely making them a particularly sympathetic group of employers. Having only four participants in the employer focus group was one limitation of the study.

Data Collection

Prior to the commencement of each focus group, participants provided informed consent and completed a short demographic questionnaire (Appendix A & B). The

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[2] Care includes time spent helping with housework, meal preparation and cleanup, shopping for groceries and other necessities, personal care, transporting the cared for person(s), time commuting to provide care and care management.

demographic survey asked caregivers about the person(s) for whom they provided care to (gender, age, relationship, health conditions, and geographic proximity), their employment or former employment, use of workplace supports, and personal characteristics (gender, age, marital status, number of children, and number of children who lived in the same household). Employers were asked about their organization, employed caregivers in their organization, availability of workplace supports, and personal characteristics (gender and age).

The moderator began each focus group by describing the project and its purpose and outlining the rules of engagement. Participants introduced themselves by first name only. Guiding questions were tailored to each stakeholder group and were informed by the Taxonomy of the Economic Costs of Care for Family/Friend Caregivers (Keating, et al., 2014), which identified four kinds of employment consequences that caregivers experience: labour force exit/preclusion; restricted work hours and absences; decreased productivity; and career limitations. Guiding questions (see Table 2) were given to participants in advance allowing them time to reflect on the personal and organizational challenges of juggling work and caregiving. Each focus group lasted approximately 2 hours.

Table 2. Guiding questions by stakeholder group

Stakeholder	**Guiding questions**
Currently employed caregivers	• What employment consequences have you experienced? • What makes it easier for you to manage both your employment job and your caregiving job? What employment supports are available in your workplace and which ones have you used? • What could your employer (or supervisor) do that would make it easier to balance paid work and caregiving? • If you had a chance, would you do anything differently in relation to your employment or caregiving?

Formerly employed caregivers	• How did your caregiving impact your employment? • What was the tipping point that caused you to leave the paid labour force? • What might have made it easier for you to manage both your employment job and your caregiving job? • What could your employer have done, that would have kept you in the paid labour force? • How has leaving or losing your job to provide care impacted your life? • If you had a chance, would you do anything differently in relation to your caregiving or employment?
Employers	• How have employees with family care responsibilities impacted your organization/business? • Are there tensions between meeting the needs of the firm and those of employees with caregiving responsibilities? • How do you resolve those? • What might make it easier for you to support employed caregivers?

Focus groups took place at the University of Alberta in a social science research lab and were audio recorded. A note taker/observer was present at all meetings to monitor equipment, record order of speakers and ensure that participants covered the scope of the guiding questions in their discussion. Her notes augmented the verification and analysis of transcripts. An experienced transcriptionist transcribed verbatim the recordings. Each transcript was reviewed and verified against the original audio recording by a graduate research assistant. The three transcripts had an accuracy rate of approximately 99.5% each. Participants' personal identifying information was removed from transcripts, and names were changed to pseudonyms.

Analysis

We used thematic content analysis to analyze the transcripts. This involved identifying and linking similarities and patterns in the data to create categories of meanings (Hennink, 2014). To begin the iterative analysis process, two members of the research team reviewed individually each transcript and identified themes in the data. They then met and discussed the similarities and differences in the list of identified themes to reach consensus on themes and determine how best to organize them. Emerging themes were reviewed by the moderator prior to the commencement of each subsequent focus group. When all three focus groups were complete, we compiled a table to compare and contrast the themes identified for each stakeholder group, and isolate those themes that were common across stakeholders. Because stakeholders were distinct and may have had differing perspectives on an issue, we reread each transcript to further explore the data for nuances on a relevant theme. Members of the full team then met to review and discuss the comparative summary table of themes to determine major issues in the intersection of care and paid work that were common across stakeholders.

FINDINGS

Participants talked at length about their experiences at the intersection of caregiving and employment and how workplace conditions enabled or limited support for caregivers. We identified three major tensions that were common to employed caregivers, formerly employed caregivers and employers: disclosure, uncertainty and 'doing it all'. Sub-themes illustrate the nuances and differing perspectives within each major issue (see Table 3). In this section, we describe each major tension, participants' varying perspectives and ways in which their needs were met or not.

Table 3. Summary of major tensions and sub-themes identified

Major Tension	Sub-themes
Deciding whether to disclose	• Recognizing and identifying oneself as a caregiver • Experiencing or observing discrimination or stigma associated with being a caregiver or with the care receiver's condition • Fearing being fired or let go • Having supportive workplace values and benefits
Trying to 'do it all' but at what cost?	• Overcompensating at paid work • Jeopardizing personal health • Increasing work load for other staff • Increasing employers' costs • Having adequate community supports
Managing the uncertainty of care	• Caregiving is unplanned and unpredictable • Making job changes to accommodate caregiving • Having flexible workplace arrangements • Having trusting relationships with supervisors and coworkers • Planning time away or absences from paid work • Knowing about 'carer-friendly' legislation and best practices • Exiting the paid labour force

Deciding whether to disclose

The first issue was about caregivers' willingness to disclose to their supervisors and colleagues at work that they were caring for a family member with a long term health condition, physical or mental disability or aging-related needs. Participants held differing viewpoints on the benefits and drawbacks of disclosing their caregiving status in the workplace.

Some caregivers did not identify themselves as employees with care responsibilities because they did not recognize that the assistance they were providing to adult family members with long term health problems or disabilities was care and that they were a family caregiver. Participants talked about not knowing that they were caregivers because the care receivers' conditions had existed their entire lives or evolved slowly over time.

> *I think we all have different stories but my story is about not even knowing that I was a caregiver because it's my whole life. So my [parent] is profoundly mentally ill and so I've grown up with that.* (Patricia, employed caregiver)

> *I've been a caregiver for over 25 years. I thought caregivers were professionals, you know? I thought they were the nurses, the aides and stuff like that, so I never even associated myself as being a caregiver.* (Shannon, formerly employed caregiver)

> *I actually had an argument with my manager that I wasn't a caregiver.* (Nicole, formerly employed caregiver)

Others recognized that they were caregivers, but were reluctant to disclose in the workplace because of stigma, associated with either the care receiver's condition (particularly mental illness or dementia) or being perceived as an employee always in need of concessions because they had caregiving responsibilities.

