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Multi-contextual Factors that Influence Work-Life Balance of Family Caregivers of Adults with Parkinson's Disease

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Abstract

Objective: The purpose of study was to explore family caregiver perspectives on work-life balance while caring for adults with Parkinson's Disease.

Methods: The study was performed using a convergent mixed methods design and a revised adaptation of the Work-Life Conflict model. Caregivers completed surveys followed by semi-structured interviews (N=40).

Results: Work-life balance is bidirectionally influenced by time, stress, and behavior across the working and caregiving role. Caregiver burden was offset by higher decision latitude at work. Supervisor support and coworker support was positively associated with work-life balance. Barriers included: physical, emotional, and financial stress and speech and cognitive changes of the care recipient.

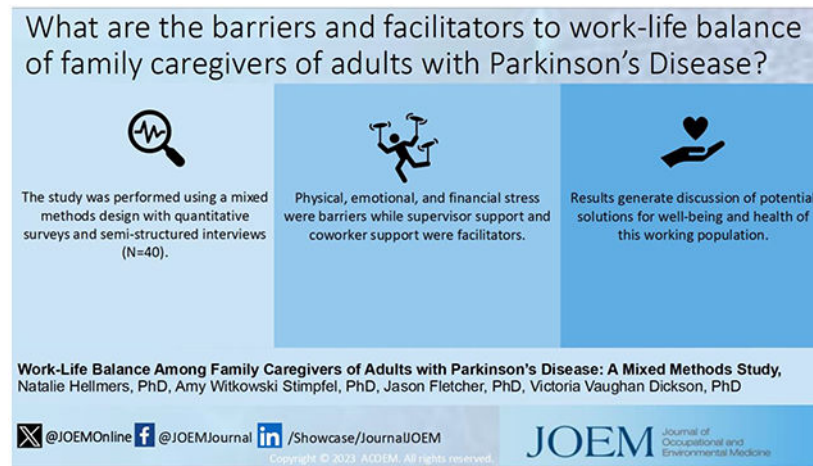
Conclusion: The results of this study identify the influence of work-life imbalance on caregiver burden and stress; and generate discussion of potential solutions that optimize well-being and health of this working population.

Graphical Abstract

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Keywords

Work-life-balance; caregiver; stress; mixed methods

Introduction

Throughout the United States, the identification of family caregivers and to what extent they assist in health care activities vary.¹ Who identifies themselves as a caregiver may not always be clear. The National Caregiver Alliance defines an informal caregiver as any relative who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.² By contrast, a formal caregiver is a provider associated with a formal service system, training, and who is usually paid. Previous studies have found that family members are the main providers of informal care for those with Parkinson's Disease (PD).³ Approximately 88% of men and 79% of women with PD identify a caregiver for help with managing their medical condition.⁴

Being a caregiver of an adult with PD is a unique role. Caregivers tend to play a major role in supporting management of this condition and as found in current literature, it is distinctively challenging for them because there is limited information on how and when this disease can progress.⁵ Most frequent activities reported include maintaining personal hygiene, managing medication, assisting with mobility, transportation to appointments, and completing other daily routines.⁶ Caregivers of adults with Parkinson's often accompany people to doctor visits and other appointments and have identified that a barrier to care is easy access to neurology specialists and limited information about future life planning.⁷ All these tasks requires both physical and mental strength, juggling activities that may fluctuate depending on the severity of the condition. These activities also require time.

As early as the 19th century, the phrase, "work-life balance" was present in the literature.⁸ Over the years, there has been a rise and fall in documented working hours. There is a need to better comprehend how technology is extending work hours outside of a primary job and how this effects work-life balance.⁹ In certain work sectors, especially healthcare

since the recent pandemic, there are workers who have also experienced a sense of reduced job stability, increased workload and increased situations at work that are potentially hazardous.¹⁰ The National Occupational Research Agenda (NORA), the legal enforcement agency for occupational safety, identified occupational stress as a research priority including examining the growing work and life balance challenges.¹¹ Additionally, working caregivers can experience stress, strain, worsening health from work but it is unclear to what extent both contribute to the overall level of work-life imbalance and stress. Early literature on caregivers indicates that high levels of stress from caregiving has a negative effect on family functioning.¹² There is also a cost burden due to loss of work productivity for caregivers.¹³ However, there are limited details on their exact employment or working role. For a family caregiver taking care of someone with PD, there is documented literature on the presence of caregiver stress and the need for better understanding the caregiver role¹⁴ and more information is needed on understanding the influence of the role of work and family demands have on each other.

The purpose of this convergent mixed methods study design is to explore family caregiver perspectives on work-life balance while caring for adults with Parkinson's Disease. The study had three aims. The first aim was quantitative: to describe work-life balance and the associations of caregiver demographic psychosocial, work-related and family-related factors. The second aim was qualitative: to explore the caregiver role and perceptions of work-life balance among family caregivers of adults through semi-structured qualitative interviews. The third aim was the data integration aim to identify barriers and facilitators of work-life balance and the relationship with caregiver burden and quality of life.

An adapted version of the Work-Life Conflict Model by Greenhaus and Beutell was used to guide this study.¹⁵ The Work-Life Conflict model divides roles into two interdependent domains: work and family. Individuals have different roles and responsibilities in each domain with time, stress, and behavior bidirectionally overlapping in each role (see Figure 1). In the original 1985 publication, the three major forms of work-family conflict include time-based conflict, strain-based conflict, and behavior-based conflict. For the purposes of this study, strain is identified as stress. The two are similar and have overlapping descriptions. For instance, Greenhaus and Beutell identified that work stressors can produce strain symptoms including tension, fatigue, irritability along with mood changes such as anxiety, apathy or depression. Stress is well documented in literature especially with regards to caregiver stress.^{16, 17, 18} In this study, the model was further adapted to show how the pressure between the roles of time, stress, and behavior in the work and family domain are conceptualized to effect health promotion and wellbeing.

