



Working Family Caregivers' Perception of Usefulness of an Online Employee Assistance Support Tool: A Pilot Study

Debra Gibbs, Julia Bilotta, Chanté Bowens, Monica Dougherty, Emma Murphy, Nicki Richardson, Molly Schneider-Adams

Belmont University, Nashville, USA

Email: debra.gibbs@belmont.edu

How to cite this paper: Gibbs, D., Bilotta, J., Bowens, C., Dougherty, M., Murphy, E., Richardson, N. and Schneider-Adams, M. (2021) Working Family Caregivers' Perception of Usefulness of an Online Employee Assistance Support Tool: A Pilot Study. *Open Access Library Journal*, 8: e7663. <https://doi.org/10.4236/oalib.1107663>

Received: June 19, 2021

Accepted: July 17, 2021

Published: July 20, 2021

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Abstract

Objectives: The population of older adults is growing rapidly, creating high demand for the involvement of working family caregivers. This concurrent mixed-methods study sought to obtain information from working family caregivers regarding their perceptions of the usefulness of an online employee assistance support tool. **Methods:** Working family caregivers (n = 15) participated in a semi-structured focus group completing a demographic survey and the Modified Caregiver Strain Index (MCSI). **Results:** Total MCSI score had a statistically significant positive relationship with hours of care provision per week and presented an inverse association with caregiver age. Caregiver age had a statistically significant inverse relationship with the perception of caregiving as confining. Qualitative data identified needs for family caregivers support in three major themes: knowledge, understanding, and connection. **Discussion:** This study highlights a myriad of caregiver burden experiences and the necessity of various supports for each caregiver's unique situation beyond the traditional workplace policies.

Subject Areas

Geriatrics, Human Resource Management, Social Issues and Public Policy, Sociology

Keywords

Working Family Caregivers, Caregiver Burden, Older Adults, Caregiver Resources, Aging

1. Working Family Caregivers' Perception of Needs and Burden

Family caregivers are individuals who provide unpaid care for a recipient from either their family of origin, such as a parent or grandparent, or their family of choice, such as a friend, neighbor, or life partner (National Alliance for Caregiving & Emblem Health, 2010) [1]. In 2015, an estimated 34.2 million American adults served as family caregivers to older adults (AARP & National Alliance for Caregiving, 2015) [2]. With an estimated sixty percent of family caregivers engaging in full-time employment (AARP & National Alliance for Caregiving, 2015 [2]; Pew Research, 2018 [3]), the ability to balance the demands of family caregiving with the demands of paid employment, or “work,” constitutes one of the challenges faced by those providing unpaid care to an ever-increasing older adult population. Furthermore, an individual’s health, well-being, and quality of life can be affected by an overall life balance or imbalance (Matuska & Barrett, 2014) [4].

Several studies associate family caregiving with increased work interference such as increased absenteeism, work productivity loss, a reduction in work hours, and/or labor market withdrawal, as well as difficulty maintaining lifestyle balance between work and caregiving occupations (Burton *et al.*, 2004 [5]; Calvano, 2013 [6]; Gaugler *et al.*, 2018 [7]; Lilly *et al.*, 2007 [8]; Liu *et al.*, 2017 [9]; Longacre *et al.*, 2017 [10]; Paulson *et al.*, 2017 [11]; Wolff *et al.*, 2016 [12]). For many individuals, the occupation of work is an integral component of lifestyle balance (Fossey, 2019 [13]; Hunt, 2015 [14]).

Engagement in employment has positive effects on health and well-being while also protecting against negative effects of caregiving (Cole *et al.*, 2009 [15]; Hunt, 2015 [14]; Stine-Morrow *et al.*, 2008 [16]).

