



Caregivers of Children with Special Healthcare Needs: A Quantitative Examination of Work-Family Culture, Caregiver Burden, and Work-Life Balance

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Abstract

The purpose of the current study was to examine the relationships between organizational work-family culture, caregiver burden, and work-life balance among employed caregivers of children with special healthcare needs. The potential moderating role of organizational work-family culture in the relationship between caregiver burden and work-life balance was also investigated. Using convenience sampling, data were collected from 150 primary caregivers who work or recently worked in the past three months and have at least one child with a special healthcare need. Participants completed an online survey. Findings revealed increasing caregiver burden was related to lower work-life balance, while organizational work-family culture was positively related to it. Organizational work-family culture, and two of its three facets (i.e., managerial support and time demands), were significant moderators, but only before COVID-19. Future researchers could focus on underrepresented groups and communities, examine organizational work-family culture in various industries, and improve work-life balance during social and economic downturns. With increases in dual earner and single parent households, employers should consider how their culture supports employees with households with a child with special healthcare needs. This is the first study to apply organizational work-family culture to employed caregivers with a child with special healthcare needs and test it as a moderator of the relationship between caregiver burden and work-life balance.

Keywords Organizational work-family culture · Caregiver burden · Work-life balance · Occupational health

Highlights

- Caregiver burden is negatively related to work-life balance.
- Organizational work-family culture is positively related to work-life balance.
- Organizational work-family culture moderates the relationship between caregiver burden and work-life balance.
- Managerial support and time demands moderate the caregiver burden—work-life balance relationship.
- Employers should consider how their culture supports employees with households with a child with special healthcare needs.

A Quantitative Examination of Work-Family Culture, Caregiver Burden, and Work-Life Balance

In this study, relationships among organizational work-family culture, caregiver burden, and work-life balance for employees who have children with special healthcare needs

were examined. In recent decades, American families have experienced both sociodemographic and economic transitions, resulting in a blurring of traditional gender roles (Donnelly et al., 2016). Women have increasingly been entering the workforce since the 1970s feminist movement, providing opportunities for a professional career in addition to a family life (Eagly et al., 2020). Furthermore, along with their work responsibilities, men have increasingly taken on a more active part in childrearing roles (Persson & Rossin-Slater, 2019). Along with sociodemographic changes, declines in the American economy have created financial hardships for families. Approximately 62% of married

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couples raising children depend on at least two sources of income, and single parents make up two-thirds of all low-income families (Sullivan, 2020).

As American families have undergone the shifts and blurring of work and family responsibilities, as well as economic challenges, a new friction has unfolded between these roles. Family demands and work demands often compete, creating challenges for working parents to efficiently maintain each equally in what researchers call *work-life balance*. A positive balance, work-life facilitation, is associated with better physical and mental health, including fewer chronic health issues (Stoiko et al., 2017). In contrast, a negative balance, work-life conflict, is related to decreased physical and mental health, such as depression and life dissatisfaction (Stoiko et al., 2017). Work-life balance factors are intensified when the family includes a child with a special healthcare need.

Children with special healthcare needs (SHCN) are recognized by the U.S. Department of Human Services as those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998, p. 138). This definition was developed by McPherson et al. in 1998 within a work group of experts to assist program guidance at the federal level. While broad, this definition recognizes the various types of chronic conditions in children including developmental, physical, and emotional disabilities, which each individually and collectively (when comorbid) impacts the child in varying severity. For the current study, Children with SHCN included those with a diagnosed chronic health condition who required additional services beyond that of a typically developing child. Examples of special healthcare needs include, but are not limited to, autism spectrum disorder, cerebral palsy, and behavioral disorders (Child and Adolescent Health Measurement Initiative, 2012). An estimated 14 million children in the United States have a special healthcare need, which is approximately 19% of children nationwide (Child and Adolescent Health Measurement Initiative, 2019).