Methods

A convergent (QUAN+QUAL) mixed methods design was used to address the aims in a sample of 40 family caregivers of adults with PD.¹⁹ Valid and reliable instruments were used to collect quantitative data about balancing work and home activities, job characteristics, levels of stress, wellbeing, caregiver burden and quality of life. These same 40 individuals participated in one-on-one audio-recorded interviews about work-life balance including details about their job characteristics such as responsibilities at work and work schedule,

social support, and their caregiver role. Concordance of the qualitative accounts of work-life balance with the scores on the scales; and the qualitative narratives of job-related characteristics were assessed for concordance with the Job Content Questionnaire (JCQ) results. With this convergent mixed methods design, the results from the quantitative aim are enhanced through the findings from the qualitative data to elucidate caregivers' perceptions of work-life balance. The study was approved by New York University Institutional Review Board.

Sample and Study Settings

A purposive sample of 40 adults were recruited and enrolled using a maximum variation sampling strategy to ensure cases have heterogeneity on specific attributes that effect the variables of interest in the study (i.e., caregiver role).²⁰ In this study, the attributes for sampling were job status (employed, not employed), gender, race/ethnicity and familial relationship (e.g. spouses, children, other). Inclusion criteria were: 1) the participant self-identified as a primary, unpaid caregiver of an adult diagnosed with PD; 2) aged 18-75 years old; 3) current paid employee working full- or part-time or have been employed within the last five years; 4) reside and work in the United States.

A flyer with summary of information on the study was shared among various PD support groups. Those who responded to the flyer and self-identified as potential participants signed informed consent using DocuSign and received a link for a sociodemographic survey that included screening questions via REDCap²¹, an online digital platform where answers were electronically stored and automatically sent to the principal investigator. The sociodemographic survey was based on the template from the National Institutes of Health Biomedical Research Informatics Computing System (BRICS).²² Once deemed eligible, the participants were sent a link to access the quantitative surveys. Upon completion they received a link to a schedule of time and date options to schedule the online Zoom interview, a secure audio-conferencing platform.

Quantitative data collection—Sociodemographic characteristics (age, sex, race/ethnicity, socio-economic status, education, occupation) and information about PD diagnosis and symptoms experienced by the person for whom they were providing care were collected using an investigator developed survey. Occupation was self-reported and categorized according to by the US Bureau of Labor Statistics Standard Occupational Classification System.²³

The Work-Life Balance Survey was used to assess the perception of the effect of work on physical and psychological well-being and ability to balance duties at work and home (e.g., "Feeling tension about balancing all your responsibilities", "Feeling that you should change something about your work in order to balance all your responsibilities").²⁴ Responses were recorded using a Likert-type scale range from 1 = "never" to 5 = "very often." The work-life balance score is the sum of the five values and the scores range from 5-25. Higher scores indicate poorer work-life balance and lower scores indicate better work-life balance. Consistent with prior research in working populations²⁵, the study sample mean was used as

the cutoff; a score ≥ 14 is considered poorer WLB. In this study, the Cronbach's alpha was calculated as 0.78, which is an acceptable level of reliability.

The Job Content Questionnaire (JCQ) is a 27-item questionnaire that includes scales that have been used extensively for psychosocial job assessment in working populations. Based on Karasek's Job-Demand-Control-Support model, it has been used in studies on occupational health where adverse health effects may occur when job demands are high and opportunities for job control and social support are low.²⁶ The JCQ consists of the following nine subscales: skill discretion, decision authority, psychological job demands, job insecurity, coworker support, supervisor support, physical job demands, decision latitude (or job control) and job strain (which comes from the calculation of physical demands and job control). Responses are on a Likert type scale ranging from 1 = "strongly disagree", 2 = "disagree", 3 = "agree" and 4 = "strongly agree." Raw scores range from 12- 48 while decision latitude ranges from 24-96, with a score above 58 as high and 70 very high. The Cronbach's alpha in this sample was calculated as 0.76, which is an acceptable level of reliability.

The Perceived Stress Scale (PSS-10) by Cohen and Williamson is a 10-item PSS-10 scale was used to measure an individual's level of perceived stress in the past.²⁷ The response options for each feeling or thought indicate the frequency with which stress occurred: 0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Fairly Often; 4 = Very Often. The ten questions were summed to provide a total score. A range from 0-13 is considered low stress, 14-26 is considered moderate stress, and 27-40 is considered high perceived stress. According to Cohen and Williamson, a score of 20 was also considered to be a valid cut off point for high versus low stress. The Cronbach's alpha score in this sample was 0.88.

The Personal Wellbeing Index-Adult (PWI-A) is a seven-item survey rated on a 0-10 scale (0 = No satisfaction at all; 10 = Very satisfied) that measured satisfaction with the following life domains: standard of living; health; life achievement; personal relationships; personal safety; community connectedness; and future security with 70-80 considered as normal range.²⁸ The Cronbach's alpha was 0.86.

The Zarit Burden Interview (ZBI) is a 22-item scale was used to appraise the burden experienced by caregivers.²⁹ The ZBI rates the frequency of various social, economic, and health aspects in relation to caregiving tasks on a 5-point Likert scale from 0-4 (never, rarely, sometimes, quite frequently, nearly always). A total score was calculated by adding the scores of each individual item with 17 as the cutoff score for burden being present. The Cronbach's alpha for this study was 0.91. Two decades later, authors throughout the literature who used the original scale to validate it on caregivers in Canada began referring to the ZBI as the Zarit Burden Inventory³⁰ and translations of the ZBI also used the term Zarit Burden Inventory.