Caregiving has been identified as having some positive aspects such as increased “sense of self-pride and fulfillment, perceptions of being needed, and opportunities to learn new skills and enhance relationships” (Grossman & Gruenewald, 2017, p 435) [17]. However, the provision of daily caregiving responsibilities can have negative consequences on one’s psychological, physical, and social health (Corvin *et al.*, 2017 [18]; Gray *et al.*, 2007 [19]; Grossman & Gruenewald, 2017 [17]; Pizzi, 2010 [20]; Schulz & Eden, 2016 [21]; Schulz & Tompkins, 2010 [22]). Evidence supports a positive correlation between the hours of care provided and caregiver stress, as family caregivers who provide 36 or more hours of care per week are more likely to experience symptoms of anxiety or depression than non-caregivers (Gray *et al.*, 2007) [19]. Additionally, caregivers who provide care for more hours per week and over a longer duration of time experience greater stress (Halpern *et al.*, 2017) [23]. Elevated levels of emotional stress positively correlate with intensity of caregiving responsibilities, such as co-residence and increased physical care, specifically provision of 3 or more personal care tasks like bathing, toileting, or feeding (Calvano, 2013 [6]; Halpern *et al.*, 2017 [23]; Longacre *et al.*, 2017 [10]; Liu *et al.*, 2017 [9]).

The degree to which caregiving responsibilities become overwhelming and cause a high degree of emotional stress depends on the individualized experience of the caregiver. Caregiver burden, or a caregiver's subjective response to the physical and/or emotional challenges of the caregiver role (Thornton & Travis, 2003) [24], is not a uniform experience and can be influenced by secondary stressors unique to each caregiver's personal context, such as paid employment, family conflict, and/or financial resources (Zarit & Zarit, 2015) [25]. Gaugler *et al.* (2018) [7] found that family caregivers who reported a greater conflict between caregiving and work responsibilities had worse scores for mental and physical health and that caregiver burden was the strongest indicator of caregiving-work conflict. Thus, caregiver burden influences caregiving-work conflict, which in turn impacts caregivers' emotional stress and mental well-being (Gaugler *et al.*, 2018) [7]. Additional research supports the association between increased caregiving responsibility, work interference, and even early labor force withdrawal (Calvano, 2013 [6]; Longacre *et al.*, 2017 [10]).

To minimize the impact of caregiving-related stressors, family caregivers report using a variety of coping strategies (Barrett, 2013) [26]. Deliberate coping strategies, such as seeking support from others to help with caregiving demands, have been associated with increased life satisfaction and decreased anxiety levels (Cooper *et al.*, 2008 [27]; Sun *et al.*, 2010 [28]). Avoidant coping strategies, such as eating, smoking, or avoiding people, situations, or tough decisions, have been associated with decreased life satisfaction and increased caregiver burden (Sun *et al.*, 2010) [28]. Additionally, family caregivers may use work participation to cope with caregiving-related stressors (Calvano, 2013 [6]; Van Dongen *et al.*, 2014 [29]). Work can mitigate some of the burden felt by family caregivers by providing social interaction, personal achievement, and personal space, or "escape," from the caregiver role (Van Dongen *et al.*, 2014) [29].

Certain governmental and workplace policies also help caregivers balance the conflicting demands of caregiving and employment. Caregivers may utilize federal programs such as the Family and Medical Leave Act (FMLA) and the National Family Caregiver Support Program (NFCSP). The FMLA is a federal law that provides employees who are over the age of sixty or providing care to someone sixty or older with twelve weeks of unpaid, job-protected leave per year (U.S. Department of Labor, 2019) [30]. While FMLA is a practical option for an individual who needs to provide short-term care to a family member, it is not comprehensive for all US workers, fails to provide support for long-term care needs, and is time limited (Yang & Gimm, 2013) [31]. Due to the fact that the leave covered under the FMLA is unpaid and does not cover all workers, it will not completely resolve the struggle to balance work and caregiving for many family caregivers (Chen, 2016) [32]. Another federal program, the National Family Caregiver Support Program (NFCSP), provides several services to caregivers, including respite, supplemental care services, and individual counseling (Administration for Community Living, 2019) [33]. Unfortunately, the NFCSP

falls short as the number of potential beneficiaries exceeds the program's capacity (Schulz & Eden, 2016) [21].

Workplace policies, sometimes known as caregiver friendly workplace policies (CFWPs), aid caregivers in combating the health and financial consequences related to family caregiving. CFWPs may include flexible work schedules, job sharing, the option to work from home, access to compressed work weeks, and permitting allocated days off (Jang *et al.*, 2010) [34]. Two major attributes that contribute to high satisfaction with CFWPs are employment policies that allow flexibility in work scheduling and assignments as well as supportive senior management (Calvano, 2013 [6]; Dembe & Partridge, 2011 [35]; Gaugler *et al.*, 2018 [7]). Control over one's work schedule and the availability of work-life balance programs are linked to greater job satisfaction and mental well-being among all workers (Jang *et al.*, 2010) [34]. Research supports the idea that employer support of caregiving demands through CFWPs improves employee retention as well as decreases turnover (Ireson *et al.*, 2018) [36].

