Research Report

Retrospective Assessment of a Carer-Employee Workplace Intervention

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Abstract

Carer-employees have become an increasingly normative phenomenon. This study sought to retrospectively assess the effectiveness of a carer employee workplace policy which had been implemented in a post-secondary institution located in Southern Ontario. The study consisted of a thematic analysis of fourteen semi-structured postintervention interviews. A thematic analysis of the interview transcripts revealed the following themes: (i) pre-existing circumstances; (ii) recommendations made to improve the intervention; (iii) benefits received from the intervention; and (iv) factors limiting the benefits received from the intervention. Furthermore, the analysis revealed improvements in self-reported mental and physical wellbeing, greater self-confidence in caregiving abilities, and respite.

Key Messages

1. Results demonstration that carer-friendly workplace programs (CFWPs) may be an effective tool in addressing the challenges faced by carer-employees
2. Carer-employees participating in the CFWP intervention experienced improvements in self reported mental and physical welling, greater self-confidence in caregiving abilities, and respite
3. Employers and human resource professionals are encouraged to incorporate tailored CFWPs that fit their workplace needs in order to better accommodate the tensions carer employees experience in juggling both their care and employment roles

Key words

caregiver tax credit; caregiver support; Canadian caregiving; caregiver amount

Introduction

Carer-employees (CEs) have become an increasingly normative phenomenon among adults living in industrialized countries with demographic transitions towards an aging population, longer life expectancies, and declining birth rates (Hilbrecht et al, 2017). The term carer-employee, or caregiver-employee, refers to individuals who provide informal, unpaid care to an adult dependent, termed a care recipient, while simultaneously engaging in paid employment (Converso et al, 2020). CEs often have some personal relationship with their care recipient; whether it be a family member, spouse, friend, or neighbour (Hilbrecht et al, 2017). As of 2012, 46% of Canadians aged 15 years or older have, at some point in their life, provided informal care to a friend or family member with a chronic health condition, disability, or aging needs (Sinha, 2013). The majority, 60%, of these carers had been simultaneously juggling their caregiving obligations with the demands of their paid work, therefore meeting the criteria of a carer-employee. This figure, representing 7.8 million Canadians, has likely grown in recent years, as baby boomer carers plan for their own long-term care needs and an increasingly elderly population places more strain on healthcare infrastructure (Finkelstein et al, 2012). As such, there is a growing body of research regarding how to best support CEs so they can remain productively employed while taking on caregiving responsibilities (Dembe et al, 2011).

The impending increase in demand for informal caregiving is likely to compound current stressors faced by CEs. For instance, caregiver or carer-burden is a well-documented phenomenon in which carers engaged in long-lasting or high-intensity caregiving are particularly vulnerable to detrimental impacts on their physical and psychological wellbeing, economic status, and social relationships (Adelman et al, 2014). Scholars in industrialized countries have noted that CEs are at a higher risk, relative to non-caregiving employees, of depression, long-term sickness, anxiety, and poor sleep (Ferrara et al, 2008; Honda et al, 2014). CEs have also, been found to experience lower levels of job satisfaction, longer leaves of absence due to illness, and higher rates of job turnover (Powers & Powers, 2010; Li et al, 2015; Mortensen et al, 2017). There is a clear and pressing need to proactively support employees with caregiving responsibilities.

In recent years, carer-friendly workplace policies (CFWPs) have been presented as a viable strategy for supporting the unique circumstances of CEs. CFWPs, also referred to as 'family-friendly workplace policies', are defined as the deliberate changes implemented by employers to reduce work-family conflict and support the wellbeing of their employees outside of work (Kelly et al, 2008). Examples of CFWPs include: flexible working hours, paid and unpaid personal leave arrangements, and resource referrals (Lero et al, 2012; Vuksan et al, 2012). While these policies are geared towards improving the wellbeing of CEs and reducing their burden, it should be recognized that employers also benefit from the implementation of CFWPs. For instance, CFWPs have been noted to provide economic benefits such as: increased employee retention, increased employee morale, increased attendance, and a positive reputation among clients and recruits (Ireson et al, 2018). While the importance and the positive impacts of such policies are clear, there is a need for additional research seeking to tailor CFWPs to the needs of CEs in different workplaces and environments.