The Patient Reported Outcome Measurement Information System Global Health Scale 10 (PROMIS-10) was developed by the National Institute of Health, and assessed participant's overall health by evaluating pain, fatigue, physical, mental, social, and overall health.³¹ The scale consists of 10 items, with higher scores representing a better life satisfaction and

quality of life (QOL). Scoring is divided into physical and mental QOL and converted to a t-score with a mean of 50 and standard deviation of 10 and the Cronbach's alpha was calculated as 0.80 in this sample.

Qualitative data collection—Guided by a semi-structured interview guide, qualitative data time, stress and behavior in the work and family domains were collected in individual interviews. Open ended questions about the caregiver's occupation was used. Interviews included open-ended questions (“tell me about your job...”) and follow up probes (“can you describe for me your average workday...” or “what is your future plan for work”...) to allow the participant to speak freely about their job and how they spend time caregiving, and how they feel about managerial support and social support. Interviews were recorded and were on average approximately 60 minutes in length (range between 50-75 minutes).

Quantitative analysis: Quantitative data analyses were performed using STATA.v17.³² Standard descriptive statistics were used to describe sociodemographics and scores of all surveys. Scatterplots were created to examine whether associations between variables was linear. Relationships among work-life balance scores, individual demographics, job characteristics, caregiver burden and individual factors were analyzed using pairwise correlations and p-values were generated with a $p < .05$ considered statistically significant. Independent groups t-tests and analysis of variance (ANOVAs) were used to compare differences in the groups (e.g., gender, education) with respect to work-life balance scores.

Qualitative data analysis: A preliminary analysis included a line-by-line review yielding clusters of data that were labeled with a with a list of *a priori* codes developed from the adapted Work-Life conceptual model. To keep data organized, the qualitative data analysis was done using *ATLAS.ti* version 22.³⁴ All codes were applied for the first ten interviews, and additional codes emerged from the data and were added to the code book. Through an iterative process, the final coding scheme was re-applied to all transcripts.

Then codes were grouped into meaningful coding categories and summarized within cases, then across cases to yield a rich descriptive analysis. Review of fit was verified.³³ Themes were analyzed within and then across subsets of participants (e.g., job status, gender, race/ethnicity) to identify commonalities and differences. A matrix was developed to capture these analyses. The sample of 40 reached saturation in this population when no new data (i.e., codes or themes) emerged while data was analyzed and no new data discovered to that point.²⁰

Integrated Data Analysis: The first step of data integration was to compare the quantitative variables (WLB and JCQ subscales) for concordance with the themes revealed in the qualitative analysis (e.g., narratives about perceptions of work-life balance, decision latitude, workplace support, caregiver burden). WLB served as the anchor;³⁵ within and across case analysis.³⁶ was used to explore the associations between the quantitative and qualitative data on WLB, job characteristics, and perceptions of caregiver burden. Quantitative data about stress (PSS-10) and personal wellbeing (PWI-A) and quality of life (PROMIS-10) were explored within the context of the qualitative narratives. Next, integrated data were analyzed to describe WLB barriers and facilitators and how they differed with those that had poor

(>14) versus adequate work-life balance (WLB score of ≤ 13). Finally, the integrated data across cases were analyzed to describe the influences of participants' decision to continue to work or leave employment.

Institutional review board approval was obtained at the researchers' university (IRB# FY2021-5551) Equator reporting guidelines were revisited and the STROBE guidelines for observational studies was used and included in the supplementary digital content of this manuscript (Supplemental Digital Content, <http://links.lww.com/JOM/B769>).

Results

Sample Characteristics

Sociodemographic characteristics of the sample ($N = 40$) are shown in Table 1. The sample was predominately female (78%) and non-Hispanic white (88%). Most participants (70%) were working at the time of the study, while 30% ($n = 12$) had retired from their main job occupation within the last three years of the time of the interview. The study sample consisted of an older working group (mean = 57.53, SD = 14.21).

Occupations were categorized by the US Bureau of Labor Statistics Standard Occupational Classification System (Table 1). In this sample the most common occupations were educational instruction ($n = 6$), management positions ($n = 5$) and sales ($n = 5$). Overall, the WLB in this sample was adequate (the group mean was 13.48, SD 4.44; 55% scored 13 or below; the median was 13; range 7-22). There were no statistically significant differences of WLB by occupational category.

In this sample, the mean decision latitude score on the JCQ was high (69.8) as seen in Table 2; however, there was no correlation between decision latitude and WLB ($r = -0.075$, $p = 0.654$) (Table 3). There was a significant association between work-life imbalance with high psychological demands ($r = 0.3976$, $p = 0.007$). Supervisor support ($r = -0.322$, $p = .052$) was considered medium in magnitude, but coworker support ($r = -0.534$, $p = .001$) was significantly associated with WLB (Table 3).

Participants in this sample reported moderate to high perceived stress levels (mean = 19.7, SD = 5.62) as measured by the PSS-10 (Cohen & Williamson, 1998); and below the normative range of personal wellbeing (PWI_A mean = 50.7, SD = 10.3). Quality of life, measured by the Quality of Life Enjoyment and Satisfaction Questionnaire PROMIS 10 (Hays et al., 2009) scores in this sample fell below the general population (mean = 48.4, SD = 8.1). Each of these factors was significantly correlated to WLB (see Table 4).

This sample reported significant caregiver burden (mean = 40.2, SD = 13.6), with 92.5% scoring above 17 which indicates high caregiver burden. Females reported greater caregiver burden as measured on the ZBI (mean = 42.2, SD = 13.0) compared to males (mean = 32.5, SD = 14.6) but two sample t-tests showed this was not statistically significant ($p = 0.431$). This was likely due to the small sample size of male caregivers. Although caregiver burden was not associated with WLB it was strongly correlated with stress, wellbeing and quality of life scores (see Table 4).