Recognizing the multidimensional nature of the caregiver role and the challenges that working family caregivers face in maintaining lifestyle balance, this mixed-methods study aimed to assess perceptions of caregiver burden among working family caregivers and perceptions of an online employee assistance support tool developed by a local non-profit agency for aging. The support tool has been designed to be flexible and individualized to the context and needs of the end user. It provides customized resources and factors to consider about aging needs and transitions, including information on housing and placement options, legal and financial considerations, support, and educational resources. All resources and decision considerations are based on answers provided by individual users. Additionally, the support tool offers a consult from a gerontology social work professional to assist in understanding the resources provided and considerations specific to the individual.

The primary research objective was to determine how working caregivers perceive the usefulness of a preliminary model of an online support tool. A secondary research aim was to identify the characteristics of the working caregivers of two local businesses and the level of perceived caregiver burden within the participants. Researchers hypothesized that working family caregivers would provide a variety of responses to the support tool describing their unique roles, caregiving situations, and perceived burden level, and that the support tool would be perceived as a helpful resource.

2. Methods

2.1. Procedure

A mixed-methods design was used. Qualitative data examined the lived experience and opinions of working family caregivers, while quantitative data surveyed the caregivers' perceived level of strain as well as the relationship between perceived caregiver strain and form(s) of support desired. Prior to commencing

the study, researchers obtained approval from a university Institutional Review Board [Protocol 791].

Two focus groups were arranged to gather information from working family caregivers in an effort to improve an online employee assistance support tool developed by a local non-profit agency for aging. The agency partnered with two local employer organizations in Middle Tennessee to conduct focus groups of working family caregivers. Participants were provided with access to the online support tool for review and were provided with an individualized report of informational resources based on their responses. Two focus groups, pre-arranged by the agency, were conducted over a span of three weeks and took place on-site at each local organization for one hour each. Prior to the commencement of each focus group, all participants signed an informed consent form to confirm their willingness to participate in a focus group and complete a survey. Each focus group was facilitated by a licensed master social worker with the researchers present to collect data.

At the conclusion of each focus group, participants were asked to complete a short survey consisting of six demographic questions and the Modified Caregiver Strain Index (MCSI). Demographic questions were based on significant caregiving factors as indicated within the literature such as age of the caregiver, age of the care recipient, relationship of the caregiver to the care recipient, residence of care recipient, hours of care provided each week, and duration of caregiving responsibilities as measured in months or years. Participants attending the second focus group were also asked to complete a brief checklist that assessed the perceived usefulness of the specific caregiving resources provided through the online employee assistance support tool.

2.2. Sample

Sample selection was based on convenience sampling of working family caregivers from two local companies identified by the local non-profit agency for aging. Recruitment of study participants was done by the employer. Inclusion criteria for caregiver participants was being 18 years old or over, employed, providing care for a family member or friend age 50 years old or over, and the ability to speak and understand English, as no translation services were available for this study. A total of 15 participants were included in the study.

2.3. Measures/Data Collection

2.3.1. Focus Group

Qualitative data gathered for the study came from focus group participant responses. A trained group facilitator led two employee focus groups (one for each local company) using a semi-structured format, posing a series of questions related to the online support tool to guide the conversation among working family caregivers. During the focus groups the aim was to explore caregiver perception of the usefulness of the online support tool and resources provided.

2.3.2. Modified Caregiver Strain Index (MCSI)

The MCSI was given to the participants to provide a quantitative measure of perceived caregiver strain experienced by the working family caregivers. The 13-item MCSI contains statements such as *caregiving is confining*, *caregiving is a financial strain*, or *there have been work adjustments* (Thornton & Travis, 2003) [24]. Items screen for strain across five major domains: financial, physical, psychological, social, and personal (Onega, 2008) [37]. Caregivers rank their responses to statements on an ordinal scale ranging from 0 to 2, where 2 indicates agreement with a statement *on a regular basis*, 1 indicates agreement with a statement *sometimes*, and 0 indicates disagreement with a statement. A total score is then calculated by adding all ranked responses. Descriptive categories are not provided to distinguish the level of caregiver strain, requiring a clinician's professional judgment to determine the level of caregiver strain according to total score and to identify "families who may benefit from more in-depth assessment and follow-up" (Onega, 2008, p. 65) [37]. Thornton and Travis (2003) [24] identified the internal reliability for the MCSI as 0.90.