In addition to complementing the existing research on CFWPs, this paper intends to provide a health geography lens to contextualize the design and delivery of CFWPs to a postsecondary institution located in Southern Ontario. This paper consists of a thematic analysis of fourteen semi-structured post-intervention interviews, in which each interview had been conducted with a carer-employee from the aforementioned post-secondary institution. The themes resulting from this process provided a snapshot of the thoughts, attitudes, and perceptions of the participants regarding the place-based, educational caregiver-employee intervention. The study represents one phase of a broader project outlined in a protocol paper by Author's own et al. (2017).

Methods

As part of a larger research project, this specific study is a qualitative post-test assessment of carer-employee experiences (N=14) with a workplace-based educational intervention. Researchers received institutional clearance (ISRCTN 16187974) to recruitment participants at an Ontario University in late 2015, with the last datapoint collected late 2018. Eligibility criteria were as follows: full-time employees at the university; and at the time of data collection, a carer to another individual for health, disability or age-related reasons.

The recruitment process applied a multi-prong approach to university employees, utilizing email listservs, snowballing, posters, flyers, and word-of-mouth. As a longitudinal study, survey and interview data were collected 3 times (Time 1-3) for each participant over the course of approximately 12-18 months, from early 2016 to early 2018. An educational intervention was introduced to participants in between Time 1 and Time 2. This paper specifically explores a fourth and distal follow-up timepoint collected late 2018 (post-Time 3), approximately 18 months after the intervention, through use of qualitative retrospective interviews.

Intervention

The actual educational intervention consisted of an individual face to face meeting between the participant and researcher. A web-based decision tool, developed for the purpose of the project, was used to generate a customized list of carer-employee resources on the workplace, community, provincial and federal level, based on inputted participant demographics. The researcher then reviewed each of the items on the resource list with the participant.

Data Analysis and Consent

While 43 participants were recruited as part of the convenience sample at Time 1, by the final follow up time point, only 14 participants remained. Participant drop out over the years were due to the following reasons: care recipient had passed away, no longer providing care, no longer employed full-time at the university, time constraints, or reasons not disclosed.

The 14 remaining participants were interviewed in-person at a neutral location on campus or over the phone. All interviews were audio recorded with participant permission and ranged from 20 minutes to 45 minutes. Written participant consent was obtained at the start of the study and verbally confirmed prior to interview. Interview questions were open-ended, semi structured, and probed the following topics: overall experience in the research project, most/least useful aspects of the intervention, impact on role strain, carer knowledge and identity, carer-employee health, work life, and a priori expectations of the intervention.

All 14 interviews were transcribed verbatim and transcripts were analyzed using thematic analysis using NVivo 1.0. Transcripts were first coded line by line, so that all data were categorized, and initial codes allowed to emerge inductively (Nowell et al, 2017). Later, these codes were developed into relevant themes deductively based on previous research [T1 paper, Time 3 paper]. These themes were subsequently reviewed and defined by all authors of this paper and are explored in the following section.

Results

Thematic analysis of the interview transcripts revealed five themes: (i) the pre-existing circumstances of participants; (ii) recommendations made by participants to improve the intervention; (iii) benefits participants received from the intervention; and (iv) factors limiting the benefits participants received from the intervention. Each theme contains three sub-themes, highlighting the recurring elements within a given theme. In the following section, participants will be referred to using their randomly-generated pseudonyms.

(i) Pre-existing circumstances of participants

While all (n=14) participants reportedly benefited from the intervention, the degree to which they benefited varied. Several factors which may account for these variations, as identified by the participants themselves, can be broadly defined as 'the circumstances of participants prior to the intervention'. Participants satisfied with their pre-intervention circumstances were less likely to need the resources shared through the intervention, and thus perceived less benefit. Three sub-themes will be discussed below: (a) difficulty managing work-life-caregiving balance; (b) social support systems; and (c) workplace culture and environment.

Difficulty managing work-life-caregiving balance

Most (n=11) participants noted that as CEs, they often struggled to balance their work obligations, their own needs, and the needs of their care recipients. These simultaneous responsibilities were often a source of physical and mental fatigue. Further, a few (n=2) participants stated that they were approaching a state of burnout:

"I just feel that I'm tired... and I don't know if it is because I'm a caregiver, I don't know if it's because of life, I don't know if it's because, you know, I'm not sleeping. You know, people have said 'you're close to burnout' and I have to look after myself… but I think for myself, personally, I need a break." (Claire)

In addition to fatigue, Sam noted that his attempts to balance these simultaneous concerns often placed a significant strain on his relationship with others, and specifically his spouse:

"An environment like this does take a toll on the relationship somewhat because you are dedicating more time to see this third-party …. it totally wears you down without you really realizing it until it really gets bad."