Having a child with SHCN can create multiple challenges for families as a unit, the individual child with SHCN, and the parents/caregivers. Children with SHCN require routine medical care and assistance that is beyond that of a typically developing child, including the administration of medications, transportation to healthcare appointments, or other at-home procedures (Javalkar et al., 2017). Other tasks include assisting the child with SHCN with daily activities, such as mobility and self-care. Along with day-to-day challenges, children with SHCN are at an increased risk for mental and behavioral health problems, bedridden days, unmet healthcare needs, and unscheduled

hospitalization (Van Dyck et al., 2004). For caregivers of children with SHCN, the responsibilities can negatively affect their own physical and mental health, resulting in indicators of caregiver burden. Pertinently, the World Health Organization officially declared the coronavirus disease (COVID-19) outbreak to be a global pandemic on March 11th, 2020 (World Health Organization, 2020). Throughout the pandemic, primary caregivers and employees adjusted their work and caregiving routines based on personal decisions, federal and state mandates, and employer decisions. Such adjustments included working remotely from home, voluntary or involuntary termination of employment, loss of childcare, and school closures for virtual learning. These changes likely exacerbated the well-being of caregivers of children with SHCN.

Given the challenges faced by families with a child with SHCN, caregivers must attempt to effectively balance personal and work demands. However, this can be difficult, especially in instances whereby caregivers experience greater levels of caregiver burden. While caregivers face such difficulties, there are opportunities for resources and support from the caregiver’s employer. One such avenue is organizational work-family culture—“an organizational environment that understands and supports the needs of employees with familial responsibilities” (Thompson et al., 1999, p. 394). Hence, the purpose of this study was to investigate the relationship between caregiver burden and work-life balance of employed caregivers of children with SHCN and whether organizational work-family culture moderates this relationship.

Caregiver Burden

Caregiver burden was first defined by Zarit et al. (1986) as “the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative” (p. 261). Caregivers of chronically ill children report lower health-related quality of life than the general population. In a study by Lee et al. (2017), caregivers of children with disabilities were more likely to report chronic health issues (e.g., back pain, chronic bronchitis, diabetes, heart conditions, joint pain, migraines or headaches, obesity) than those of children without disabilities. Caregiver burden is also associated with psychological effects, such as anxiety and depression (Puka et al., 2019), as well as feelings of frustration, sadness, and helplessness or hopelessness (Caicedo, 2014). Mothers of children with SHCN often experience distress, anguish, and regret due to reducing or terminating employment to commit more time toward caring for their child (Scott, 2010).

Finally, approximately 50% of families with a child with SHCN face financial burden due to additional services required to care for their child (Ghandour et al., 2014). Examples include expensive prescriptions, dental services, and home healthcare not covered by health insurance; increased electricity, heating, and water bills; and special clothing, equipment, and food (Lindley & Mark, 2010; Looman et al., 2009). Within these families, health insurance premiums cost \$2058 to \$3593 more than families without a child with SHCN (Lindley & Mark, 2010). They also spend \$2669 to \$69,906 on annual out-of-pocket medical expenses compared to \$679 to \$3181 in families with non-SHCN children (Lindley & Mark, 2010). Financial problems are more typical within families with a child with SHCN who are living in poverty, without full health insurance, and with a child whose healthcare needs are more severe (Schuster et al., 2009).

Organizational Work-Family Culture

Organizational work-family culture is the “shared assumptions, beliefs, and values regarding the extent to which an organization supports and values the integration of employees’ work and family lives” (Thompson et al., 1999, p. 394). There are three main components: organizational time demands, negative career consequences of utilizing work-family benefits, and managerial support of work-family needs. First, organizational time demands include the organizational norms surrounding the level of commitment an employee is expected to uphold, such as the number of hours worked (Thompson et al., 1999). The more hours employees work for an organization, the less time available for them to devote to family-related needs.

Second, negative career consequences of work-family benefits involve the negative spillover of using work-family benefits into the organization and the employee’s job (Thompson et al., 1999). For example, reducing or altering hours at work to care for a child can decrease opportunities for promotions and negatively influence performance ratings. In a study by Schuster et al. (2009), 42% of employees with a child with SHCN said leave had a bad or very bad effect on their job performance. Overall, reducing hours of employment and hence physical presence at work, can convey less organizational commitment. An organization with a supportive work-family culture provides reasonable accommodations and understands when an employee must make new arrangements to care for their child. Therefore, opportunities may be lost for career advancements.