2.4. Data Analysis

2.4.1. Quantitative Analysis

Total scores were calculated for each participant's MCSI questionnaire. All demographic data and MCSI content were analyzed using descriptive statistics. Data analysis was conducted using IBM SPSS Statistics (version 25) software and summarized using frequency distributions for nominal and ordinal categorical variables. Median and interquartile range were used to summarize the continuous data due to small sample size. The strength and direction of the associations between continuous and ordinal caregiving variables with the perceived burden of the caregiving (MCSI total score and three components: confining, family adjustments, and work adjustments) were assessed using Spearman's rho coefficients. The associations of where the person being cared for lived (nominal) with those perceived burden variables were assessed using the Kruskal-Wallis test (MCSI total score) and Pearson Chi-Square (MCSI components). An alpha of 0.05 ($p < 0.05$) was used for determining statistical significance.

2.4.2. Qualitative Analysis

All focus group data were analyzed via thematic analysis allowing the investigators to identify patterns of meaning from the complex and detailed perspectives of focus group participants in a rigorous and trustworthy way. Researchers followed the process of thematic analysis as outlined by Nowell *et al.* (2017) [38]. Trustworthiness of data analysis was ensured by following the criteria of credibility, transferability, dependability, and confirmability as outlined by Lincoln and Guba (1985) [39]. Dependability of data analysis was ensured via an audit trail of records of notes, audio recordings, and transcripts. Techniques utilized to ensure credibility included researcher triangulation. Participant responses

were transcribed by two researchers. A second group of two researchers read the transcripts identifying and coming to a consensus of themes and definitions. The themes were then reviewed by a third group of two researchers for refinement. Finally, all researchers reviewed the themes for final consensus and clarification on the themes and definitions.

3. Results

3.1. Quantitative Data

3.1.1. Sample Characteristics

Among the 15 participants in this study, the median age was 50 years. A majority cared for someone between 65 and 84 years of age who was a parent or other family member living in their own home. While the number of hours per week spent providing care varied widely, a majority of participants provided care for 20 hours per week or less and for a length of 2 - 4 years. All sample characteristics are summarized in **Table 1**.

Table 1. Summaries of the sample characteristics.

Characteristic	n	Median (IQR)
Age	15	50 (40, 59)
Age of person cared for (years)	14	n (%)
50 - 64		1 (7)
65 - 74		6 (43)
75 - 84		5 (36)
≥ 85		2 (14)
Relationship	15	
Spouse		1 (7)
Parent/In-Law		12 (80)
Other family		2 (13)
Where does person live	15	
With caregiver		3 (20)
Own home		10 (67)
Other		2 (13)
Hours care (per week)	15	
<1		1 (7)
1 - 8		8 (53)
9 - 20		4 (27)
21 - 40		1 (7)
>40		1 (7)
Length care	14	
6 months - 1 year		3 (21)
2 - 4 years		5 (36)
5 - 9 years		3 (21)
≥ 10 years		3 (21)

3.1.2. MCSI Findings

The total MCSI scores for the sample were highly variable ranging from 0 to 20 with a median score of 10. Generally, older caregivers scored lower on the MCSI, reporting lower levels of caregiver strain. Additionally, quantitative analysis revealed a statistically significant inverse association between caregiver age and agreement with the MCSI statement, *caregiving is confining* ($r_s = -0.56$, $p = 0.031$) (Table 2). No statistically significant associations between the age of the person being cared for the length of time spent providing care were observed ($p > 0.05$). However, the more hours per week spent providing care, the higher the participant's total MCSI score ($r_s = 0.87$, $p < 0.001$). The MCSI statement, *there have been work adjustments*, was significantly associated with providing more hours of care per week and reporting higher levels of caregiver strain ($r_s = 0.75$, $p = 0.001$). No statistically significant associations were found between the caregiver's perception of strain and where their care recipient resided. Internal reliability of the MCSI in this study was 0.88.