Participants often had to dedicate much of their time and energy to maintaining this precarious balance, often choosing to put either their work or caregiving first and shifting their focus away from personal relationships. In addition to reducing their commitments elsewhere, their limited time and energy also forced participants to turn down additional responsibilities, as seen in the following excerpt:

"I have a certain amount of workload that needs to get done and it's hard to find enough hours in the day for it at the best of times …. I'm saying 'no' to various requests in admin roles, because I realize I'm strapped to the limit here, and I'm not going to take any extras that I otherwise might've." (Dani)

Participants explained how the emotional and physical demands of their responsibilities often manifest as stress, anxiety, and depression. Several (n=10) participants said their experience as CEs has impacted their mental health. The following excerpt highlights one such instance:

"It's been a tremendous amount of work to get to this point, maintain, and manage my position here, maintain and manage my mother, not let either one of them defeat me and put me in the loony bin... It generates a huge amount of stress because it's anxiety driven. You're always anticipating the worst case scenario 'cause you know it's coming." (Ben)

Generally speaking, participants who had more difficulty maintaining their work-life-caregiving balance reported greater benefits from the intervention. Conversely, participants who had less difficulty maintaining their work-life-caregiving balance often reported fewer benefits from the intervention.

Social support systems

Most (n=9) participants had a social support system, consisting of friends, family members, or peers that they could turn to for assistance. Regardless of the type of assistance provided, the presence of a strong social support system in itself provided participants with a sense of security. For instance, Jasmine stated that her social support system had instilled her with greater confidence in her caregiving duties:

"My sisters and I, in a minute, if I said to either of them 'we need something for mom right now', ...there's nothing else which interferes with that at all, and that ability to focus on her needs as opposed to - it's not about who's turn is it or what's fair or what's not fair or any of that kind of stuff, it's about caring for her and giving her the best end of life experience she can have."

Similarly, Kelly highlighted an instance in which the members of her social support network agreed to temporarily cover her caregiving responsibilities. Kelly stated that this assistance not only relieved a significant burden from her work-life-caregiving balance, but also provided her with much-needed respite:

"Other friends have taken on a greater role which has been really nice probably because I was working. That first episode where I was laid off I could be with her pretty much 24/7 but when she had other issues since then, I've been working so other friends have been forced to step in and be involved and that's been great. It's been really nice to kind of just breathe and share that caregiving role."

Another participant, Dani, confided in members of her social support system who also happened to be CEs. Due to their shared experiences, Dani felt that she was able to receive a greater degree of understanding than could be found elsewhere and did not have a need to use some

of the resources listed in the intervention:

"I talk to my friends in my carpool about this a lot and they have some similar issues. Particularly Amberlyn, like her mother's in Kingston but she's doing a lot of support, so I do talk to those people. So no, I don't think I would seek an external support group and try to fit that in on top of everything... I have social support in terms of my network."

This suggests that participants benefited less from the intervention if they were satisfied with their prior circumstances. In this case, Dani felt satisfied with her existing social support network, and thus did not feel the need to access the emotional support opportunities offered by the intervention.

Workplace culture and environment

Most (n=12) participants stated that their workplace culture impacted their ability to maintain their work-life-caregiving balance. Participants referred to 'workplace culture' as the behaviours that were informally encouraged by their employers through workplace policies, actions and attitudes of supervisors. Several (n=5) participants felt their workplaces did not adequately accommodate their needs as CEs. Jasmine explained how she felt discouraged by the lack of compassion from her supervisors:

"My site really is not very interested in my personal issues and being supportive in that way. The staff know that I have an elderly mother, they don't ask about mine or anybody's, and if we had to use one of the benefits, they'd view that as an inconvenience to them, and it would be very unlikely that we get a phone call or 'we're sorry'. And that makes me kind of sad, but that's the way it is now."

Jasmine also felt her supervisors were dismissive of the role strain she experienced as a carer employee. For instance, when Jasmine had to cancel a day of work to take her mother to the hospital, she was disappointed when her employer did not offer any sympathy:

"I had to cancel a day, take a vacation day, to take my mom to the hospital. And I emailed my boss and the person who does the record of hours, and her response to that email was, to the person who keeps a record of hours, 'make sure you change the template'. That's the kind of situation I'm in. My mom was in the hospital really unwell, I was going through a very difficult time, and there wasn't even a 'I'm sorry your mom is sick'. And I'm like, 'yeah, I know what you're worried about'."

