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Caregivers in the Healthcare Workplace

Findings from a 2008-2011 Action Research Project

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Introduction

In the past twenty years there has been increasing recognition of the challenges facing individuals who juggle paid work and unpaid caregiving responsibilities. According to a 2009 report by Duxbury, Higgins & Schroeder, there are more than 1.7 million employees in Canada who are also providing care to family members. At least 60% of caregivers make adjustments to their paid work arrangements as a result of their caregiving responsibilities: missing whole or partial days of work, reducing their hours of work, quitting or retiring early from their jobs (Fast, Lero, Duncan, Dunlop, Eales, Keating & Yoshino, 2011). While there is information about caregivers in the workplace in general, we are only beginning to address the complex reality of balancing work and caregiving in the context of the healthcare workplace. For healthcare workers who offer care at work and at home, often called “double-duty caregivers” (Rutman, 1996), the issue of balancing care may be experienced as more difficult. Developing an understanding of this particular population will enable employers and policy makers to appropriately organize support and health programs for this unique group of caregivers.

This paper documents the findings of an action research project conducted between 2008 and 2011, which addressed the issues facing healthcare employees who also provide care to family members at home. Undertaken at a local community healthcare center in Montreal, the researchers engaged employees in multiple conversations to better understand their experiences, challenges and realities, and to make recommendations to help these working caregivers juggle their multiple roles. The project coordinators used several strategies to collect data (an interdisciplinary agency-wide survey, an on-site focus group and an employee forum), which were then analyzed, summarized and presented to human resources administrators. The findings of this project helped to illuminate the unique challenges experienced by “double-duty caregivers” and the ways in which employers can respond. The broad questions explored throughout the project included: What are the experiences of caregivers who work at a local community health service center in managing familial, social and employment responsibilities? How can the healthcare workplace assist “double-duty caregivers”?

Caregivers and work

There is an extensive amount of literature on caregivers in general. A caregiver can be defined as “an individual providing care or assistance to a family member in their home or the care recipient’s home who has a physical or mental disability, is chronically ill, frail, or at the end of life” (Duxbury, Higgins & Schroeder, 2009, p. 1). Those who provide care for elderly or disabled relatives face a wide range of challenges, including negative impacts on their physical health and well-being (Bainbridge, Cregan & Kulik, 2006), increased depression (Pavalko and Henderson, 2006), increased stress (Bainbridge, Cregan & Kulik, 2006; Duxbury, Higgins & Schroeder, 2009) as well as social isolation. Financial stress is also identified as a critical issue given the extra demand on resources (Bainbridge, Cregan & Kulik 2006), the expense of in-home services, and difficulty in accessing pensions and other benefits due to restrictive eligibility criteria (Arksey and Glendinning, 2008). However, despite requiring increased financial resources, the earning capacity of many caregivers is compromised due to their caregiving responsibilities. Many must reduce their hours or leave work, jeopardizing their employment status, income and future pensions (Fast et al., 2011; Torjman, 2011).

Cuts to healthcare funding have also resulted in increased pressure being put on caregivers to provide services that were once offered by homecare programs or hospitals (Navaie-Waliser and Feldman, 2002). Most affected by these changes in the healthcare context are women. According to a Canadian study, "...women have been burdened disproportionately with the impact of recent healthcare restructuring, both in the workplace as healthcare providers and in the home as family caregivers" (Ward-Griffin, Brown, Vandervoort, McNair & Dashnay, 2005).

Effects of employment and caregiving

While there is debate in the literature about whether paid employment increases caregiver stress (Duxbury, Higgins & Schroeder, 2009; Pavalko and Henderson, 2006) or decreases it due to social contact and the break from personal care responsibilities (Bainbridge, Cregan & Kulik, 2006; Arksey, 2002; Arksey and Glendinning, 2008) there is consensus that the workplace can be negatively impacted by an employee's lack of energy, lethargy and difficulties concentrating (Arksey and Glendinning, 2008).

Personal caregiving often impacts absenteeism and decreases productivity (Ward-Griffin, 2004; Duxbury, Higgins & Schroeder, 2009), since individuals might need to leave work with little notice, in order to attend appointments, or make telephone calls during work time (Arksey, 2002). Individuals who are working while caregiving can miss opportunities for advancement or end up leaving their employment all together (Ward-Griffin, 2004).