Lastly, managerial support of employees with families includes managers who are understanding and sympathetic of employees’ family obligations (Thompson et al., 1999). Perrin et al. (2007) conducted a study on benefits offered by

employers in four major U.S. cities and the opinions of employees who have a child with SHCN. One suggestion was for supervisors to receive sensitivity training to increase their understanding and supportiveness toward employees dealing with challenges related to having a child with SHCN. Another suggestion was for organizations to examine their individual organizational culture surrounding work-life balance and support. A positive organizational work-family culture is essential for the support of caregiving employees and encourages work-family benefit utilization.

Work-Life Balance

With the sociodemographic and economic transitions of the 1970s, researchers began studying the interactions between work and family life. In 1986, *work-life balance* was first introduced, and companies began implementing programs to promote it in the 1980s and 1990s (Lockwood, 2003). However, work-life balance does not have a single, clear definition in the literature; its meaning changes based on the theoretical model and the context. For instance, an employee might define it as “the dilemma of managing work obligations and personal/family responsibilities” (Lockwood, 2003, p. 3). Conversely, an employer might describe it as “the challenge of creating a supportive company culture where employees can focus on their jobs while at work” (Lockwood, 2003, p. 3). The common definition of work-life balance involves the relationship between work-life conflict and work-life facilitation (Brough et al., 2014).

There is a breadth of literature pertaining to work-life balance. When examining the work-life balance of parents and organizational programs to promote it, flexibility is a key asset, such as with telecommuting and flextime (Hammer et al., 2005). Other helpful programs include those involving financial support, such as paid leave (Brown, 2014). Other studies indicate factors related to work-life balance include family characteristics, such as children’s ages and the number of children in the home. Greater numbers of children and households with young children are related to lower levels of work-life balance (Brown, 2014).

Theoretical Model

The Pearlin Stress Process Model was adapted to develop a multi-dimensional approach to explain caregiver burden and the physical and psychological influence on the caregiver (Carretero et al., 2009). In this model, there are four key dimensions: background and context of stress, stressors,

mediators of stress, and outcomes or manifestations of stress (Pearlin et al., 1990). Pearlin and his colleagues also include objective primary stress factors, which are the caregiver demands, and subjective primary stress factors, which are the negative emotional reactions of the caregiver (Pearlin et al., 1990). Primary stress factors (i.e., the responsibilities and tasks of being a caregiver) affect secondary stress factors, which are other roles and responsibilities of the caregiver (e.g., work, housekeeping, financial management, etc.). Within secondary stress factors, role tensions are created with the caregiver's other responsibilities, resulting in reduced free time, social relationships, economic factors, and employment of the caregiver (Pearlin et al., 1990). Finally, intrapsychic tensions are developed in the form of lowering self-esteem.

However, the stress process can be facilitated with various interventions to reduce negative influences of stress with coping and social support. The primary foci of literature for employer interventions involve accessibility to various employer-provided benefits (e.g., paid/unpaid leave), health insurance, flexible work arrangements, telecommunication, on-site childcare, and employee assistance programs (Chung et al., 2013; Gnanasekaran et al., 2015; Perrin et al., 2007). While the previous literature has addressed the impact on the primary caregiver (i.e., caregiver burden) and whether caregivers have access to benefits, few studies have focused on how to effectively intervene so that caregivers of children with SHCN can best maintain a positive work-life balance via a supportive organizational culture. In the current study, organizational work-family culture was evaluated as a potential solution for this problem. It is theorized that a work environment that facilitates effective time demand management, reassures employees that benefit utilization will not negatively impact their career, and support from managers could ameliorate the effect of caregiver burden on employed caregivers' work/life balance. This is the first study to our knowledge to apply organizational work-family culture as a moderating variable for this population as a possible remedy.