All (n=14) participants acknowledged the potential benefits of an accommodating workplace culture. As documented in the literature, noted above, a flexible workplace culture results in benefits for both CEs and employers. For instance, Claire discussed how the compassion she had received from her employer allowed for a trusting employer-employee relationship:

"Yeah I think [my supervisor's] just flexible with everybody... I think people can actually work from home as well, and they can do their work and have those accommodations to people who

are caregivers. And you know, I think that's something that works for both the supervisors and the employees, because you know you have that trust from your employer, and it'll make you produce results, right?"

Marie stressed the distinction between a 'flexible' and a 'supportive' workplace culture. She explained that while a workplace may have mechanisms in place to accommodate the needs of CEs (e.g. temporary leaves of absence), these mechanisms may not be backed by a genuine sense of compassion, and may still result in the estrangement of CEs:

"Yeah I think it's very flexible but I don't think it's very supportive. Which I think like it's a distinct kind of thing, like I don't know if you were to know everything that I'm living or that I need to do and how I juggle everything that they would be really supportive. I think because it's flexible they just kind of not notice and they're just like, "oh yeah, she's working, she's doing what she's supposed to, all good you know."

(ii) Recommendations made by participants to improve the intervention

Participants were asked to share the strengths and weaknesses of the intervention. In response to this prompt, most (n=10) participants suggested modifications to the intervention which they believed would improve its effectiveness. These suggestions were organized based on shared characteristics and presented as the following three sub-themes: (a) individuals who should be involved in the intervention; (b) resources which should be included in the intervention; and (c) ways the intervention could be delivered more effectively.

Individuals who should be involved in the intervention

Several (n=6) participants suggested that the intervention could be improved with the integration of certain perspectives into its design and delivery. For instance, Sam noted the importance of including family carers, or healthcare professionals familiar with care burden, in the design of the intervention. He argued that such individuals could draw upon their own experiences to provide a more nuanced perspective on the resources which should be included:

"I think they need to be a caregiver themselves. Unless you really do it you don't really understand it ….. You do want somebody that is knowledgeable about the processes … it would be better for the health care professional who actually works with this on a day-to-day basis to be the one who is actually doing the intervention."

Some (n=3) participants stated that they would prefer to have these interventions delivered by individuals external to their workplace rather than, for instance, their employers or members of their human resource team. These participants cited confidentiality as their main concern, with some suggesting a loss of confidentiality could render the intervention ineffective:

"Strangers would've been better. You know you and I are having this conversation and it's great,

it's confidential. We don't have a room full of people. If there was a room full of people, I would have the same conversations, but then if I end up in a meeting with the same person that would change the work relationship and not for the better." (Ben)

Marie echoed these concerns, stating that they would be hesitant to share personal concerns if their supervisor was involved in the intervention:

"If I were in a group outside of work but maybe say the same demographics we can still relate. Without a supervisor in the group I would share more personal struggles. But if I was in a working group to improve the situation like I wouldn't be so personal and I would be more focused on maybe like talking more broadly and not necessarily about my own experiences."

Many (n=10) participants described their workplace culture as unaccommodating, which suggests the exclusion of their supervisors from the intervention may be explained by a fear of repercussion. In the absence of confidentiality, CEs may hesitate to speak candidly about the impact of their workplace on their wellbeing, which would weaken any attempts to tailor the intervention to suit their needs.

Resources which should be included in the intervention

Several (n=9) participants stated that the resources listed in the intervention were unable to address their specific needs at the time. When asked, participants identified resources which they would have liked to see included in the intervention. For instance, Dani explained that she would have liked to see more resources dedicated to senior loneliness. Such a resource would not only benefit the care recipient, but also the carer, by providing them with respite:

"If there was an organization that would make home visits just to deal with senior loneliness, that would be really nice... She's very socially isolated, and even though she lives in a senior residence, she doesn't integrate well with people... She's very mobility impaired, which limits her ability to participate. Other things as well, like psychological things …. mental health issues."

Marie stated that they would have liked to see more resources offering some form of community support, providing an environment in which CEs could speak candidly about their experiences. In contrast to resources already provided in the intervention, Marie envisioned that such a resource would be therapeutic in nature:

"Maybe even just group support where you're just sharing your experience, knowing you're not alone without really gaining more than, just you know kind, of having just a community feeling or support feeling."