Qualitative Results

The qualitative results revealed that work-life balance was influenced by a combination of barriers and facilitators. The following barriers emerged: physical stress, emotional stress, financial stress, and role conflict. Facilitators included work-related characteristics, such as being able to disclose the diagnosis to one's supervisor, and tangible resources and emotional support that the caregiver was able to leverage to offset caregiving demands and facilitate WLB. A summary of qualitative thematic results with exemplar quotes are provided in Table 5.

Barriers

Physical stress, whereby the job was physically demanding, or the aspect of caregiving was physically demanding, was reported as a frequent barrier to work-life balance. Physical stress included the mechanics of caregiving (e.g., having to lift someone, loss of sleep due to caregiving demands at night). Participants described feeling physically exhausted having to help their family members who are declining from motor impairment. Activities of daily living such as getting dressed required physical tasks of helping them stand up, change positions, or help them get their clothing on. For those caregivers who were older and with physical ailments themselves, this added to additional physical stress. Losing sleep at night resulted in physical exhaustion and added to the caregivers' stress.

Emotional stress was described in multiple ways. One participant, a husband whose wife had PD for 14 years, described feeling exhausted and attributed these feelings toward a constant fear that she was going to fall. Others described emotional stress that was linked to feeling irritable or frustrated (*I'm irritable far more, particularly around issues around things that I feel like he can do, but he won't try to do them*). Caregivers described feeling frustrated and stressed about the person they were taking care of and linked this stress with their care recipient not wanting to engage in recommended therapeutic activity or treatment. This frustration seemed rooted in the amount of time and effort required by the caregiver and the reluctance on the care recipients' side to "follow along". For example, getting up alone without assistance for those at high risk of falls, refusing to take walks or exercise, to take medications on time, or adapt to a healthier diet all came up as sources of emotional stress for the caregiver. These issues often caused fear, anger, and led to arguments. One caregiver described feelings of resentment "*he used to dust and clean and be involved in the house...the whole purpose of treatment and therapy is so that he can do more again...he used to be so active... I don't mind doing more, but I've become resentful about seeing him decline without trying*".

Caregivers also described emotional stress as they struggled with communicating with the person with PD (*Her voice is soft. I struggle and it's frustrating, too, because it's very hard to have a conversation*). Additionally, several participants described cognitive changes that contributed to emotional stress. For example, one husband described his wife needing help with understanding simple tasks that she previously was able to do independently. Anything new or out of routine could contribute to anxiety for the care recipient, thus contributing to additional emotional stress of the caregiver. There were many reports of participants feeling unsure how to handle complex hallucinations and delusions which also added to emotional

stress. One wife described a particularly stressful event in which her husband wandered off: *“When he came back with the police, what do I do? I think maybe someone should write scenarios about what to do when your husband has X or your person with Parkinson’s does Y”*.

Financial stress was another frequently reported barrier to work-life balance. Some participants described being unable to afford formal caregivers. In this sample of 40, many described being unable able to afford formal caregivers and discussed the decision to cut their own work hours or leave the workforce (e.g., retire) to provide the needed care themselves.

Role conflict was described as a barrier to WLB when participants were unable to delegate tasks to family members due to financial constraints, geographical barriers, or family dynamics. Even when family members were local, the caregiver might not want to *“burden them”* by engaging them in ongoing care needs. Caregivers who had children expressed that they wanted those children to focus on their own work and family needs rather than burdening them with caregiving tasks.

Facilitators

In this sample facilitators to work-life balance included job related characteristics such as job proximity and job flexibility. For some, disclosing the diagnosis at work was as a facilitator because it provided a sense that the supervisor was aware of the caregiver’s home situation. On the contrary, not being able to share this diagnosis frequently added to tension and stress. Other pragmatic aspects of work included job proximity which saved the caregivers time from commuting. Several in this sample opted to work minutes away and be able to leave work quickly when needed by the care recipient. Job flexibility, especially if it meant being able to take time off as needed for doctor appointments, was also frequently described as a facilitator.

Another facilitator to work-life balance in this sample was the caregivers’ ability to leverage tangible and emotional resources. Tangible resources were described as home services such as professional caregiving or home food delivery services. Emotional resources included having family members present which provided the caregiver with a sense of feeling supported. Participants with family nearby that offered to spend time with the adults with Parkinson’s alleviated some of the caregiver burden. When a family member offered to spend time, this allowed the caregiver to focus on other tasks and activities, and sometimes simply gave the necessary respite for the caregiver to work on personal or work related-tasks or to rest and relax.

Integrated Data Results

The integrated data aim described the influence of barriers and facilitators on work-life balance in the context of time, stress and behavior and the associations with caregiver burden and quality of life. When qualitative and quantitative data were integrated, there was adequate (85%) concordance of the qualitative accounts of work-life balance with the scores on the WLB survey. Similarly, the qualitative narratives of job-related characteristics were concordant with the JCQ scores. The results of the integrated analysis identified that WLB

is influenced by individual and multi-contextual factors. Time required for caregiver support, the stress associated with caregiving and the behavior required to fulfill the role of both caregiving and work were associated with caregiver burden and WLB.

There were three main findings identified from the integrated data analysis. First, among those who were still working, WLB was facilitated by meaningful job characteristics and caregiver burden was offset by caregiver resources and unique job-related characteristics (e.g. being able to take a few hours away from the work-day, or schedule work time in the late evenings after returning from medical appointments). Second, those who were still working but struggled with WLB were compromised by caregiver burden when the time, stress and behaviors of the caregiver role influenced the ability to be fully present at work. Third, balancing life, for some, required giving up one's work.