The choice to work while providing care is one that is complex and varies depending on each situation. Research has shown that most caregivers work because of financial need (Arksey and Glendinning, 2008; Bainbridge, Cregan & Kulik, 2006). The decision to remain in the workplace or commit to full time caregiving is often influenced by the types of support and services that are available (Arksey and Glendinning, 2008). Still, it is important to consider that the decision to work for pay is rarely identified as a choice by caregiving employees. In this case women are differentially affected. Women are more likely than men to reduce their hours or quit their jobs if they are caregivers (Pavalko and Henderson, 2006; Killien, 2004). In a recent study, it was found that employed caregivers had different experiences based on their gender. Employed women caregivers made more sacrifices in their jobs than their male counterparts. Thirty percent of women missed full days of work, 6.4% retired early, quit, or lost their paid job, and 4.7% turned down a job offer or promotion (Fast et al., 2011).

Issues specific to healthcare professionals

Several research studies have addressed the specific realities of "double-duty caregivers", paying attention to the strengths and challenges of the fluid boundaries between caregiving roles, responsibilities and expertise. A "double-duty caregiver" is defined as a paid healthcare professional, who simultaneously provides unpaid care to an elderly dependent, and/or a dependent adult or child, in their time off (Rutman, 1996). These "double-duty caregivers" are primarily women, as studies have shown that women are the main caregivers both in the home and in healthcare professions (Ward-Griffin et al., 2005; Bullock and Morales Waugh, 2004). According to a Quebec report, 60% of all informal caregiving is done by women (Cranswick and Dosman, 2008). It has been found that "...women dedicate almost twice as much time to their [caregiving] tasks as men" (Stobert and Cranswick, 2004),

report more stress and burden (Ward-Griffin et al., 2005), and incur more employment consequences due to their caregiving responsibilities (Fast et al. 2011).

In a study on nurses who were also caregivers, Bulloch and Morales stated that even though the nursing profession is thought to be “woman-friendly”, women who are caregivers are “still forced to select positions based on the flexibility of the hours and to turn down opportunities for advancement due to long, unaccommodating shifts” (Lane, 2000 as quoted in Bullock and Morales Waugh, 2004). They also make the argument that those with closer contact with patients, such as beneficiary attendants, make less money and experience more stress. This stress is compounded by additional caregiving responsibilities (Bullock and Morales Waugh, 2004). Additionally, those lesser paid employees do not have offices to which they can retreat, and some of them also live in crowded conditions giving them no privacy in their personal lives either (Bullock and Morales Waugh, 2004).

Ward-Griffin et al. (2005) explain that “while a healthcare professional might have faster access to resources and medical referrals because of their healthcare connections” (p. 388), they may also feel overburdened by their own sense of obligation to provide care because of their expertise. Dual roles can cause resentment as family members rely heavily on them to advocate, negotiate/coordinate care, and be the “family spokesperson” (p. 384). An overlap in duties and the need to be compassionate and gentle at work can create additional stress in personal situations and affect the amount of energy caregivers have left to care for the individuals in their lives (Bullock and Morales Waugh, 2004).

Workplace culture also seems to impact the experience of healthcare professionals and affect the degree of support they seek from their colleagues. In some situations, employees can rely on their peers to cover for them during absences but in other cases they do not discuss their needs with co-workers because these “types of discussions [are] not encouraged in the workplace nor [do] they feel comfortable about discussing their private affairs with co-workers”(Ward-Griffin et al., 2005, p.387). Healthcare restructuring has also changed the workplace to one that is more stressful and competitive, and at the same time, less flexible and less understanding. In this environment, it might be difficult to take time off or rearrange one’s schedule (Ward-Griffin et al., 2005).

Methodology

Given our interest in understanding the experiences and needs of working caregivers at a healthcare organization, and identifying ways in which the organization could respond to those needs through policy and program changes, we chose to develop a methodological approach consistent with a needs assessment. A needs assessment approach uses a data collection model that is designed for program planning purposes across a variety of contexts (Rossi, Lipsey and Freeman, 2004; Rubin and Babbie, 2008). The needs assessment evaluates the “nature, magnitude, and distribution of a social problem, the extent to which there is a need for intervention, and the implications of these circumstances for the design of the intervention” (Rossi, Lipsey and Freeman, 2004, p. 54).