Current Study

Based on gaps in the extant literature, the purpose of the current study was to investigate relationships among caregiver burden, work-life balance, and work-family culture (as well as its facets) in employed caregivers of children with SHCN. We were particularly interested in organizational work-family culture as a potential moderating variable to improve the work-life balance of employed caregivers of children with SHCN, thereby providing a culture of support within the workplace.

Hypotheses

The Stress Process Model explains the relationship between the caregiver's primary stress factors (e.g., caring for their child with SHCN), secondary stress factors (e.g., work), and the subsequent role tensions resulting from these competing demands (e.g., balancing the demands of being a caregiver and work-related obligations) (Pearlin et al., 1990). Higher levels of caregiver burden are associated with negative influences on the physical and mental health of caregivers. However, coping and social support, including positive organizational work-family culture, should help reduce this tension.

In the current study, perceived organizational support was examined to determine if a positive organizational work-family culture is associated with employed caregivers' levels of caregiver burden, including the three main components of this concept (i.e., managerial support, career consequences, and time demands). First, managerial support as a method for social support can be an effective coping mechanism for caregivers and an intervention within the Stress Process Model (Pearlin et al., 1990). The social support of a supportive manager can reduce the role tensions experienced by the caregiver.

Another component of organizational work-family culture is the possible career consequences (e.g., reduced opportunities for promotions) a caregiver faces by altering their job commitment due to caregiver responsibilities. Career consequences are a potential outcome of role tensions between the primary stress factor of caregiving demands and the secondary stress factor of employment demands.

The final component of organizational work-family culture is time expectations as dictated by an organization's norms. Increased caregiver needs, and therefore influence in the form of caregiver burden, result in physical and mental effects on the caregiver. It is theorized that increased organizational time expectations will compound perceptions and feelings of stress on caregivers, as explained by the Stress Process Model (Pearlin et al., 1990). Per the model, primary and secondary stress factors can result in reduced availability of time. Therefore, the additional weekly hours an employee is expected to work will add to the secondary stress factors related to employment and, accordingly, the influence of caregiver burden on the caregiver. Thus, the following hypothesis was postulated:

Hypothesis 1 (H1): Caregiver burden can be significantly predicted from organizational work-family culture, managerial support, career consequences, and organizational time demands.

Organizational work-family culture and its three components were also investigated in terms of their relations with work-life balance. First, the potential relationship

between overall organizational work-family culture and work-life balance was examined, such that improvements in culture could promote better work-life balance. This design can be explained by the Stress Process Model as an intervention to improve work-life balance of the various role strains associated with competing primary and secondary stress factors (Pearlin et al., 1990).

Managerial support provides employees with social support as a coping mechanism in the form of emotional support and role modeling (Greenhaus et al., 2011). The literature has shown a positive relationship between family supportive supervision and employees' work-life balance (Greenhaus et al., 2011). Also, supportive managers understand employed caregivers' levels of responsibilities and encourage the utilization of work-life benefits or other reasonable accommodations to help their caregiving needs. This encouragement can promote participation in work-family policies, thereby empowering them to make appropriate decisions to best balance work and life commitments.

One aspect of work-life balance is effectively adjusting scheduling and commitment to best care for work and life/family responsibilities. When an employer punishes an employee for reducing their work schedule or demands, this affects the work aspect of work-life balance by increasing the secondary stress factor of employment on the caregiver. While the employee can better manage family demands, their work demands are accordingly reduced, and their career can be negatively affected based on how an employer responds.

Contrariwise to career consequences following work-life benefit utilization, increased organizational time expectations emphasize the work portion of work-life balance. According to the Stress Process Model, while the secondary stress factor of employment demands is addressed by increasing work hours, time spent addressing the primary stress factor of caregiving demands is reduced (Pearlin et al., 1990). Thus, while obligations to work demands increase, the opportunity for effectively managing life or family demands decreases. Therefore, the subsequent hypothesis was posited.