> *Because of the nature of my [parent's mental] illness, I've had to protect myself. I try to keep a separation because of the negative impact that I've had in the past.* (Patricia, employed caregiver)

> *I wouldn't reveal, I wouldn't let my co-workers know why and then one day my manager and the office manager, they called me in and they demanded me to tell them what the situation was. I had to tell them that my spouse attempted to commit suicide and ever since then it just was an uneasy work*

> *environment. I felt like I was being judged that I was the reason why this happened.* (Shannon, formerly employed caregiver)

> *I think part of it is just that perception of that time away from work. I'm not advertising if I make up that time or don't make up that time or how I accommodate that in my own life but I know people see that … so generally, my health [Laughter] might come later or…maybe my vacation, I'll hold up on that because it looks like I'm gone all the time anyway, right?* (Amy, employed caregiver)

Willingness of caregivers to disclose was influenced by the perceived workplace environment. Some caregivers were reticent to disclose their caregiver status because they did not see their work environment as trusting or caregiver-friendly. Their perceptions were often informed by prior experiences, either their own or that of other employees who lost jobs because of their care responsibilities.

> *I've lost jobs because of my [parent], where she's shown up at a workplace and then I've been let go the next day.* (Patricia, employed caregiver)

> *I went to very great lengths to make sure that no one, and I mean no one, that I worked with knew what I was dealing with at home, because through the course of my career, I have seen what has happened to people who have had handicapped children or a situation. It would be really, really nice to think employers want to keep us, but we're pretty replaceable, at least in my profession.* (Cynthia, employed caregiver)

> *My life experience with work is that typically when your domestic needs are too high, your work…you can be replaced. So generally the pressure is put on. You're given options and then you have to pick or choose who's more important and that happens in some of the most surprising professions.* (Donna, employed caregiver)

> *I tried to deal with our HR department and everything and they wouldn't budge. So I ended up having to go down to three days a week and there was a lot of judgement, a lot of criticism. My peers were doing the, "Oh, how did you get to this three day a week gig?" and all of this other stuff and I*

> *wasn't telling anybody what was going on.* (Nicole, formerly employed caregiver)

In contrast, employers thought some employed caregivers may not disclose because they were private individuals or knew they would not qualify for available workplace benefits such as paid sick leave. One employer thought their corporate values, which focused on wellness and work-family balance, encouraged disclosure.

> *Some people are really private, to be honest. There are a lot of people who don't bring a lot of their personal life to work and sometimes it's their escape. I find that if it's a very difficult time at home, you're coming to work to kind of just be.* (Melissa, employer, broader educational sector)

> *They don't identify for that very purpose because they wouldn't be eligible for paid sick leave. Looking at it, you need to be the injured or sick individual, right? Not your mom or your dad, so that's becoming an issue. I've had only two people come out and tell me exactly what's been going on. The rest I've found out through management or absence management.* (Sharon, employer, broader educational sector)

> *One of our corporate values, and it's been that way since '98, is wellness and balanced lifestyle. So that gives us a little bit more leeway to bring the supportive out of people. I think because of the values, people are more inclined to self-disclose and I walk away feeling very lucky.* (Carol, employer, financial sector)

Other caregivers felt comfortable letting supervisors and colleagues know because their workplace environment was perceived as supportive. Some caregivers believed that being up front about their care responsibilities enabled the work environment to become more flexible and responsive to their needs. Likewise some employers felt that the availability of workplace benefits encouraged disclosure. Employees with care responsibilities who worked in 'caregiver-friendly' environments were able to schedule their time to better handle the demands of both employment and caregiving.

> *I told my boss what was happening in my personal life, right up front, right off the giddy up, because I felt it was extremely important that he knew that my family came first.... They [employer] bent over backwards to assist me. So that [disclosure] assisted me, instead of having to quit or hide everything. It was enough stress in my life, caring, but to have the added stress of work, I couldn't handle that.* (Joyce, formerly employed caregiver)

> *So people do ask me sometimes. They know about my sister and they know the situation. They know I need to leave exactly on time on these days...They probably believe in me more than I do, that you know, you can handle it, you know how to do these things. Maybe you need to take time but that doesn't mean that you're weak in your position which is, for me, huge. I don't want to be known as that person who always needs accommodation.* (Amy, employed caregiver)

> *I don't think that they're reluctant to come forward, but we have things in place [in our organization] that is our go-to place. So out of our 12 sick days that are yearly there for them, three of those are available for family care. So that's the first place we go. Then we also have an earned day off program... We go to vacation, whatever we can do to make sure that they're able to do what they need to do on a paid basis. In one or two rare cases we went the leave without pay route for a little period of time, which was okay with them [employed caregivers].* (Carol, employer, financial sector)

From employers' perspective, disclosure was important because it enabled them to anticipate employees' needs and provide support before absenteeism or performance management became an issue. Work could be shared among co-workers and back-up plans could be discussed. When employees did not disclose their caregiving status, managers were less likely to respond positively when they did find out because by then the employee had established a history of missed days or deadlines.

> *Any type of situation where you're self-identifying earlier in the situation is better because you haven't hit that point of frustrating your employer or your manager. You have that understanding, there's an awareness and you can*

> *plan. Everybody can plan then, in that case.* (Melissa, employer, broader public sector)

> *We had a really great, wonderful performer and all of a sudden they're not. There's complaints coming in because this person's very private and they don't want to share. All it ended up doing is kicking them in the behind at the end of the day because now they've got poor absenteeism, a frustrated employer and their situation's spiraled.* (Sharon, employer, broader public sector)

> *I have two staff members out of the six that I supervise that have caregiving responsibilities. They've just come and talked to me about it and said, "This is the situation that I'm in." We're very open and talk about it and what their time requirements are and how we can try to balance those.* (Kimberly, employer, government sector)

> *It's an office of ten and I think at least four of us have caregiving roles that everybody knows about. There's one of my coworkers who will get a phone call and you hear the phone ring and you hear her go out the door and we just know that she's gone because her mom had an emergency and she had to go… We kind of have an informal buddy system almost. If somebody's supposed to present at a certain meeting we assign a backup 'cause we know that person, that's the one who runs out [Laughter] whenever the phone rings. We always kind of think about that eventuality when we're planning.* (Jennifer, employed caregiver)

Trying to 'do it all', but at what cost?

Paid work provided caregivers with a sense of identity and normalcy outside of their caregiving role. Caregivers were committed to their jobs and needed the financial security associated with it, especially if they were primary wage earners. While both work and care responsibilities can be very demanding, juggling them can be a delicate balancing act for many employed caregivers. Caregivers' responsibilities can increase at any time without warning, yet work commitments still have to be met. Many caregivers spoke about trying to “do it all”, putting in additional work hours to ‘build their credits’ while jeopardizing their own health. Employers remarked that the “Wonder Woman” personalities of some caregivers contributed to their efforts to try to “do it all”.