Our approach was identified as “demand-based”, as we were interested in specifically targeting individuals who experienced the challenges; that is, employees who provided care both in the context of their professional and personal lives (Rubin and Babbie, 2008), in order to get a full picture of their

current situation. As such, we incorporated several “typical” techniques used in organizational needs assessments that specifically target “demand” populations. Within the three-year period of this study, we engaged practitioners working in the specific healthcare setting to explore their experiences as “double-duty caregivers”. The techniques included a survey of all employees at the agency, in order to determine the extent of the need (Rossi, Lipsey and Freemane, 2004), a focus group with affected employees in order to gather details regarding their experiences and to inquire about possible responses, and an employee forum in which we reported on findings from the survey and invited members of the organization to express their views. This employee forum also provided important information on the nature of the need (Rubin and Babbie, 2008), which was then analyzed and developed into an action plan to submit to the human resources department. Our objective was to use the findings from the study to help shed light on the challenges of these employee caregivers and to highlight the gaps in support and services for this group in order to initiate change.

Results

The results from the survey, the focus group and the employee forum confirmed that the number of employed caregivers balancing care and work at the same time is an emergent reality. An action plan was developed based on the recommendations that emerged from these results.

Survey results

The survey was the first part of a targeted outreach plan. In 2010, it was distributed in hard copy to each employee of the local community service center with his or her paycheck. There was a drop off box for replies at a central location. The results were then compiled and analyzed. Of the 133 staff members who completed the survey, 41% identified themselves as caregivers (well above the national average of 25%), 96% of respondents were female, 25% were caring for someone with multiple conditions (physical, cognitive and mental disabilities), 90% found it difficult to balance work with caregiving, 85% found their health was declining due to caregiving, and 75% were missing work due to caregiving. Of those who said that they were not currently caregivers, 50% anticipated that they would be caring for someone in the future. In addition to their family caregiving responsibilities, 72% of respondents were also working full time and 56% were working in front-line health and social services professions. Sixty-five percent of caregivers reported spending 1 to 9 hours per week doing unpaid caregiving work, and 15% devoted between 10 and 19 hours per week.

The survey results showed that caregivers requested flexible hours more than any other support resource. The second most popular request was caregiver leave (with job security), followed by support groups, information (conferences, workshops, literature, internet), counseling services, day care, job sharing and a resource guide (referrals to community resources).

The working caregivers who participated in the survey also provided numerous suggestions for how to improve their quality of life. These suggestions included workplace flexibility, work environment support, financial support, psychosocial support and homecare support.

Following the survey, a focus group was conducted with the local community service center employees to discuss their realities. The focus group included six participants who were caregivers for a family member or friend. The participants had varied amounts of caregiving help from their siblings, other family members and organizations. In addition to their caregiving responsibilities, some participants were employed full-time, others part-time, and some had children to care for. The results from the focus group yielded similar recommendations as those expressed in the survey. They are presented briefly below:

Focus group results

The financial and emotional impact of “double-duty caregiving”

Participants stated that they struggle financially, feel stressed and guilty about time away from work, as well as time away from caregiving responsibilities. In an attempt to juggle work and family caregiving, many participants had to cut back on their work hours or switch to part-time employment. Four out of the six participants had to make this change to part-time employment.

Those who are not financially able to work on a part-time basis, and those who do not have assistance with caregiving responsibilities from other family members, are in an even more disadvantaged position. One participant mentioned that if it weren't for her husband's salary she would be living below the poverty line because she must work part-time in order to have the time to care for her ill mother. A participant who works full-time and is a caregiver to her mother said that she is bankrupt and that she worries about retirement. This sentiment was echoed by the rest of the participants, who have felt the impact of “double-duty caregiving” on their finances. Besides cutting down on hours or having to take a leave and therefore losing income, there are other costs to caregiving that have impacted on the participants' financial situation, as one participant said:

There are many incidental costs when you are caregiving in your family, like with my daughter for example. There are a lot of things that with Medicare or our system or whatever are covered and what not or you'll wait and you'll get it and there are so many things that are just not. It's a huge chunk of money that comes out of every family.

Whether or not they work full or part-time, all participants expressed some feelings of guilt and stress when having to take time off or when having to leave work early due to their caregiving responsibilities. One participant talked about feeling less guilty if time away from work was planned in advance, but that oftentimes crises occur with her ill mother that require her to leave work without much notice. Another participant described the guilt she feels about leaving work early to go care for her grandfather, even though she makes up the time by working through her lunch break.