By integrating the suggestions of participants, regarding resources which they felt were missing from the initial design of the intervention, future iterations of the intervention could be rendered more comprehensive and more relevant to the needs of CEs.

Ways the intervention could be delivered more effectively

Rather than providing recommendations related to the content of the intervention, some (n=5) participants offered suggestions on how the delivery of the intervention could be rendered more effective. For instance, while the intervention had been delivered in a one-on-one setting during the study, Sam suggested that there may be benefits to a group environment:

"It would be nice to have it in a group setting rather than one on one, because I think a lot of this stuff is more, here is a resource right, and at least the way I like to learn is I learn just as much from other people that are in the audience... If you're bringing people like me, we have individual experiences where we learn some stuff from other people, the people who are in the same boat as me, but have a slightly different take on things."

Sam had another recommendation, regarding the individual assigned to assist with curating and using the list of caregiving resources provided in the intervention. He stated that the individual seemed to only have a superficial understanding of the resources, and was unable to answer some of his questions. Sam suggested that the intervention would have been more effective if the individual assigned to assist him had a comprehensive understanding of the resources:

"My personal opinion was just that, I know I asked some follow-up questions like 'okay here's a particular benefit and I had some questions about it' …. I just thought that in terms of intervention I know she was told what to say, I just don't think she had spent the time herself internalizing information and understanding what the pros and cons were."

Kelly suggested that it may be beneficial to provide a centralized, standardized list of caregiving resources, similar to the one provided in the intervention only not tailored to the circumstances of each individual. She suggested that this could be helpful for CEs who may not be aware of relevant policies offered by their workplaces or at a government level:

"If there is information available at the department level then everybody, no matter where they are, can access it... You should be able to phone your department and say 'where should I go for help?' And they should always know how to direct you… People should not have to do an extensive search of [workplace's] website to try to figure out where to go for help. So at least if someone in every department knows where to send someone and employees know who that someone is."

These suggestions are key to improving the intervention going forward.

(iii) Benefits participants received from the intervention

As had been mentioned prior, all (n=14) participants reportedly benefited from the intervention, albeit to different extents. Participants were asked how they benefited from the intervention. The authors noted several patterns in their responses, and these commonalities were used to create

the following three sub-themes: (a) increased mindfulness of their caregiving role; (b) benefits through the contents of the resources; (c) physical and mental health relief.

Increased mindfulness of their caregiving role

Several (n=8) participants stated their involvement in the intervention prompted them to reflect on their carer-employee status and how it has impacted them. One participant, Ben, stated that the intervention provided him with the framework to introspectively assess his role as a careremployee, and the space to explore his thoughts on the matter:

"You didn't solve my problems, but you gave me an opportunity to talk about them and I have always found solutions better when I'm talking than when I'm sitting there brooding …. It's the physical act of speaking and then that immediate review of what I said, you know?"

Emily also believed that the intervention resulting increase in mindfulness regarding her identity as a carer-employee, allowing her to develop the confidence needed to act in the best interests of herself and her care recipient:

"This has given me more confidence to think about being proactive, in terms of talking to employers or supervisors or whatever when trying to navigate the caregiving role and work responsibilities and balancing that out. So I think that having more confidence to be able to say 'yes I am going to work from home at times' and being confident that's not going to be seen as me trying to shirk my responsibility or not engage in the workplace and really it's accepted that it's my way of balancing those responsibilities."

Anne noted that participating in the intervention allowed her to understand the extent of the carer-employee phenomenon. Through the insight provided by the educational portion of the intervention, she learned how many individuals, even within her own community, identified as CEs and thus faced similar challenges and stressors. She stated that knowing this resulted in a change in mindset, allowing her to feel less isolated and encouraging her to get more involved in local carer-employee groups:

"I was amazed that even people that I am know of or acquainted with, they were in the same situation I was without me even knowing it. So it was like, as they say, misery likes company. Yeah, that's the same thing. It was a little bit comforting that there are more people like me and again they rely on each other and learn from each other, with our resources, with helping deal with this or that."

The aforementioned benefits of the intervention may have a longitudinal impact on the participants well beyond the scope of the study. In these cases, the intervention allowed for an initial period of introspection, which in turn resulted in a reportedly positive change in attitude and behaviour.