> *I felt like I could do it all, you know? …I figured, hey, I’m good at my work, I can do it all. I can take care [of my spouse].* (Shannon, formerly employed caregiver)

> *I was getting up at 3:00 in the morning to get all the stuff ready for [spousal care recipient], his lunch and a list of things, reminders for him, when to take his medications and things and then I’d go to work. I used to start at 7:00 in the morning and I was there for 6:00 so that if it’s quiet time then I could get a bunch of emails read and done and organized for the day and then once the staff would come in it was hectic and you’re working full out… I would stay ‘til 7:00, 8:00, 9:00, sometimes 10:00 [at night] to catch up and get a start on the next day and in the meantime I always had contact with [care recipient] to make sure that he was okay and that he could heat some supper up or whatever when I wasn’t there.* (Rebecca, formerly employed caregiver)

> *We can’t do caregiving seven days a week, 24 hours a day, 365 days a year. Nobody can do that. I did and I died.* (Donna, employed caregiver)

> *I think I have three people on my caseload right now that are definitely sick and caregiving right now and doing [work responsibilities], out of the goodness of their heart…. because this is their personality; they’re going to look after the whole world except for themselves and that’s part of the problem…. You’ve got almost like a personality there that’s like Wonder Woman that’s going to do it all and they can’t.* (Sharon, employer, broader public sector)

For some employed caregivers, having workplace accommodations, such as the opportunity to telework or have flexible schedules, encouraged them to work harder so they were not perceived as taking advantage of the organization. Perceptions of fairness and equity permeated their remarks.

> *I think you become very acutely aware of the "optics": How does this look to other people?* (Cynthia, employed caregiver)

> *I'm not even in the office. I don't want anyone thinking I'm less productive than people in the office. There's maybe 800 people where I work. I think two or three of us work from home. So no one does it. You don't want people to think that you're slacking off at home.* (Jessica, employed caregiver)

> *There's this period of time between Monday to Friday where you're supposed to be there and present and doing your job …so even just working extra hard when I'm there or making sure I don't let any balls drop at work because what if that comes back as something that's about my [care] situation.* (Amy, employed caregiver)

Employers wanted to retain good employees, offer a pleasant, respectful workplace environment, and have "healthy, happy employees". But there were limits to the extent to which employees with care responsibilities could be supported to 'do it all'. Employers spoke about a tension between 'compassion and cost', particularly when employees were providing intense amounts of care. Workplace factors, such as important projects or deadlines, also influenced employers' willingness to be accommodating. As one government sector employer stated: "I don't mean it to sound harsh but work still needs to be done."

> *She missed a fair amount of work and she was very open with me about it [caring for a parent], but it was very hard for her, physically and emotionally, as well as difficult for us in the workplace to continue with some of the projects that we had to do, because we are a very small staff unit and when you take somebody out of the mix, then things simply don't get done, and when she was at work, she wasn't ALL at work.* (Kimberly, employer, government sector)

> *There is a double cost. If I've got employees working overtime in order to be able to fill that [loss of productivity], then we have to pay overtime and we're still paying for that absence.* (Kimberly, employer, government sector)
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> *We've got to get a [replacement worker], and pay that sick leave. The costs are enormous.* (Sharon, employer, broader public sector)

Both caregivers and employers spoke about the importance of community supports. Employers acknowledged that they were largely unaware of community supports that they might refer their employees to, yet having adequate community programs and supports enabled some caregivers to manage both paid work and care responsibilities.

> *I think the employer is a player but also there's many other players in the community as well. Some of my problems have always been around transportation. Like this one time I had [child] in an after school care program but they wouldn't pick him up from the school and it was just like this whole thing. So I had to leave work, pick [child] up, take him to [program], and it was like two or three blocks [away].* (Kathy, formerly employed caregiver)
>
> *I've been fortunate in being able to do self-managed care for the past, almost, I guess, two years, so we get funding for some time. So that helps quite a bit, but we're kind of maxed out at that. If [spouse] gets much worse, we're going to have to look at…like I'm not sure at what point he would need to be in an extended care [facility], but we may have to look at that.* (Linda, employed caregiver)
>
> *The only way that I found any support in doing that [job] was by having care partners. If I didn't bring in a care partner, I couldn't function anymore. [Moderator: What do you mean by a care partner?] Someone else to take my place during the day so I could go to work and be [productive] at work.* (Donna, employed caregiver)
>
> *Referrals to providers that could provide support to people, if there's groups out there… We don't necessarily have all the information. There might be a*

> *group out there that you can be part of… I'm guessing that somebody who is going through elder care may need help navigating a lot of the health system too. There's huge pieces there [in the community].* (Melissa, employer, broader public sector).

Managing the uncertainty of care

Caregiving is often unplanned and has an unpredictable trajectory. Dealing with its demands often presented uncertainty for both caregiver employees and employers. Caregivers spoke about the uncertainty and unpredictability as being "on guard", "always being on high alert", and "continually being challenged with 40 balls in the air and [wondering] which one is going to come down next". Sometimes crises could be anticipated while other times they could not. Some caregivers made career decisions that enabled them to manage the unpredictability of their care situation by working part-time, taking an alternate job with less demanding responsibilities, or truncating their careers.

> *I am fortunate to be able to work part time. I went back after my second child only part time, to be home with my kids and then I realized I could probably work full time, and then my parents got sick.* (Heather, employed caregiver)

> *I chose the job that I'm in now because I saw my future. I wasn't going to go up higher [in the organization] because how would you ever get time off? How would they ever get it in the director's office? …I would like to [make more money] for my next five years of employment but … I cannot do that right now as a caregiver, there's no way.* (Barbara, employed caregiver)

> *I went from a site administrator type position to just a regular frontline position because of course, in any kind of management position there is no such thing as an 8 hour day.* (Nancy, employed caregiver)

> *I've talked about all the benefits but the cost to me is at the cost of career fulfillment. I kind of think to myself, okay, maybe someday, but just like Jessica said, I am where I am right now. I'm there for reasons that are more*

> *important to me right now so maybe someday I'll focus on career.* (Jennifer, employed caregiver)

Having flexibility in where and when caregivers worked enabled some caregivers to navigate the uncertainty without jeopardizing their income or careers. Such workplace accommodations allowed employed caregivers to meet their paid work and family care responsibilities simultaneously, particularly in times of crisis.

> *I have a very flexible job, so I don't have to negotiate to be away, so that's very useful. When there's a really big crisis, I just make up the time in my own time.* (Patricia, employed caregiver)

> *I was able to take a truckload of files with me and work while I was accompanying my [sibling] for a weeklong series of tests. So basically while I was waiting for her, I was able to do work.* (Lisa, employed caregiver)

> *I try to go in one day a week to work with my coworkers as well, but the rest of the time I can work from home, which has been a real blessing.* (Linda, employed caregiver)

> *So I telecommute from my job in [city], actually, so I come up two days every two weeks and my job has been really good so far, they've let me do that [work from home].* (Jessica, employed caregiver)

In contrast, employers had more difficulty dealing with the uncertainty of caregiving. It was easier for them to accommodate employees with care responsibilities if they could plan for absences.