3.2. Qualitative Data

Overall, focus group participants perceived the employee assistance support tool as a useful resource for supporting their roles as family caregivers. Considering participant responses in aggregate, researchers defined this overarching idea of support as “emotional or practical assistance in performing a life role” and further categorized it into three major themes: knowledge, understanding, and connection.

Theme 1: Knowledge

The first theme, knowledge, was defined as “the state of knowing about or being familiar with a particular subject” (Knowledge, n.d.) [40]. Two subthemes emerged, the first being *knowledge about eldercare terminology*. Focus group participants wanted frequently-used eldercare terminology and acronyms, like IADLs and ADLs, defined. One participant wanted more information about the costs, roles, and responsibilities of a geriatric care manager. The second subtheme,

Table 2. Associations of caregiver characteristics with MCSI scores and components (N = 15).

	Total MCSI Score	Confining	Family Adjustments	Work Adjustments
Age	-0.41 (0.128)	-0.56 (0.031)	-0.37 (0.178)	-0.34 (0.217)
Age Person Cared For	-0.01 (0.971)	-0.06 (0.838)	<0.01 (0.990)	-0.07 (0.808)
Hours Care per Week	0.87 (<0.001)	0.62 (0.015)	0.60 (0.017)	0.75 (0.001)
Length of Time Giving Care*	0.34 (0.222)	0.37 (0.187)	0.32 (0.265)	0.35 (0.227)

Note. Values in the cells are r_s (p-value); *n = 14 (one participant did not answer this question).

knowledge about care needs, referenced the participants' interest in learning about the breadth of care needs. Participants expressed an interest in various living options for older adult loved ones, checklists of important information to consider, and financial information to help plan for care needs.

Theme 2: Understanding

The meaning of the theme of understanding, as defined by the researchers, is “awareness or insight for the application of knowledge to an individual circumstance”, with three subthemes emerging. The first, *understanding choices to support decision-making*, refers to the participants' interest in an assortment of options that empower them to make an informed decision. Participants noted that the online tool “opens up a bunch of solutions” and “makes suggestions, but you felt that you still have the power to make a decision”. The online tool also helped one participant feel reassured about decisions she had already made, stating, “...it lets you know that there are other options out there. You don't have to look at one thing and think, oh I made this wrong decision”. Participants' vocalized the importance of *recognizing individualized circumstances* as the online tool presented information directed toward their specific caregiving situation. In the third subtheme, *insight into having hard conversations*, participants expressed interest in information about how to have tough conversations with loved ones on topics related to care needs, such as driving and determining when home is no longer the best care option. One participant noted, “It'd be nice to have links [for] difficult conversations. How to start these conversations, either with other members of the family or the person [I'm caring for]”.

Theme 3: Connection

The researchers defined the third theme, connection, as “establishing a link between two or more people, ideas, or services”. The first subtheme that emerged was to *create new connections for personal support or assistance*, wherein participants requested online support or chat groups with fellow caregivers and helpful contact numbers for local organizations like area agencies on aging. In the checklist given to the second focus group, it is relevant to note that all participants displayed interest in the item, *finding services to help your loved one or you as a caregiver*, including that a phone consultation with a professional would be beneficial. The next subtheme identified was to *reinforce existing connections*. Participants were interested in sharing information generated by the online tool with the care recipient or other family members who assist with caregiving responsibilities. Participants noted that this information could help facilitate caregiving conversations with all stakeholders. For example, one participant noted that the tool would be useful to “sit down with [her] loved one and easily toggle through it and make it a little less scary as [they] start the planning process”. Lastly, many participants expressed interest in *connection to outside resources* for caregiving, such as a national database of eldercare resources, a directory of firms that specialize in aspects of eldercare law, applicable documents for estate planning or power of attorney, and other relevant services.

4. Discussion

The objective of this mixed-methods study was to explore the perceptions of working caregivers on the usefulness of an online employee assistance support tool. Overall, the results emphasize the need to consider factors related to each family caregiver's unique role and caregiving situation when providing supportive services. A secondary objective was to quantitatively examine factors related to caregiver burden experienced by working family caregivers as a pilot assessment of factors that may be considered in further tool development.