So if I work through lunch and then leave that half an hour early I feel bad leaving early. I feel like I'm not doing something right, and I don't see clients but the people in my department might say oh she's...you know they don't know where I'm going or what I ate for lunch or where I ate it. So for me that's an issue, because I'm not supposed to work through lunch and then leave early, that's not what anyone is allowed to do.

The culture of the work environment: Supporting “double-duty caregivers”

The culture of the work environment has a direct impact on participants' experiences of stress and guilt as described above, but has also provided participants, depending on their position and supervisor, with a supportive team and understanding colleagues. Outside of peer support, participants have access to an employee assistance program. However, accessing this program for emotional and psychological support has been challenging for one participant. She explained that when she has attempted to make use of this service, appointments were offered during work hours, which rendered the service inaccessible to her. Participants agreed that accessible emotional and psychological support is needed.

All participants expressed the need for respite. One participant stated:

“You don’t get a break. You live that life outside; you live it every day at work”. Participants explained that in their agency, respite is not available unless you provide it yourself by taking a leave or using vacation days. For many of the participants, vacation days are used for family caregiving situations, and it is not financially feasible to take an unpaid leave. Participants said they would appreciate the option of a caregiver leave, which might resemble a maternity leave, and include a percentage of one’s salary. Currently, the only type of leave that allows employees to continue receiving part of their salary is a deferred leave, which must be planned in advance. This is not particularly helpful for caregivers as *“most crises and things like that where you absolutely have to be there and you need that income and there is no other way, you can’t plan it in advance”*. Participants added that a drop-in service, or another type of resource at the workplace where participants could bring their care recipient when needed, would ease some of the stress of juggling work and caregiving responsibilities. But as one participant noted, for these options to be put in place more staff would be required and budgetary issues would arise.

A main theme that emerged from the discussion on how the employer could better support “double-duty caregivers” was flexibility. Depending on your position, your department and your relationship with your manager, informal and unofficial flexibility does exist. For example, working through lunch in order to leave early, or organizing one’s schedule to accommodate caregiving responsibilities, are strategies used by participants even though they are not officially allowed to do so. Participants expressed that most supervisors in their organization are sensitive and accommodating to their situation as “double-duty caregivers”. One participant explained: *“I think that it’s almost like the level above you is sensitive and kind, and then the level above them is like pushing down on the whole system”*.

Although, over the years, participants have seen an increase in management’s awareness of the needs of staff, the organizational climate is currently one that emphasizes productivity and efficiency, which is measured by workplace statistics. As one participant said: *“Stats, stats, stats, that’s our world”*. This reality has made it difficult for staff to avoid burnout and to be sensitive to their own and their team’s needs. One participant shared her perspective on how the organizational climate has changed:

It’s the new reality and it’s horrendous in that it’s not anybody’s fault it’s just the way that it is. But there has to be some kind of a balance between the two and most of the managers, I have to say, are sensitive to all of this, a couple that are not, but the reality of ‘we see that you are burning out, we see that you have a problem, can’t help you, where are your numbers, let’s go.

Participants mentioned that those who can't move from full-time to part-time work for financial or other reasons can still benefit from flexible hours, shared jobs or having the option to work from home if needed. A participant elaborated on why allowing for flexibility or implementing other changes in the work environment that support the realities of "double-duty caregivers", is so important:

There are many ways to make a difference. Being in healthcare, we know for a fact, and lots of studies have been done, people that work in the healthcare system are at a higher risk for depression, for psychological problems, and then if you look at them being caregivers it's added on top of it. Because we know that caregivers also are at high risk... I think it's an important piece that needs to be looked at.

Implementing changes to the work environment that can support "double-duty caregivers" can also have a positive impact on work performance and job satisfaction. Some participants felt that their performance and job satisfaction are compromised by their caregiving responsibilities and the stress created from juggling both work and family caregiving. One participant said that she worries about how much her work is impacted by being a family caregiver: *"I am tired, I am distracted, my mind is elsewhere, focusing sometimes is a struggle and at those times I don't see, I don't perceive job satisfaction"*. Another participant said: *"Although I really love my job and am very appreciative of it, I find that sometimes it's a bit of an additional burden"*.