Time, Caregiver Burden & WLB

Those with an adequate WLB score (13 and below) described facilitators that helped them (e.g., job proximity, job flexibility) to save time in other aspects of life. Participants also describing the benefit of job proximity that allowed for saving time commuting. Several described having job locations minutes away from home, allowing them to return home quickly when their family member needed them. For most participants, caregiver burden may have been offset by several job characteristics and resources that supported WLB. Generally, this sample reported high decision latitude at work (JCQ subscale sample score <69) but not everyone who had high decision latitude in this sample group reported adequate WLB (score < 14). In these cases, WLB may have been influenced by caregiver burden within the context of time spent providing care as well as other household responsibilities. For example, several participants described sharing housework for years before the Parkinson's symptoms became severe. These qualitative results provide insight into the quantitative correlation between caregiver burden and quality of life. As symptoms worsened, participants described the need to take on more domestic tasks, thus shifting their sense of balance for time available for their professional work (*my husband used to cook, vacuum, do all the maintenance around the house...now I'm in charge of everything plus I do the laundry and help him get fully dressed...I have to find time for my work*).

Stress, Caregiver Burden & WLB

Stress level scores correlated to WLB (higher stress positively correlated with poorer WLB scores ($r=0.315$, $p=0.054$) and the qualitative data illuminated that the sources of stress included physical and emotional demands of caregiving as well as financial stressors. Even when decision latitude for work was high, stress in both domains, home and work, was identified qualitatively as well as quantitatively. For example, a teacher who had been at the same school for 25 years and had a high decision latitude (score=66), described a hectic work schedule that led to feeling "stressed out", which was concordant with her PSS10 score of 20, and JCQ subscale, psychological demands, score of 19, both of which were higher than sample mean. Emotional and physical stressors at home involved her caregiving tasks; while at work she worried about her husband and was concerned that he may fall or have difficulty managing on his own. Collectively, her WLB score (18) reflected work-life imbalance which was explained by the qualitative data.

Another female participant described high level of stress both at home and at work. She felt she could not disclose her husband's diagnosis to her coworkers due to the high stress and competition in her real estate job ("*<coworkers> may not see me as a partner ...lose opportunities...*"). Another compared her role of taking care of her husband to coworkers who had children but felt she could not full share her situation for fear of not being understood (*I think I downplayed it a bit...my coworkers are mostly women and they have children. I think that they have understanding of it, but, in some ways, I think that their responsibility is much more concrete*").

Results of the quantitative data showed a significant association of personal wellbeing and perceived stress scores across cases; when wellbeing scores declined, stress scores were significantly higher ($r = -0.520$, $p = 0.001$). Furthermore, caregivers described that they had to make personal adjustments in hobbies or personal activities due to high demands of caregiving. They described "giving up" these activities as contributing to increased stress and decline in quality of life.

Behavior, Caregiver burden & WLB

Participants described that high caregiver burden at home affected their ability to work. They described being limited in their ability to meet the expectations of their job performances due to various aspects of caregiver burden (e.g. fatigue, lack of energy, difficulty concentrating). This contributed to a poor WLB. For some with high decision latitude (JCQ decision latitude scale score ≥ 64) having job control, including familiarity with the work that needed to be done, were able to offset caregiver burden. Several reported modified or accommodated job behavior expectations of their supervisor (*My immediate boss, who is a national sales manager... I've known 20 years. He started a year before me, and we're quite friendly, so I have a lot of latitude with the firm. They're not expecting me to hit any quotas or anything. I'm very blessed in that sense*).

Some participants with higher WLB scores which reflects poor work-life balance (>14), described challenges adapting to the behavior expectations of being a family caregiver (*I am not a caretaker mentality... I'm a businessman; my mind thinks one way*). Another husband described a similar challenge with role conflict (*...being a loving and supportive husband... that was a role that I wanted... I also needed to be the person who was working in a professional capacity...thinking of how to care for her around the clock.... That was not a role I wanted...It was just necessary*). A female participant who was taking care of her father with PD with a high WLB score of 18 indicating work-life imbalance, and low decision latitude of 52 described that she was transitioning to a new job at the time of the study interview. In addition to being the primary caregiver of her father who has severe PD and recently suffered a stroke, she has two children. She described her husband as financially supportive but not "helpful" with caregiving. She explained that in their culture, the female was expected to take on the caregiver role. Another spouse with a high WLB score (poor WLB, score of 20) described "running late for work" because she had to help her spouse with medications. As a result, she had to decrease work hours to meet increasing caregiver demands at home.

Balancing life and not working

In this sample when caregiving outweighed balancing life, the caregiver contemplated giving up the working role. One daughter who retired from teaching and became a full-time caregiver for her mother stated “*if not now, when*”. She reflected on the point in time when she felt her mother really needed her help given the complexity of the PD symptoms, and she was the best person to understand and care for her mother. Additionally, she described that for her financial situation utilizing services for professional caregivers was expensive. Though she valued her work and it was meaningful, her decision to stop working reflected the dilemmas faced by many caregivers in this sample who have to balance financial demands. Perceptions of work-life balance in this sample group reflected the additive effects of perceived stress, quality of life, personal wellbeing. While the quantitative data did not show a significant association between work-life balance and caregiver burden, caregiver burden was more related to one’s personal stress, in those cases they considered giving up work.