> *I have another staff member who's a caregiver for both her mother and father, but she has siblings that are able to assist with it and they make a schedule. They're very well organized about it and she is able to book in advance when they know that somebody has to take someone to a doctor's appointment or that kind of thing.* (Melissa, employer, broader public sector)

> *At [organization] there is always a possibility [of flex work options], depending on what position you're in and what the requirement is. If you're frontline, kind of out there, probably not so much, whereas if you're working*

> *on projects, there's a possibility of having some time to work from home, for sure. (Sharon, employer, broader public sector)*

> *The work still needs to be done so we still need to do it. In cases where it's [care is] very sporadic or there's not that [self] identification, you don't have that plan in place to get the work done. You can't bring somebody in temporarily and in some cases you can't do that anyways.* (Melissa, employer, broader public sector)

Some caregivers were forced to leave their jobs, while others could not make it work and consciously chose to withdraw from the labour force altogether. Formerly employed caregivers' decisions to relinquish their labour force participation were based on an accumulation of care receiver, family, workplace and health care system factors, "trading a rigid schedule for flexible poverty."

> *Eventually I lost my job. They explained it to me that they were going in a new direction. How much of it was because of my work performance during my challenges as a caregiver? I think it had at least part of it due to it [caregiving].* (Shannon, formerly employed caregiver)

> *The option was laid out to me like this: "Your husband has mental health issues." Brain injury just at that time. "You have a choice, to place him and stay employed or to keep him and you're terminated." Your choice. I was terminated and there went my income of $10,000 a month, right out the window.* (Donna, employed caregiver)

> *I just was completely at the end of my rope. Of course my family had said that whatever I needed to care for my [parent] they would be there and they absolutely were not. So it was all on my own. I have [adult] children and they have young family and my husband was good, but the brunt of all of that responsibility fell onto my shoulders. I couldn't actually see my way through anything. So I called my boss and I said, "I have to leave my work." and he said, "Okay." And that was the end of it.* (Brenda, formerly employed caregiver)

> *I ended up quitting because they kept changing my schedule and it was just really hard to get [care organized]…I have support staff but it just became stressful…I find that what seems to work best for me is just to take on contract work and work from home… The only bad thing about that is it's sporadic and it's not constant, so I just go with that. But it's certainly easier in terms of managing [adult child] and his care.* (Kathy, formerly employed caregiver)

> *She's been talking about retiring for about 18 months already and as the caregiving became more and more time consuming for her, she just decided, okay, this is the time to retire.* (Kimberly, employer, government sector)

> *I was working hard. I felt like the good jobs were getting diverted for the men in the company. I would bring up my issues with the boss and he would basically just shut me down and said, "If you don't like it here, you can leave." I just felt like I wasn't growing, I wasn't getting anywhere. And as I could see things were starting to go downhill for my [parent], I found the workload was just even being piled up and piling up and I wasn't getting any help. I was so stressed about where my [parent] was going, 'cause I didn't know how much time I had left with him [emotional] so I finally said to my boss, "I can't do this anymore. I gotta go. I want to spend what time I have left with him. I don't know how long it is but I want to spend as much time I have left with him." So I left my job*. (Amanda, formerly employed caregiver)

Employers acknowledged the importance of accommodating employees with care responsibilities where possible and within the constraints of existing benefit programs afforded under collective agreements. Workplace supports contributed to a positive milieu and overall employee productivity and retention.

> *[Employee's parent] unfortunately passed away now but it was probably about a three month period that she was away, in that three month period I would say probably more than 50% of the time and it was very difficult for her and it was very difficult for us and even with all of the issues that go*

> *along with that, obviously her [parent] was very ill, so when she did come into work you would spend a lot of time talking about things and then work isn't happening either.* (Kimberly, employer, government public sector)

> *I stay in my job because both systemically and in my workplace, there's a lot of leave options, so you can do leave with income averaging, which I've taken advantage of before, we can go back and forth between full and part time, I can do a compressed work week.* (Jennifer, employed caregiver)

> *One of the things that's great about my employer and my employment situation is that people are quite caring and there is a package that includes counselling services and wellness opportunities*. (Patricia, employed caregiver)

> *There is a huge amount of compassion from the employer's perspective. It's just that we're very limited. The spiraling cost of health care; our insurance company is very expensive. And you start putting all of these [sick] leaves on and it will explode and we'll have an unfunded liability.* (Sharon, employer, broader public sector)

> *There's so many people between the ages of 50 and 60 right now who are going to be retiring in the next five to ten years. It's going to leave a really big gap and I think we need to try to ensure that we have that flexibility so people aren't leaving [to provide care].* (Kimberly, employer, government sector)

While availability of workplace supports and benefits is important, having trusting relationships was also critical to employed caregivers' perceptions that they could disclose their status as a caregiver and access workplace supports. Employers acknowledged too the importance of relationships in accessing flex options.

> *Everybody is so understanding about that [caregiving] at my workplace, so it's really amazing. So we're all just scared, 'cause my manager is going to probably retire in the next few years and we hope that her successor is as supportive.* (Jennifer, employed caregiver)

> *My leadership team and my supervisor changed in June 2012 and that's when a lot of my problems started. I was part of a two-person team prior to that and then I turned into a 12-person team. They didn't know me, they didn't know my personal situation, there was no flexibility, there was no understanding, there was a lot of judgement and criticism.* (Nicole, formerly employed caregiver)

> *He [caregiver] was in a team that was very close, so each of the fellow team members gave him one of their days, vacation days to [use].* (Carol, employer, financial sector)

> *It really depends on what area you work with and who your management and supervisor is as to the level of flexibility that they will allow in their work units. I'm fortunate, the area that I work in, I'm a manager and my director is supportive as well. So it allows me, as the manager, to be able to better support my employees.* (Kimberly, employer, government sector)

As the population ages and family caregiving becomes the norm, employers will need to better manage employees with care responsibilities. Employers spoke about the importance of knowing about existing legislation and best practices that other employers have instituted to support employees with care responsibilities.

> *We want to keep our people if we can. We can't afford to lose them, really. And we need to change the way we do business in order to do that.* (Sharon, employer, broader public sector)

> *Knowing what other employers are doing, for me, is better, because we strive to be [a] best practices [organization], so that would really help.* (Carol, employer, financial sector)

> *We don't like to scare our managers or anything but if I just casually mention, "Geez, I hope this [case] doesn't go to Human Rights," [Laughter] it tends to win a lot of cooperation.* (Carol, employer, financial sector)

> *I've read some research about new generations of workforce. Caregiving aside, the priority for younger workers is flexibility, always. Flexibility over*

> *pay, flexibility over career advancement, it's all about flexibility and vacation time… I think it's going to be an interesting intersection between that and the critical mass of [the] caregiving population who want that same thing.* (Jennifer, employed caregiver)

DISCUSSION

Through our focus groups with currently and formerly employed caregivers and employers, we explored the intersection of caregiving and employment. Comparing stakeholders' experiences, three tensions existed for both employees with care responsibilities and employers: deciding whether to disclose; trying to do it all; and managing the uncertainty of care. In the discussion we build on the detailed description of these tensions in the findings to identify what employees with care responsibilities and employers need to resolve those tensions and then describe specific strategies that will meet their needs.