Benefits through the contents of the resources

An integral component of the intervention was the curated list of relevant caregiving resources

offered at the workplace, as well as through provincial, and federal governments. Several (n=10) participants described the benefits of receiving this list of caregiving resources. For instance, Anne stated that the list had introduced her to relevant resources which she had not previously known about, including a community homecare program, which she later signed up for:

"The one that I had found through the community centre …. It was about the caregiver people coming over to my house and looking after my mum. They were on the schedule, even those two hours a day I was getting twice a week, all of that support helped me get ready for work, helped me get her ready, bathe her, change her, go with her for a walk, and that meant a lot."

Participants already familiar with the resources provided by the intervention were still able to benefit from receiving this list. For instance, although Emily was familiar with most of the caregiving resources shared in the intervention, she still found it useful to cross reference the contents of the list with her own understanding of what was available. She also explained that the intervention had validated her understanding of some of the caregiving resources she was using, which in turn increased her confidence regarding her own decision-making:

"I think it was a helpful reminder of some of the things that are available. In the busyness of life you don't always go seeking out some of the smaller things and yes they can be helpful. It was a good opportunity to bring back to mind things like tax benefits and that sort of thing that we hadn't really gone exploring for but knew were there... It was good to hear that we've already used some of the things listed. It was reassuring to know I was on the right track."

Although Jasmine had similarly been familiar with many of the resources, they also benefited from receiving the curated list. For instance, Jasmine benefited from seeing these familiar resources presented in new contexts, allowing them to gain new insight:

"It was a learning process …. You always learn something new about it by the way it's presented or maybe you've learned that they changed it a little bit."

The latter two excerpts highlighted instances where participants were able to benefit from the intervention without using the caregiving resources. As such, experienced CEs, who were already familiar with the relevant resources, benefited from the intervention alongside less experienced CEs.

Physical and mental health relief

Participants were asked whether they had perceived any physical or mental health benefits as a result of the intervention. A majority (n=8) of participants reported some sort of improvement to their mental health corresponding with their participation in the intervention. Most (n=5) of these participants stated that their participation in the intervention had reduced their overall stress. For instance, Megha described how their stress levels had gone down after using one of the caregiving resources they had discovered the intervention:

"Yes, and that gives me more time to reconnect with my friends and to have more social time and pursue the things that make me happy. So two happy people is better than two stressed out people, right?... I think my stress level has gone down all around."

In addition to decreased stress levels, several (n=3) participants stated that the intervention had provided them with the framework to address some of their previously untapped emotions and accept their identity as a carer-employee. This was illustrated in the following excerpt:

"I see a slight improvement coming from this self reflection and labelling yourself and kind of just like acknowledging and accepting you're a caregiver and that's part of who you are and that's fine, you know. So that is probably how it's affecting me." (Marie)

An additional group (n=2) of participants stated that the intervention reduced their feelings of loneliness and isolation, as illustrated in the following excerpt from Barbara:

"I think having these different places to access for different resources is helpful as well. The more you can access and the bigger your network is, the less stress you'll feel and the more support you'll feel. If people feel like they're getting supported, it's helpful. You need it from your family, you need it from your work, you need it from your community."

While the majority of participants only reported benefits to their mental health, one participant reportedly received benefits to their physical health. Ava stated that their increased mindfulness towards their carer-employee role, prompted by their participation in the intervention, had encouraged them to look after their own physical health:

"I think because I've been talking about it, I'm probably actively working to take better care of myself, to make sure that I'm going to be able to continue to be a caregiver. So I'm probably more involved in thinking about physical activity for myself to keep myself strong. So that's probably an outcome of my role and the things that go along with it… Just in the last two weeks I've been working with a personal trainer to sort of come up with some systems for how I can strengthen myself physically just to make sure that I'm staying healthy."

(iv) Factors limiting the benefits participants received from the intervention

Participants identified factors which they believed to have limited their ability to benefit from the intervention. While some factors could be resolved through changes to the design and delivery of the intervention, several existed outside of the intervention's locus of control. The factors identified by participants were grouped into the following three sub-themes: (a) repercussions for using the resources; (b) irrelevance of the resources; and (c) lack of motivation to use the resources.

Repercussions for using the resources

Several (n=3) participants explained that although they would have benefited from some of the resources listed in the intervention, they determined that the time and energy costs associated with using said resources would be prohibitive. For instance, Emily explained that as their prior responsibilities had left them pressed for time and energy, they couldn't easily alter their schedule to fit new commitments:

"I didn't use a whole lot of the resources, and I think it's about time too and energy. You know,...a lot of people, , they don't do stuff because they don't have the energy. I don't do stuff because I don't have the energy. I don't have the time and energy as is."