Discussion

The results of this mixed methods study provide insight into the multi-contextual factors that influence WLB among working adults caring for adults with PD. The majority of this sample reported having high decision latitude at work and high caregiver burden; their WLB was influenced by a combination of job-related factors and individual stress. Work was seen as meaningful for many and most expressed wanting to stay in their job occupation. National trends in United States show older workers want to keep working beyond expected retirement age³⁷ and many retirees are proceeding with some type of work to remain active.³⁸ Current data suggest that people who report leaving their work to maintain personal work-life balance leave when there is lack of support or encouragement from their supervisors.³⁹ Similarly in our study, supervisor support was commonly cited as facilitating WLB. Support from supervisors and coworkers has also been identified as important and helpful to older workers with chronic disease⁴⁰ as well as other caregiver groups taking care of older adults and adults with other conditions.⁴¹ Our results reinforce that to retain this experienced workforce, employers need to be aware of the important role that supervisors have in supporting workers and evaluate solutions to facilitate WLB.

Our study illuminated some of the unique factors that contributed to the caregiver stress among these working caregivers. Others have not explored this specific working population and caregiving in PD, an ever-increasing neurodegenerative condition expected to increase in prevalence to 1.2 million adults in the United States by 2030 which will thus require a greater need for family caregivers as the number of available professional caregivers will be harder to meet demands.⁴² Our sample described the emotional stress and frustration in caregiving while trying to maintain their work. Some of this stress was based around specific symptoms including cognitive and speech changes. Progression of cognitive and speech changes have been described to be a source of distress for caregivers in other literature.⁴³ Studies have shown that even those with an earlier diagnosis are vulnerable for mild cognitive impairment that can affect daily function and those who experience memory problems and challenges in organizing and making decisions result in a greater emotional

impact on their caregivers who witness their partner or relative decline.⁴⁴ Caregivers of family members who had both Parkinson's and cognitive decline had significantly lower quality of life scores compared to those who had normal cognition.⁴⁵ These results reinforce the need for clinicians to assess symptom severity and identify their impact on ADLs, and support caregivers with services and identify appropriate referrals. With this support, working adults with caregiver roles may be able to better manage their dual roles.

Currently, family caregivers are not identified systematically in the United States, and there is no standard assessment for addressing their role or the degree to which they assist in health care activities.⁴⁶ This study provided for a broader assessment of caregivers and indicates that more research on working and caregiving is needed to help healthcare professionals fully understand the relationship between demographic variables and informal caregiver needs and problems.

The results of this study also provide support for the Work-Life Conflict model and its application to those with dual roles. Our sample described the emotional stress and frustration in dealing with PD symptoms in the context of time, stress and behavior which align with this model. While many concepts have emerged over the years, the original Work-Life Conflict model has been consistently revisited to examine this important phenomenon. For those with longer work hours, the work domain seems to increasingly impose on family and personal life.⁴⁷ Literature suggests that employees who experience extensive work-family conflict may suffer a wide variety of negative consequences such as diminished satisfaction and productivity in both work and family domains and deteriorated physical health and emotional well-being.^{48, 49, 50} This study explores these issues not just through the lens of one role, but how a person manages both working and taking care of a person with a long term, progressive neurological disease.

Study Limitations

There are several limitations to this study. First, the sample size was small (n=40), and predominantly white, female, and with higher level of education and exclusively white collar occupations. Previous studies have shown that the level of education has a positive relationship with the intention to continue working.⁵¹ Others have recommended that work and retirement for caregivers should be explored as a longitudinal process⁵² rather than cross-section analysis which is a limitation of our study. Length of time of caregiving was not recorded in this study. Thus, longitudinal studies with larger, more diverse sample sizes are needed to better understand WLB perspectives, predictors and examine outcomes. Additionally, while this sample had many in education, administration and sales, other job occupations were missing from this sample and would require a wider net of recruitment. Our study focused on the perspective of family caregivers and not the patient perspective. Future studies that examine the dyadic relationship of family caregiver and patient perspectives may expand on this information and how they collectively manage the disease. Patient and caregiver perceptions of the social impact of PD symptoms can vary.⁵³ Studying caregivers and patients may help to understand how decisions on in getting more support or eventually deciding whether assisted living or palliative care are made and therefore can help tailor intervention throughout their PD trajectory.⁵⁴ Finally, despite

our maximum variation sampling technique, our sample was mostly spouses; exploring the dual working and caregiving role among other relationship types (e.g., children, sibling) is warranted. Durante et al. explored caregiving of adults with heart failure, which, like Parkinson's Disease, is a chronic, progressive illness requiring increasing levels of help over time.⁵⁵ In that study of 229 caregivers, 58% were spouses, while 42% were non-spouses and had a harder time accepting their caregiving role. As the number of people advance with this neurodegenerative illness, a growing demand for family members will be required to step in and accept the caregiver role.

Implications

This study has several implications for employers and providers. Parkinson's Disease is a long-term chronic condition that is projected to require more support over time resulting in work interruptions or permanent work separation. Given the vulnerability toward stress, poorer quality of life and wellbeing, employers also need to acknowledge that some of their employees may be caregivers at home and address potential needs and challenges. **Job accommodations and family leave options may help support workers who also are caregivers.** The results of this study may increase awareness of the influence of work-life imbalance on caregiver burden and stress. This serves as an implication to occupational healthcare providers and others who encounter caregivers who may be taking care of a family member with such a chronic, progressive illness.

Conclusion

This study explored barriers that offset the harmonious existence between caregiving and working and the facilitators that foster balance between the two. Higher stress in caregivers can lead to poorer work-life balance, an important factor for occupational healthcare providers to be aware of. On the contrary, supervisor support and coworker support can improve a sense of work-life balance for family caregivers that are pulled in two directions of working and caregiving. Future research is needed to include larger groups of caregivers with more diverse demographics to better understand the barriers and facilitators to work-life balance. A better understanding of these barriers and facilitators may aid in creating policy and practice recommendations for family caregivers.