Employed caregivers' needs

Caregivers and employers had different perspectives about juggling paid work and care responsibilities. Yet there were four common needs among stakeholders that emerged from their stories. Caregivers need to:

- Recognize they are a caregiver
- Feel safe to disclose without risking their jobs
- Have flexible workplace arrangements and benefits
- Have access to community supports

First, caregivers need to recognize that the support they are providing to family members and friends is care. Without this recognition, caregivers cannot disclose to their employers that they are a caregiver nor can they expect their employers to make accommodations. More than one in four Canadians (28%) is a caregiver and nearly half (46%) had provided some type of care to a family member of friend at some point in their lives (Sinha, 2013). Yet often people do not recognize that the support they provide to kin and 'chosen families' is defined as care. Spouses, in particular, often do not identify themselves as caregivers until they are providing substantial amounts of assistance and feeling overwhelmed (Dobrof & Ebenstein, 2004; Molyneaux, Butchard, Simpson, & Murray, 2011; O'Connor, 2007). Rather, providing assistance is viewed commonly as 'the way we do things' or as 'a way of giving back' what has been received from others, particularly parents. However, care is distinguished from routine assistance when the help provided is because of someone's long-term health condition, physical or mental disability, or problems related to aging (Statistics Canada, 2013).

Second, while employers need caregiver employees to disclose, employed caregivers need to feel safe to do so without jeopardizing their jobs, relationships with colleagues and supervisors, and financial security. Some caregivers feared, observed or experienced firsthand discrimination, job loss, or the denial of career-related opportunities. Although being fired because of caregiving is rare (less than 1% or about 31,000 in 2012), when it does happen, the financial implications are substantial (Keating et al., 2014). Yet when caregivers feel safe to disclose they are more likely to do so (Kim & Bock Mullins, 2014); having corporate values such as wellness or work-family balance contributes to a workplace culture that encourages disclosure. In the UK, Yeandle and her colleagues (2006) found that workplace culture rather than regulation is the key: "the commitment to an organizational culture which values each employee and respects the importance they attach to their lives outside work is a strong company value, developed by its managing director and senior managers, and cascaded throughout the firm" (Yeandle et al., 2006, p. 16)

Third, caregivers need access to workplace flexibility so that they can deal with the uncertain trajectories and unpredictability of care and juggle simultaneously their paid work and care demands. Having flexible work place policies seemed to enable many of the employed caregivers we spoke with to manage, at least moderately well. But availability of flexible work arrangements does not guarantee access. In 2012, more than ¾ of employed men and women caregivers in Canada said they had the ability to take short or extended leaves to deal with care responsibilities, one-third could work a flexible schedule (starting and ending their work day according to their needs, but within limits), but few had the option to telework (W10%, M14%) (Fast et al., 2014). Yet overall, almost half (W47%, M45%) of employed Canadian caregivers surveyed felt that they could not use flex work arrangements without it having a negative impact on their careers (Fast et al., 2014). Without both the availability of and access to needed workplace accommodations, employed caregivers are at risk of burning out and reducing or discontinuing their labour force participation by trying to "do it all".

Caregivers also felt they needed greater flexibility in using their workplace benefits, such as using personal sick days to provide care to others. Caregivers already sacrifice their vacation time, social activities, relationships, and their own health and well-being to provide care (Sinha, 2013; Turcotte, 2013). Furthermore, caregivers with heavy caring responsibilities are 2-3 times more likely than other workers to have health problems of their own (Yeandle et al., 2006). If caregivers are permitted greater flexibility in using workplace benefits, such as using personal sick days to provide care to others, they risk not having benefits available to support them personally when they get sick.

Finally, caregivers need access to community supports. Caregivers felt obligated to provide care and they needed the income as well as personal fulfilment and social networks associated with their jobs. Having community supports enabled some caregivers to provide care while remaining attached to the labour force. One study of employees who had used employer-sponsored eldercare programs found that these services helped most employee caregivers to keep working productively (74%), avoid job absences (65%), stay employed (58%) and maintain a good family life at home (72%) (Dembe, Partridge, Dugan, & Piktialis, 2011). However, most respondents did not feel that the services helped minimize caregiving expenses. This finding is congruent with other research that shows a multi-pronged approach is needed to support family caregivers (Glass & Finley, 2002). Evidence shows that when formal services are provided early on, caregivers are able to provide care over a longer period of time (Penning & Keating, 2000). The provision of community services also need to be flexible to meet the needs of caregivers and respond to the uncertain trajectories of care.

Employers' needs

The experiences of caregivers and employers in managing the intersection between paid work and care shed light on several needs relevant to employers, managers and supervisors of employees with care responsibilities. Employers need to:

- Have employees disclose that they are a family caregiver
- Understand the lived lives and demands on family caregivers' time that lead to work-care conflict
- Have stability and predictability for work force planning
- Honor collective agreements, including benefit plans
- Understand the business case for employer supports for caregivers
- Know best-practices around supporting employees with family care responsibilities
- Know and be confident that community supports are available so that they can refer their caregiver employees accordingly

First, employers need employees to disclose that they are a family caregiver. They cannot provide support to employees unless they know about the demands on their time outside of work that might conflict with their job responsibilities. However, employees' willingness to disclose was dependent, in part, on the quality of the employee-employer relationship and employers' awareness of family caregiving. Employers in our focus group spoke about the need for increased awareness about caregiving as a workplace issue. While employers are generally aware of family care as an emerging workplace issue, they are ignorant of its magnitude in the labour force and its impact on Canadian workplaces, and only marginally engaged in responding to it (Cullen, & Gareis, 2011; Employer Panel for Caregivers, 2015; Katz, Lowenstein, Prilutzky & Halpern, 2011; Lero et al., 2012; Schroeder, MacDonald & Shamian, 2012). When employers, supervisors and HR managers are aware of caregiving as a workplace issue, they are more likely to be able to initiate conversations with their employees thereby encouraging them to disclose. It seems that only when people in supervisory positions have firsthand experience as a family caregiver that they 'get it'; they have a greater awareness of and appreciation for caregivers and their struggle to juggle paid work and care.