Claire identified another factor deterring her from using the resources shared in the intervention, namely the potential for stigma from her peers:

"Sometimes I'm like do I leave [workplace]? Do I ask for a break? What do I do? Do I make a bad name for myself and be like 'oh I'm taking a leave of absence?'. Are people going to look at me as weak and start judging me or start talking about me or saying negative things about me?"

In a similar vein, Sam noted that using caregiving resources, especially those offered by employers, would have been detrimental to his career at his prior workplace. He suggested that the supervisors at his prior workplace would have likely looked down on those who sought to use these resources, making it harder for them to gain promotions or other job advancement opportunities:

"When I worked there, they put in place a work-life balance kind of program, which everybody laughed about because even though they were trying to couch it as they were trying to make things better for their employees. But two or three employees took advantage of it because they all knew each other and they were all relatively young in their mid-20s, but this is a careerlimiting move if you're going to take advantage of it because you're not going to be promoted."

Although Sam described his current workplace as being more accommodating and tolerant in this regard, his experience in his prior workplace raises several noteworthy points. It suggests the need for workplace culture change, given that employees working in similar environments would be incentivized against using the caregiving resources shared through the intervention. It also points to the need for additional research on CFWPs in different workplaces and settings.

Irrelevance of the resources

As had been stated previously, several (n=9) participants stated that the resources listed in the intervention were unable to address their needs at the time. In some cases, as had also been discussed prior, this may be explained by an absence of resources relevant to the participants' needs and circumstances. Dani explained:

"In her current situation, it's mainly me doing all her finances and visiting her as often as

I can because she's very isolated and stuff, so there's not a lot of resources for that."

Sarah, along with several (n=3) other participants, explained that they were ineligible for some of the caregiving resources listed in the intervention. Oftentimes, this ineligibility was due to the health, age, income, or needs of their care recipient falling outside of the parameters set by a resource's mandate:

"There was something for tax things, but because of the amount of money I made, I wasn't eligible, and because of the amount of money my grandmother made, she wasn't eligible. So that was unfortunate."

Recognizing that caregiving is a complex phenomenon which can take on many different forms, future studies could address the circumstances of CEs who are ineligible for formal caregiving resources and assistance. Such research could reveal strategies for catering to their needs while advocating for additional caregiving resources.

Lack of motivation to use the resources

Finally, there were several (n=2) instances in which participants cited a lack of motivation to use the resources in the intervention. Anne identified one factor contributing to this lack of motivation, noting that some CEs may not be comfortable acknowledging that they need help due to a combination of internal and external pressures:

"A lot of people that are dealing with mental stress are not acknowledged …. I think the first step is to acknowledge within yourself 'I need help'. And then lots of people do not do that because they are ashamed ..."

Another participant, Megha, suggested that this lack of motivation could be the product of the personalities of the individuals in question. In such cases, some CEs may be predisposed to taking advantage of the resources offered by the intervention, whereas others may be predisposed to not using said resources:

"I'm always looking for that to improve, to understand, to add… but there's some people who don't have it in their DNA to do that. So it's like, you can do all of that, and in certain cases you have to help people go to it. There are situations where you need to help individuals, but sometimes individuals are just not helpable."

Knowing these limitations to the intervention is critically important in informing its' next iteration going forward.

DISCUSSION

The findings of this study complement much of the existing literature on CFWPs. For instance, the positive experiences of study participants, such as those conveyed through the theme of 'benefits participants received from the intervention', support the notion that CFWPs may be an effective tool in addressing some of the challenges faced by CEs. One such challenge is the vulnerability of CEs to negative physical and psychological health outcomes (Pilapil et al, 2017). With regards to psychological health, prior studies suggest that CEs are susceptible to negative consequences to their psychological health, especially in the form of depression or anxiety, when they experience high levels of perceived strain towards their caregiving (Pilapil et al, 2017). In this case, perceived strain is a subjective, self-reported measure of the extent CEs view their caregiving as being burdensome (Driscoll et al, 2010). The findings regarding participant 'physical and mental health relief', highlight self-reported improvements to their psychological wellbeing after participating in the intervention. It could be argued instead that while the intervention did not directly improve the mental health of participants, it provided them with several avenues through which they could alleviate their perceived strain, thereby improving their mental health by proxy.