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Learning Outcomes:

- Identify at least one of the multi-contextual barriers and facilitators to work-life balance of working caregivers of adults with Parkinson's Disease that were described in the manuscript.
- Interpret the mixed methods findings that elucidate the relationship between job content characteristics of family caregivers and their levels of work-life balance, stress, wellbeing quality of life, and caregiver burden.

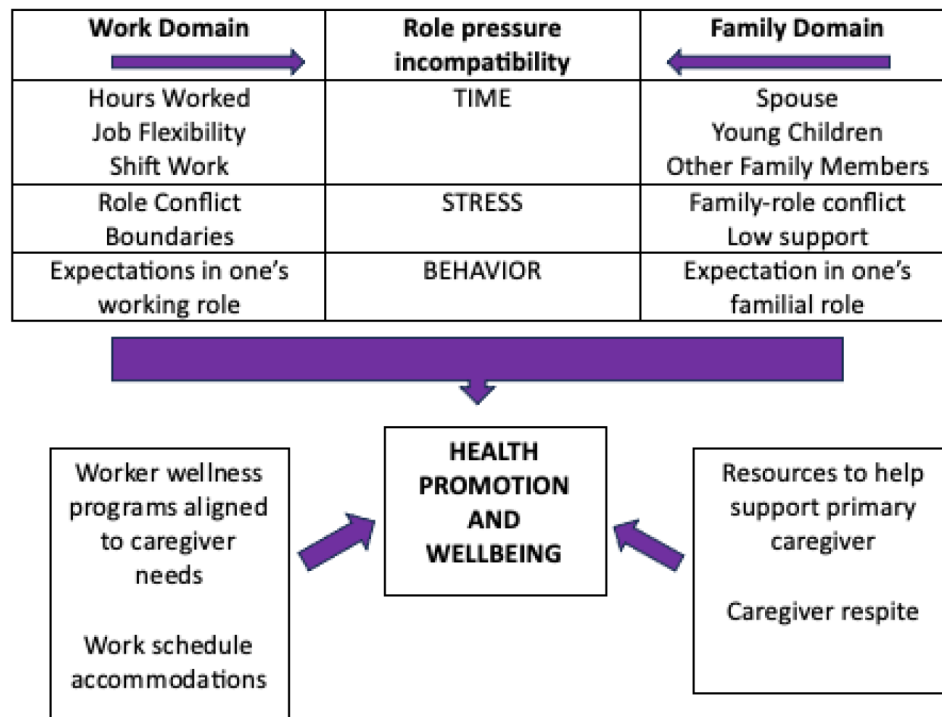


Figure 1. Newly Adapted Work-Life Conflict Model

This scale represents an adaptation of the Work-Life Conflict Model by Greenhaus & Beutell (1985). For each participant, the time, stress, and behavior of one role makes it difficult to be present in the other role. Individualized factors can support the health and wellbeing of the caregiver.

Table 1.

Sociodemographic characteristics of participants (n=40)

	Range, Mean (SD)
Age, years	57.53 (14.23)
	<u>N (%)</u>
Gender	
<i>Female</i>	31 (77.5)
Race	
<i>Asian</i>	4 (10.0)
<i>Black or African American</i>	1 (2.5)
<i>White</i>	35 (87.5)
Ethnicity	
<i>Hispanic or Latino</i>	4 (10)
Marital Status	
<i>Married</i>	27 (65.9)
Relationship to person with PD	
<i>Spouse</i>	21 (52.5)
<i>Child</i>	17 (42.5)
<i>Sibling</i>	1 (2.5)
<i>Other</i>	2 (5.0)
Living Together	
<i>Yes</i>	30 (75.0)
Taking care of children under 18	
<i>No</i>	36 (90.0)
Education	
<i>High School, some college (no degree), associate's degree, occupational/technical program, vocational program</i>	9(22.5)
Bachelor's Degree	10 (25.0)
<i>Master's Degree, Professional Degree (e.g., MD, JD)</i>	21(52.5)
Currently employed	
<i>Yes</i>	28 (70.0)
Work status:	
<i>Working full time (>32 hours/week)</i>	20 (50.0)
<i>Working part time (32=< hours /week)</i>	5 (12.5)
<i>Self-employed</i>	3 (7.5)
<i>Retired</i>	12 (30.0)
Major group occupations	
<i>Management</i>	5 (12.5)
<i>Business and Financial Operations</i>	3 (7.5)
<i>Life, Physical, and Social Science</i>	3 (7.5)
<i>Community and Social Service</i>	3 (7.5)
<i>Legal</i>	1 (2.5)
<i>Educational Instruction</i>	6 (15.0)

<i>Arts, Design, Entertainment, Sports, and Media</i>	4 (10.0)
<i>Healthcare Practitioners</i>	4 (10.0)
<i>Healthcare Support</i>	2 (5.0)
<i>Sales and Related</i>	5 (12.5)
<i>Office and Related</i>	4 (10.0)
Frequency of Parkinson's symptoms reported	
<i>Unable to walk independently</i>	16 (40)
<i>Frequent falls</i>	23 (57.5)
<i>Tremors</i>	16 (40)
<i>Involuntary movements</i>	22 (55)
<i>Memory problems</i>	26 (64)
<i>Behavior problems</i>	17 (41.5)
<i>Speech problems</i>	22 (55)
<i>Inability to dress, bath care for personal hygiene</i>	20 (50)
<i>Requiring night assistance</i>	23 (57.5)

MD= medical degree, JD=juris doctor

Table 2.**Job Related Characteristics and Work-Life Balance (WLB)**

	N	Mean	SD	Range	95 % Confidence Interval
JCQ subscales					
Decision latitude	38	69.84	12.96	42-92	65.58 - 74.10
Psychological Demands	39	13.77	5.44	3-28	12.01 - 15.53
Physical job demands	39	2.18	0.91	1-4	1.88 - 2.48
Supervisor support	37	11.97	2.51	4-16	11.14 - 12.81
Coworker support	37	12.49	1.85	7-16	11.87 - 13.10
Job insecurity	37	5.35	2.05	3-10	4.67- 6.04
WLB survey	40	13.48	4.44	7-22	12.05 - 14.90

JCQ= Job Content Questionnaire

WLB= Work life balance

Table 3.