Once caregiver employees disclose, employers, HR managers and supervisors need to have a level of understanding about the everyday lives of family caregivers and the demands on their time that lead to work-care conflict.

Lack of awareness is also a barrier to accessing workplace supports (Sprung, Toumbeva & Matthews, 2015). It is important to create a compassionate work place culture in which caregiving can be discussed in a respectful, collaborative and timely manner. Carol (employer, financial sector) spoke of how corporate values of wellness and a balanced lifestyle facilitated disclosure and flexibility in meeting the needs of employees with care responsibilities in her organization. Others have found that company values and workplace culture that cascade throughout all levels of an organization are critical to creating a 'caregiver-friendly' milieu that respects work-family balance and employee wellness (Katz et al., 2011; Schroeder et al., 2012; Yeandle et al., 2006).

Employers also need stability and predictability for work force planning. The lack of awareness of employee caregivers and the uncertain trajectories of care undermined employers' ability to plan for absences, leaves, and lost productivity associated with care. When organizations have an environment that is more flexible, the uncertainty of care becomes easier to manage, helping employees manage work and care while reducing avoidable costs to employers (Appelbaum & Milkman, 2011; Heywood & Miller, 2014; Lee & DeVoe, 2012). For example, having a flexible schedule, the opportunity to work part-time, or take a leave of absence reduced the risk of missing work days or reducing paid work hours (Fast et al., 2014). Similarly, workplace flexibility enhances employer profitability when implemented within a strategy centered on employees, but decreases profitability when implemented within a strategy focused on cost reduction (Lee & DeVoe, 2012). Other workplace factors like type of position, industry, and size of the organization may influence the extent to which employers can be flexible (den Dulka, Petersb & Poutsmab, 2012; Glass & Fujimoto, 1995).

Employers need to honor collective agreements, including benefit plans. Benefits are only beneficial if employees are able to use them and if the organization is able to facilitate their use, which may, in some instances, mean making the benefit more flexible to meet the needs of the employee. Access to workplace accommodations are often handled on a case-by-case basis (Employer Panel for Caregivers, 2015; Lero et al., 2012). Yet organizations are encouraged to build accommodation into the way they do business (Canadian Human Rights Commission, 2013).

Part of creating a compassionate work place involves presenting the business case to employers and providing best practice examples. Companies that allow flexible work arrangements have been able to reduce absenteeism, improve morale and retention, and increase productivity (Carers UK, 2013; Columbo et al., 2011; Heywood & Miller, 2014; Lee & DeVoe, 2012). Furthermore, employees with care responsibilities worked harder and were more loyal to their employers. They have a 'give and take' attitude, founded in a sense of reciprocity and trust, which develops when they feel well supported at work (Yeandle et al., 2006).

Finally, employment policies are but one component needed to support employees with family care responsibilities. Both caregivers and employers spoke about the importance of adequate community supports. Evidence, mainly from outside Canada, suggests that individuals, employers, service planners and local communities all have a role in offering caregivers timely access to resources so they remain healthy and productive (Bernard & Phillips, 2007; Grayson, 2013; Yeandle et al., 2006). Employers need to know and be confident that community supports are also available so that they can refer their caregiver employees accordingly.

Strategies that will meet needs

In this section, we offer specific strategies that will meet the expressed needs of both employees with care responsibilities and employers. **Building awareness of family caregiving**, both among the general public and employers, is a critical first step to helping people recognize that they are caregivers and encouraging them to disclose to their employers. Possible strategies:

- Raise Canadians' awareness of care and the diversity among caregivers through public awareness campaigns. Currently, caregiver recognition days are fragmented across jurisdictions. Having a national campaign week will: enhance understanding of care as assistance provided to someone because of their health conditions, disabilities or aging; raise the profile of family caregivers; and add value to the essential support they provide. Using a multimedia approach through TV, radio, print, and social media will ensure key messages are heard by the lay public.

- Educate employers, HR professionals and supervisors about family caregiving as a workplace issue and the demands on their time that may lead to work-care conflict. Strategies include lunch and learn sessions, professional development workshops, webinars, podcasts, and informational materials.

Employers need employees with care responsibilities to disclose their status as a family caregiver. Employers cannot provide support to employees unless they are aware of the situation. Yet caregivers need to feel safe in order to disclose without risk of discrimination, denied opportunities, or job loss. **Creating a compassionate workplace culture** will foster disclosure and enhance morale, commitment and productivity. Possible strategies:

- Have an organizational commitment that values employees’ wellness and work-family balance.

- Coach supervisors to be aware of and be open to discussing family caregiving before work-family responsibilities conflict. Guides for employers which outline collaborative approaches for a supportive and well-performing workplace, including how to discuss the issue, develop solutions and ensure that solutions are effective, are emerging (Canadian Human Rights Commission, 2014; Employer Panel for Caregivers, 2015).

- Offer employees a quiet room with a door to make personal calls or have silence.

- Employee and Family Assistance Programs may offer counselling services that can support employed caregivers’ wellness and ability to cope under stressful conditions.

While employers need stability and predictability for work force planning, employed caregivers need flexibility to meet unexpected or unpredictable care demands. Employers also need to honor collective agreements, including benefit plans. In accommodating employees with caregiving responsibilities employers are encouraged to be creative and flexible (Canadian Human Rights Commission, 2014); regulatory interventions would be inefficient (Employer Panel for Caregivers, 2015). **Having workplaces that are flexible and willing to accommodate employees' needs** also contributes to a compassionate workplace culture. Possible strategies:

- Educate employers, HR professionals and supervisors about the business case for why employers should invest in supporting employees with care responsibilities and the best-practices available to do so. Businesses that are 'caregiver-friendly' have reduced avoidable costs in terms of absenteeism, turnover, productivity and performance management.
- Develop Canadian case studies and best-practice guides for Canadian employers. Case studies of organizational practices designed to support employed caregivers and minimize absenteeism, productivity losses and role strain are emerging in Europe (Yeandle, Wigfield, Crompton & Dennett, 2002; Yeandle, Phillips, Scheibl, Wigfield & Wise, 2003), but parallel studies in Canada are warranted.
- Encourage employers, employees and unions to work together to ensure that collective agreements are progressive and allow for the flexibility that employees with family care responsibilities are requesting.
- Offer flexible workplace arrangements where possible, such as flexible schedules, flex time, compressed work week, ability to telecommute or work from home, job share or work part time. Ensure that employees can access flexible work arrangements without it having a negative impact on their careers.

- Cross-train employees or have informal buddy systems in place so that employees can support each other when unpredictable family care needs arise.
- Educate employers and HR professionals about existing or new legislation requiring employers to accommodate employees with family care responsibilities, such as employers' duty to accommodate under the Canadian Human Rights legislation.