The majority of participants in the present study were similar to the demographic profile of the "typical" caregiver in that they were female, an average age of 50 years old, and employed full time (National Alliance for Caregiving & AARP Public Policy Institute, 2015) [41]. An important distinction between the working family caregivers in this study was that the majority provided between 1 - 8 hours of care as compared to the "typical" caregiver who provides 20 or more hours of care per week (National Alliance for Caregiving & AARP Public Policy Institute, 2015 [41]; Schulz & Tompkins, 2010 [22]). Consistent with the literature, this study found that providing more hours of care per week was associated with increased caregiver burden (Gray *et al.*, 2007 [19]; Halpern *et al.*, 2017 [23]). Additionally, having to make work adjustments to meet caregiving needs significantly contributed to caregiver strain (Longacre *et al.*, 2017 [10]; Gaugler *et al.*, 2018 [7]).

The primary quantitative finding of this study was an inverse association between caregiver age, strain score, and the MCSI variable, *caregiving is confining*. Younger caregivers noted that caregiving was confining and reported higher levels of burden, whereas older caregivers were less likely to report this. Researchers hypothesize that employed middle-aged adults 45 - 65 years old may find themselves striving to achieve accomplishments that will outlast them (Cronin, 2016) [42]. Often these individuals have more demanding responsibilities, including those related to work and parenting, that may contribute to greater perceived burden. The addition of caregiving for an older adult can further increase perceived burden, as it may conflict with their participation in work and other life activities. Caregiving-work conflict can negatively impact physical and mental health resulting in greater caregiver burden (Gaugler *et al.*, 2018) [7], whereas life balance promotes health and well-being (Cole *et al.*, 2009 [15]; Hunt, 2015 [14]; Stine-Morrow *et al.*, 2008 [16]).

This study was novel in that it considered the opinions of working family caregivers by gathering qualitative information about their perception of the usefulness of a range of support options offered in an online employee assistance support tool. Within the literature, several studies examine the effects of caregiving on workplace factors, but few studies gather qualitative information about the types of support working family caregivers perceive as beneficial. In general, caregivers report needing more information to guide them in managing the caregiving process (AARP & National Alliance for Caregiving, 2015 [2]; LaValley,

et al., 2019 [43]). In this study, working family caregivers requested support as categorized by the major themes of knowledge, understanding, and connection. Participants expressed a need for both factual information, such as financial and legal resources, and personal support to aid in decision making, provide insight into having difficult conversations, and create personal connections through support groups or phone consultations. Researchers have identified similar themes of support from spousal and adult children caregivers who evaluated the beneficial aspects of a community-based peer support program for caregivers (Zhou *et al.*, 2020) [44].

The majority of participants in this study were caring for a parent and, as such, this relationship may have impacted the types of information and forms of support identified as beneficial. This notion is reinforced by findings in multiple studies that conclude the role of the caregiver can influence the types of aid sought (Grigorovich *et al.*, 2016 [45]; Sundar *et al.*, 2014 [46]; Wilcox, *et al.*, 2001 [47]). In order to be truly supportive, assistance needs to match the individualized needs of the caregiver (Milliken *et al.*, 2019) [48]. Furthermore, the ability to choose specific “services and supports empowers caregivers to make their own decisions and may reduce feelings of burden” (Sundar *et al.*, 2014, p. 762) [46].

This study had several limitations. The population was a convenience sample, as participants volunteered through a local non-profit agency for aging. The population sample also lacked variability in demographics, as most of the participants were women from the same geographic area and the participants lacked diversity in race and socioeconomic status. Many components of the study also lacked variability in response, specifically related to the amount and duration of time spent caregiving. Variables such as the complexity of the impairment of the care recipient were not examined. Finally, the study has limited generalizability due to its small sample size (n=15) and having only examined caregivers who were employed full time.

5. Implications

Caregivers express a need for factual information and emotional support to aid them in their caregiving role that is beyond current workplace policies such as FMLA. Online tools, such as the online employee assistance support tool piloted in this study, can provide the factual, evidence based, and emotional support for which caregivers have expressed a desire. The online format provides greater accessibility by allowing sharing with multiple family members in different geographic areas to assist in the decision making process for needed supports. Employers can offer more individualized resources for their working caregiver employees to mitigate the negative impact the stress and burden of caregiving could have on the work environment. Future research should explore if the knowledge and supports provided by an online support tool for working caregivers can reduce the perceived caregiver burden, enhance the working caregiver’s quality of life and make positive contributions to the workplace.

Conflicts of Interest

The authors declare no conflicts of interest.

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