Correlational Analysis

	<i>WLB score</i>	<i>Perceived Stress scale</i>	<i>Personal Wellbeing Index</i>	<i>PROMIS10 QOL</i>	<i>Zarit Burden Interview</i>
JCQ subscales					
<i>Decision latitude</i>	-0.0751	-0.287	0.274	0.140	-0.269 *
<i>Psychological Demands</i>	0.425 *	0.399 *	-0.330 *	-0.198	0.218
<i>Supervisor support</i>	-0.322 *	-0.120	0.343 *	0.425 *	-0.307
<i>Coworker support</i>	-0.534 *	-0.308	0.400 *	0.414 *	-0.316
Individual Factors					
<i>Perceived Stress Scale</i>	0.321 *	-	-0.522 *	-0.542 *	0.407 *
<i>Personal Wellbeing Index</i>	-0.461 *	-0.522 *	-	0.634 *	-0.381 *
<i>PROMIS 10 QOL</i>	-0.310 *	-0.542 *	0.640 *	-	-0.344 *
<i>Zarit Burden Interview</i>	0.092	0.407 *	-0.381 *	-0.344 *	-

* statistical significance $p < 0.05$

Job Content Questionnaire= JCQ, WLB= Work Life Balance, QOL= Quality of Life

Table 4

Barriers and Facilitators to Work-Life Balance

BARRIERS	Exemplar Quote
Physical stress	
	<i>The responsibility has a lot to do with moving her in and out of bed, to the bathroom, in the shower. A lot of wheelchair pushing.</i>
Emotional stress	
Refusing care	<i>She refuses to change her diet and she refuses to exercise... She does not listen to me when I remind her to take her medication.</i>
Speech changes	<i>Her voice is soft. I struggle and it's frustrating, too, because it's very hard to have a conversation</i>
Cognitive changes	<i>He thinks they're wearing his clothes, they're wearing his hat. I don't know what to do. I try to beat the coat rack so he knows that they're not alive.</i>
Financial stress	
	<i>It is financially less expensive if I do the caretaking myself so I retired earlier than I wanted to.</i>
Role conflict	<i>if I asked them to do something, I'm not sure they would. My sister-in-law is afraid to be with him.</i>
FACILITATORS	Exemplar Quote
Work-Related	
Disclosure	<i>My board of director's says, "<Name>, whatever you do is enough for us. We're gonna support you, and we take <Name>'s health in consideration for that."</i>
Job proximity	<i>Here I have a six-minute walk. Last year when my mother had problems, I knew I could go back home quickly if she needed me.</i>
Job flexibility	<i>This job because of the flexibility... if didn't log in on Tuesday, but I logged in Wednesday... and I got all of his work done...my boss was ok.</i> <i>I can self-schedule myself for my shifts. I usually choose to work weekends so I can be free during the week for appointments, take my husband to the doctor.</i>
Caregiver leverage	
Tangible support	<i>We do have a mobile chair lift to come up to the steps. It would take so much time to get him up the stairs without it.</i>
Emotional support	<i>My sister-in-law occasionally comes here, the boys... It still gives me a break because there are other people in the house.</i>

Table 5

Example of Correlational Matrix

Pertinent demographics	QUAL and QUANT concordance	Within case integrative data
Subject 4 58 year old White female Job category: Sales High education Caregiver role: spouse PD symptoms: Cognitive, safety, ADL issues WLB: 20 Decision latitude:76 Supervisor support: 10 Coworker support: 7 PSS-10: 23 ZBI - 44	WLB score: 20 Poor sense of WLB <i>When I'm not working, I'm being a caregiver.</i> High decision latitude score (76) <i>I can control my schedule.</i> ZBI (44) <i>After the fall, he has to have a walker...he has to be watched all the time. That changed everything and I feel more exhausted.</i>	Barriers Emotional stress- <i>Emotionally and mentally it is a lot to deal with for me...It's planning the meal. It's getting the food. It's preparing the food. It's serving the food. It's cleaning up the food... Filing the taxes, dealing with the accountant, taking out the garbage, making the bed, making sure there's soap. I mean, you name it...</i> Financial stress-<i>Money's an issue. To have time for yourself means you need to hire somebody to do what you're doing or take over what you're doing</i> Role conflict- <i>It's impacted my work in that I've had to partner up with people to cover me when I can't be there. I've run late for work to give him medications...He gets meds five times aday...I have to be on a timer for that.</i> Facilitators -Flexibility- <i>Other times I am working at home, writing up reports or scheduling or on the phone.</i> -Tangle support: <i>I have someone Monday through Friday (Housekeeper, Sibling). Then the weekends, I'm here.</i> - emotional support: <i>When my husband fell in May, my son was terrific. My son was there in the emergency room with me and visiting him in rehab.</i>
WLB was compromised by caregiver burden, this participant was still working but struggled with WLB when the time, stress and behaviors of the caregiver role influenced the ability to be fully present at work.		

PD= Parkinson's Disease, WLB= Work life Balance, ZBI- Zarit Burden Interview, PSS= Perceived Stress Scale, ADL=activities of daily living