Caregivers need to have access to community services and employers need to know and be confident that community supports are available so that they can refer their caregiver employees accordingly. Yet communities differ in availability of and access to caregiver support services. **Having adequate community supports** will enhance caregiver employees' ability to remain in the labour force. Possible strategies:

- Day programs and home care services can ensure care receivers remain safe while their caregivers are at work.
- Advocacy organizations like the Alberta Caregivers Association can provide information sessions for both caregivers and employers.
- Community referral programs like the United Way Centraide's Canada 211 can provide information on government and community-based health and social services.

CONCLUSION

Managing employment and care has become a key issue in the lives of Canadians. The need for innovative solutions to effect a balance between these two demands will continue to increase in the face of high levels of employment and increasing need to support older adults with chronic health problems.

Canadian public policy to support employed caregivers is in its infancy, although there exist programs with potential to be of significant assistance. Job protection for caregivers on leave can allow for labour force re-entry. Programs that provide financial support to caregivers who have left the labour force if implemented in Alberta, could reduce economic strain on caregivers. Workplace solutions are beginning to emerge, although most workplaces still manage care needs of employees on an ad hoc basis.

There is much work to be done to support both employed caregivers and employers so that workplaces can continue to be productive and caregivers can manage their dual paid and care work roles. The policy and practice suggestions that emerged from this project can provide a guide to the development of a more transparent and integrated approach to meeting the needs of caregivers and of their employers as they navigate the caregiving journey.

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APPENDIX A. Background information for employed and formerly employed caregivers

Thank you for participating in this study. In this questionnaire we ask for some background information on: the people you provide care to, your employment and use of workplace supports, and you. This information will help us describe focus group participants as a whole in presentations and reports about the project. All information will remain strictly confidential.

The person(s) you provide care to
Please provide the following information about the person(s) you are providing caring to.

1. During the last three years, how many adults (family members, friends or neighbours) with long-term health conditions, physical or mental disabilities, or problems related to aging have you provided care to? ☐

We'd like to ask you a set of five questions about each person that you are providing care to. Let's start with the person who you have spent the most time helping.

1. What is the first name of this person? ______________________________[Person A]

2. Is this person: ☐ Male? ☐ Female?

3. How old is this person? ____________________years

4. What is the relationship of this person to you?
   - ☐ Spouse/partner
   - ☐ Adult child (son or daughter)
   - ☐ Mother or father
   - ☐ Mother-in-law or father-in-law
   - ☐ Grandparent
   - ☐ Other family member
   - ☐ Friend, neighbour or colleague
   - ☐ Other, please specify: ______________________________

5. What are the health conditions or problems for which this person receives help?
   - ☐ Aging-related needs / frailty
   - ☐ Alzheimer's disease or other dementia
   - ☐ Cancer
   - ☐ Cardiovascular disease
   - ☐ Mental illness
   - ☐ Neurological diseases
   - ☐ Developmental disability or disorder
   - ☐ Arthritis or osteoporosis
   - ☐ Back problems
   - ☐ Diabetes
   - ☐ Injury resulting from an accident
   - ☐ Mobility or physical disability
   - ☐ Respiratory problems
   - ☐ Other health problem

6. How close does Person A live to you?
   - ☐ In the same household
   - ☐ In the same building
   - ☐ Less than 10 minutes by car
   - ☐ 10 minutes to less than 30 minutes by car
   - ☐ 30 minutes to less than 1 hour by car
   - ☐ 1 hour to less than 3 hours drive by car
   - ☐ 3 hours or more by car

<u>Person B</u>

7. What is the first name of the second person you help? ______________________ [Person B]

8. Is this person: ☐ Male? ☐ Female?

9. How old is this person? ______________________years

10. What is the relationship of Person B to you?
    - ☐ Spouse/partner
    - ☐ Adult child (son or daughter)
    - ☐ Mother or father
    - ☐ Mother-in-law or father-in-law
    - ☐ Grandparent
    - ☐ Other family member
    - ☐ Friend, neighbour or colleague
    - ☐ Other, please specify: ____

11. What are the health conditions or problems for which Person B receives help?
    - ☐ Aging-related needs / frailty
    - ☐ Alzheimer's disease or other dementia
    - ☐ Cancer
    - ☐ Cardiovascular disease
    - ☐ Mental illness
    - ☐ Neurological diseases
    - ☐ Developmental disability or disorder
    - ☐ Arthritis or osteoporosis
    - ☐ Back problems
    - ☐ Diabetes
    - ☐ Injury resulting from an accident
    - ☐ Mobility or physical disability
    - ☐ Respiratory problems
    - ☐ Other health problem

12. How close does Person B live to you?
    - ☐ In the same household
    - ☐ In the same building
    - ☐ Less than 10 minutes by car
    - ☐ 10 minutes to less than 30 minutes by car
    - ☐ 30 minutes to less than 1 hour by car
    - ☐ 1 hour to less than 3 hours drive by car
    - ☐ 3 hours or more by car

<u>Person C</u>

13. What is the first name of the third person you help? ________________________[Person C]

14. Is this person: ☐ Male? ☐ Female?

15. How old is this person? ______________________years

16. What is the relationship of Person C to you?
    - ☐ Spouse/partner
    - ☐ Adult child (son or daughter)
    - ☐ Mother or father
    - ☐ Mother-in-law or father-in-law
    - ☐ Grandparent
    - ☐ Other family member
    - ☐ Friend, neighbour or colleague
    - ☐ Other, please specify: ____

17. What are the health conditions or problems for which Person C receives help?
    - ☐ Aging-related needs / frailty
    - ☐ Alzheimer's disease or other dementia
    - ☐ Cancer
    - ☐ Cardiovascular disease
    - ☐ Mental illness
    - ☐ Neurological diseases
    - ☐ Developmental disability or disorder
    - ☐ Arthritis or osteoporosis
    - ☐ Back problems
    - ☐ Diabetes
    - ☐ Injury resulting from an accident
    - ☐ Mobility or physical disability
    - ☐ Respiratory problems
    - ☐ Other health problem

18. How close does Person C live to you?
    - ☐ In the same household
    - ☐ In the same building
    - ☐ Less than 10 minutes by car
    - ☐ 10 minutes to less than 30 minutes by car
    - ☐ 30 minutes to less than 1 hour by car
    - ☐ 1 hour to less than 3 hours drive by car
    - ☐ 3 hours or more by car

19. In an average week, how many hours of care or help do you provide to ALL of the people mentioned in question 1? Include time spent helping with housework, meal preparation and cleanup, shopping for groceries and other necessities, personal care, transporting the cared for person(s), your time commuting to provide care, and care management.________ hrs/wk

20. How many years in total have you been providing care to ALL of the people mentioned above? ____years

Your employment

Please provide the following information about your current employment situation.