Due to the time and energy taken up by family caregiving, some participants said that they have missed out on career opportunities. Lost income is also a factor for participants who have cut down on their hours. Working fewer hours at one's paid employment due to caregiving demands means less contribution to retirement and uncertainty about future financial stability.

Employee forum results

In conjunction with Caregiver Week in November 2011, the project managers organized an employee forum where the research results were presented by PowerPoint. Discussion ensued with many professionals offering suggestions and expectations for employer support which has ultimately led to the development of an agency wide support plan for employee caregivers.

Discussion

The local community service center's survey, focus group and employee forum for employee caregivers were developed in order to assess the actual situation and needs of employees balancing work and caregiving responsibilities between 2008 and 2011. The intentions of this three-pronged approach were to gather information regarding the experiences of "double-duty caregiving" with the ultimate goal of developing support services to assist employees who are or will be in a position where they are balancing work and care duties.

The findings presented above show that "double-duty caregivers" experience considerable emotional and financial stress. Working in the health and social services system has meant that participants confront additional expectations from family and colleagues, and get little, if any, respite from care work. Some advantages to working in the system include supportive colleagues, increased access to

resources and information, and a particular knowledge of the way that the health and social services system works. Increased awareness about the experiences of “double-duty caregivers” can lead to programming and/or policy changes that meet the needs expressed by participants.

This three-pronged approach was an excellent starting point for creating an open exchange between managers and employees on issues that can be emotionally laden, including feelings of vulnerability, sadness, stress, fear and anxiety. Providing supportive services to local community service center employees is a natural extension of the work currently done on behalf of our community-based clients, and promotes a healthy and productive work environment. Managers need to ensure the well-being of their employees who may be experiencing added burden and stress resulting from excessive work and care demands. Creating and maintaining an environment of genuine care, trust and loyalty heightens the collective strength of the organization while maximizing individual wellness. Positive perceptions among workers pay dividends in loyalty, commitment and productivity.

Employers, who have made a commitment to caregivers as part of a work/life initiative, report that their investment in these support initiatives pays for itself many times over by reducing the negative effects that can result from “double-duty caregiving”.

Recently, there have been positive shifts in employer and organizational awareness of caregivers and their needs. For example, a large Canadian survey, Caregiving and Work: Programs, Policies & Practices Survey has close to 200 employers participating in the first group (Torjman, 2011). Additionally, elder care services have been implemented in several major companies, however small and medium sized companies continue to face challenges in providing such benefits (Torjman, 2011).

Conclusion and recommendations

“Double-duty caregivers” are in a unique situation where there is often no respite. Their caregiving responsibilities extend beyond work hours, as this role continues once they go home to provide care for their family member. Caregiver leave, particularly paid or partially paid, would address this need for respite and lessen some of the financial burden on “double-duty caregivers”. Flextime or job sharing would be highly beneficial as well.

The need for psychosocial support can be addressed by implementing changes to the current employee assistance program, allowing for an increased number of sessions and more accessibility to services outside of regular work hours. Psychological support outside of the workplace employee assistance program, at a fee subsidized by the organization, as well as support groups or individual counseling within the local community service center would benefit employee caregivers. There are also telephone and web-based networking resources that can be utilized to hold supportive and educational teleconferences for employee caregivers.

Emotional and psychological support can come from colleagues, supervisors and managers. Creating a supportive and understanding work environment can help “double-duty caregivers” manage stress, guilt and other emotional impacts of their situation. Exercise initiatives and other stress reducing, health promoting activities and programs can be implemented in the organization.

In order for health and social service organizations to retain their employees and continue to offer needed services to the public, it is necessary to create opportunities for feedback, critique and discussion, and implement strategies to address needs and create positive changes. Future directions for research include the planning, implementation and evaluation of programs and services designed to support “double-duty caregivers”. Organizations can benefit from developing these needed programs and services; outcomes can include increased work performance, job satisfaction, mental and physical health and well-being of employees.

This project revealed that the number of working caregivers in the local community service center has increased and will need support for their challenging roles. The corresponding increase in the number of individuals entering the workforce and an aging population are among the predictors for an increasing demand for working caregiver resources and support systems. Implementing programs and practices that address the needs of working caregivers in the healthcare network is a necessary preventative measure to address a growing problem.

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