Our findings suggest that CFWPs may also be a viable tool for addressing another challenge faced by CEs: an insufficient recognition of the difficulties they face (Lilly, 2011). Prior studies have noted that CEs often feel that their caregiving contributions are overlooked by their peers, friends, and employers, and this lack of recognition causes them to feel discouraged and isolated in their dual-role (Lilly, 2011; Pilapil et al, 2017). Lilly (2011) suggests that one way of alleviating this concern is through the implementation of information and referral programs, CFWPs designed to help CEs access caregiving resources. She argues that such programs may convey the message that employers recognize and care about the challenges and contributions of their CEs. This argument is supported by the experiences of CEs in this study. Several participants stated that their involvement in the intervention had reduced their feelings of loneliness and isolation. Upon receiving a list of caregiving resources, many stated their appreciation of the knowledge that there are organizations which not only recognize the difficulties associated with their dual-roles but are also willing to advocate for and support them.

In addition to benefiting CEs, the study findings suggest that CFWPs may also have an indirect, positive impact on the care recipients and employers of CEs. For instance, carer burnout and compassion fatigue are both well-documented phenomena for CEs, culminating in physical and emotional exhaustion (Lynch & Lobo, 2012). Further, previous studies also recognize that these negative impacts may spillover into their relationship with their care recipients (Lynch & Lobo, 2012; Blair et al, 2017). As the caregiving relationship is rooted in empathy, burnout and fatigue may prevent CEs from fulfilling their care responsibilities, resulting in a lower quality of care, and thus a lower quality of life for care recipients (Blair et al, 2017). The study findings suggest CFWPs may have an ameliorating effect, as participants reported that their participation in the intervention allowed them to gain respite from their caregiving, thereby reducing their vulnerability to burnout and fatigue. There were also instances where participants noted that their participation resulted in a greater level of satisfaction, from both

themselves and their care recipient, in the quality of caregiving provided.

The findings also corroborate the extensive body of literature on how employers may benefit from implementing CFWPs in their workplace. An economic evaluation by Mofidi et al. (2019) suggests that there is not only a benefit from implementing CFWPs, but that there also consequences from not doing so. It was estimated that, in the absence of an intervention, the burden of caregiving by CEs at a given post-secondary institution cost employers 8,674 Canadian dollars per case (Mofidi et al, 2019), due to absenteeism, presenteeism, turnover, and inhibited work performance resulting from caregiving. Absenteeism and presenteeism were addressed by several participants of this study, many of which pointed out the difficulty in maintaining a work-life-caregiving balance, and how it often resulted in a loss of productive engagement in all areas, including employment. Several participants noted that prior to the intervention, their caregiving had forced them to disengage from their employment by: taking leaves of absence to focus on caregiving, taking half-days to attend appointments, and altering work hours to accommodate their care recipient. In contrast, many participants felt that their involvement in the intervention allowed them to disengage from their caregiving and, instead, focus their time and energy elsewhere, such as their employment. This may be indicative of the potential of CFWPs in addressing carer-employee absenteeism and presenteeism. The study findings also suggest that although many CEs value support and flexibility from their employers, few would describe their workplaces as accommodating. Lack of accommodation, if unaddressed through workplace culture change, may contribute to the higher rates of turnover and early retirement observed among CEs.

There are several limitations of the study. Although small sample sizes are common in qualitative research, only 1/3 of the 43 intervention participants took part in the evaluative research. The potential for self-selection bias should also be taken into account, as individuals with stronger attitudes towards the intervention may have been more compelled to participate, potentially biasing the results.

CONCLUSION

In addition to revealing positive impacts on CEs, such as: improvements to mental and physical wellbeing, greater confidence in caregiving abilities, and respite from caregiving duties, this study suggests several ways in which CFWPs may offer benefits to employers. These findings not only serve to strengthen the aforementioned place-based educational intervention, but also align with the larger literature.

The findings of this study may also offer direction regarding policymaking and future research. For instance, the study findings suggest that CFWPs can be made more effective by tailoring their design and delivery to reflect the circumstances of CEs at a given workplace. In a similar vein, the study findings highlight that there is no one-size-fits-all CFWP, and that more research is needed to better understand how the impacts of CFWPs may vary for CEs in different workplaces and contexts. Without a nuanced and comprehensive understanding of the circumstances of CEs, the effectiveness of a CFWP may be impaired as a result of being inaccessible, incompatible with workplace culture, or irrelevant to CEs needs.

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