21. My job title is (please specify): ____

22. How many hours per week do you work for pay? ______________________hours per week

23. The industry I work in is best described as:
    - ☐ Financial (Banking, Insurance, Investing)
    - ☐ Professional Services (Legal, Accounting, Consulting)
    - ☐ Communications
    - ☐ Education
    - ☐ Healthcare / Social services
    - ☐ Public administration
    - ☐ Retail / Hospitality
    - ☐ Manufacturing
    - ☐ Natural Resources
    - ☐ Technology
    - ☐ Transportation
    - ☐ Other, please specify: _____________________

24. The organizational sector is (choose only one):
    - ☐ Private sector (privately held)
    - ☐ Private sector (publicly traded)
    - ☐ Family Enterprise/Family Business (privately held)
    - ☐ Government public sector (federal, provincial, territorial, municipal, local)
    - ☐ Broader public sector (education, colleges/universities, hospitals/health care)
    - ☐ Crown corporation
    - ☐ Federal agency
    - ☐ Not-for-Profit/Voluntary sector/Charitable sector
    - ☐ Social Enterprise
    - ☐ Self-employed/Entrepreneur/Owner-Operator
    - ☐ Other, please specify: ______________________

Use of workplace supports

This section asks about provisions for job flexibility or other workplace supports with your employer. As a caregiver, have you used any of the following workplace supports?

25. Working some of your regular paid hours at home or off site?	Yes	No	Not available
26. Taking time off during the work day to attend to important family needs without losing pay?	Yes	No	Not available
27. Coming to work late or leaving early to accommodate caregiving?	Yes	No	Not available
28. Working reduced hours for a period of time (at reduced pay) to accommodate caregiving needs?	Yes	No	Not available
29. Moving from full-time to part-time work, while remaining in the same position or level?	Yes	No	Not available
30. Compressing your workweek by working longer hours on fewer days for at least part of the year?	Yes	No	Not available
31. Phasing into retirement by working reduced hours over a period of time prior to full retirement?	Yes	No	Not available
32. Taking a leave of absence for caregiving?	Yes	No	Not available

	Yes	No	Not available
33. Did your organization offer any information or resources (such as information and referral, on-site services, or other forms of assistance) to employees with caregiving responsibilities?			

You

This section asks some background questions about you.

34. Are you: ☐ Male? ☐ Female?

35. What is your date of birth?

Month	Day	Year

36. What is your marital status? Are you:

☐ Married
☐ Living common-law
☐ Widowed
☐ Separated
☐ Divorced
☐ Single, never married

37. How many children do you have? Please include all birth, step and adopted children. _______

38. How many children live with you in your household? ________________________________

Thank you for your participation. **Please bring the completed background information form with you to your focus group.**

If you have any questions or require more information about this project, please contact the research coordinator, Jacquie Eales at (780) 492-2865 or jacquie.eales@ualberta.ca

APPENDIX B. Background information for employers

Thank you for participating in this study. This short questionnaire has three main sections: your workplace, awareness of employed caregivers and availability of workplace supports within your organization. This information will help us describe focus group participants as a whole in presentations and reports about the project. All information will remain strictly confidential.

Your organization
Please provide the following information about your workplace.

39. My current role is (choose only one):
    - ☐ CEO / President
    - ☐ Partner
    - ☐ Owner / Operator
    - ☐ Manager / Director / Supervisor
    - ☐ Other, please specify: ____

40. I have been working for this organization since (insert year you began): ________________

41. How many employees work in your organization? About _________________employees

42. The organizational sector is (choose only one):
    - ☐ Private sector (privately held)
    - ☐ Private sector (publicly traded)
    - ☐ Family Enterprise/Family Business (privately held)
    - ☐ Government public sector (federal, provincial, territorial, municipal, local)
    - ☐ Broader public sector (education, colleges/universities, hospitals/health care)
    - ☐ Crown corporation
    - ☐ Federal agency
    - ☐ Not-for-Profit/Voluntary sector/Charitable sector
    - ☐ Social Enterprise
    - ☐ Self-employed/Entrepreneur/Owner-Operator
    - ☐ Other, please specify: ______________________

43. The industry I work in is best described as:
    - ☐ Financial (Banking, Insurance, Investing)
    - ☐ Professional Services (Legal, Accounting, Consulting)
    - ☐ Communications
    - ☐ Education
    - ☐ Healthcare / Social services
    - ☐ Public administration
    - ☐ Retail / Hospitality
    - ☐ Manufacturing
    - ☐ Natural Resources
    - ☐ Technology
    - ☐ Transportation
    - ☐ Other, please specify:

Employed caregivers in your organization

This section asks about your awareness of employed caregivers within your organization.

44. During the last three years, approximately how many employees are you aware of have faced challenges combining work and caregiving for an adult or elderly family member? ☐

45. Approximately how many of these employees still work for your organization? ☐

46. Compared to five years ago, have requests / needs for support by employees with caregiving responsibilities in your organization:

- ☐ Increased
- ☐ Decreased
- ☐ Stayed the same
- ☐ Don't know

47. Over the next five years, do you expect requests / needs for support by employees with caregiving responsibilities in your organization to:

- ☐ Increase
- ☐ Decrease
- ☐ Stay the same
- ☐ Don't know

Availability of workplace supports in your organization

This section asks about provisions for flexibility in your organization. Does your organization allow at least some employees who are caregivers to:

48. Be able to work some of their regular paid hours at home or off site?	Yes	No	Don’t know
49. Take time off during the work day to attend to important family needs without losing pay?	Yes	No	Don’t know
50. Come to work late or leave early to accommodate caregiving?	Yes	No	Don’t know
51. Work reduced hours for a period of time (at reduced pay) to accommodate caregiving needs?	Yes	No	Don’t know
52. Move from full-time to part-time work while remaining in the same position or level?	Yes	No	Don’t know
53. Compress their workweek by working longer hours on fewer days for at least part of the year?	Yes	No	Don’t know

Does your organization allow at least some employees who are caregivers to:

54. Phase into retirement by working reduced hours over a period of time prior to full retirement?	Yes	No	Don't know
55. Take a leave of absence for caregiving?	Yes	No	Don't know
56. Does your organization offer any information or resources (such as information and referral, on-site services, or other forms of assistance) to employees with caregiving responsibilities?	Yes	No	Don't know

You

This section asks some background questions about you.

57. Are you: ☐ Male? ☐ Female?

58. What is your date of birth?

Month	Day	Year

Thank you for your participation. **Please bring this completed questionnaire with you to the focus group.**

If you have any questions, or if you require more information about this project, please contact the research coordinator, Jacquie Eales at (780) 492-2865 or jacquie.eales@ualberta.ca