Hypothesis 2 (H2): Work-life balance can be significantly predicted from organizational work-family culture, managerial support, career consequences, and organizational time demands.

Lastly, organizational work-family culture will be tested as a possible moderator of the relationship between caregiver burden and work-life balance. If stressors of caregiving complicate one's ability to maintain work-life balance, then higher caregiver burden will be related to lower work-life balance. However, based on the Stress Process Model, a more positive organizational work-family culture will ameliorate this relationship due to scheduling flexibility, supportive management, and reduction in career

consequences (Pearlin et al., 1990). Hence, the final hypothesis was theorized:

Hypothesis 3 (H3): Organizational work-family culture will moderate the relationship between caregiver burden and work-life balance, such that the greater the level of organizational work-family culture, the weaker the relationship between caregiver burden and work-life balance.

Method

Participants

The final sample consisted of 150 employed primary caregivers (e.g., mothers, fathers, stepparents, grandparents, etc.) of at least one child with SHCN. Most (95%) participants self-identified as the child's parent, as Caucasian/White (89%), and as female (89%). Furthermore, 86% have a higher education beyond high school and 62% reported an annual income of \$60,000 or higher. The most prevalent diagnoses listed by participants were autism spectrum disorder (ASD)/sensory processing disorders (23%), ADHD (11%), chronic physical illnesses (9%), developmental disorders (9%), and motor/muscular disabilities (9%). Also, 59% of participants had at least one child with two or more diagnoses, and 3% stated they had two or more children with a SHCN. For participants who reported children with two or more diagnoses, 59% identified having a child with ASD and/or sensory processing disorders. This is unsurprising as ASD is commonly comorbid with other conditions, such as ADHD, behavioral challenges, intellectual disabilities, and chronic physical conditions, particularly when the ASD is more severe (Antshel et al., 2016; Jang & Matson, 2015). On average, participants reported having two children (46%), ranging from 1 to 7 children. See Table 1 for additional participant and child demographic characteristics.

Procedure

The study design was cross-sectional, and data collection occurred in an online setting. After the study was approved by the Institutional Review Board, recruitment began by establishing contact with Facebook and Reddit pages who serve children with SHCN and their families (e.g., Easter Seals, Autism Speaks, hospitals, daycares, caregiver support groups). Facebook is the most popular social media platform among parents, and it provides an avenue for mothers to give and receive support from others (Duggan et al., 2015). Similarly, Reddit as a social media site includes "subreddits" which are forums for users with similar interests, and it serves as a space for discussion surrounding the topic of each subreddit (e.g., r/parenting, r/

Table 1 Demographic characteristics of participants

Characteristic	Description
Caregiver	
Age (years)	$M = 39.31, SD = 6.67$
Gender	89% female, 10% male
Race/Ethnicity	89% Caucasian/White, 1% African American/Black, 3% Native American or American Indian, 1% Hispanic or Latino, 1% Asian/Pacific Islander, 3% other/multiple races
Education	7% doctorate degree, 31% bachelor's, 26% master's, 19% associate degree, 14% high school, 2% professional degree
Marital Status	77% married/domestic partnership, 4% separated, 10% divorced, 2% widowed, 7% single/never married
Number of Children	$M = 2.05, SD = 1.27$
Income (yearly)	38% less than \$60,000, 49% \$60,000 to \$149,999, 13% \$150,000 or more
Hours Worked (total weekly; remote weekly)	$M = 38.24, SD = 10.56; M = 16.12 \text{ h}, SD = 17.88$
Career Status	14% entry-level, 58% mid/intermediate level, 28% senior level
Years of Experience	$M = 6.80, SD = 6.04$
Work Setting Before COVID-19	83% office/building, 9% from home, 8% hybrid
Work Setting During COVID-19	45% office/building, 35% from home, 19% hybrid
Relationship with child with SHCN	95.3% parent, 0.7% stepparent, 0.7% foster parent, 1.3% grandparent, 1.3% adoptive parent, 0.7% other guardian
Quit a job to care for child? (Because of COVID-19?)	65% no, 35% yes (93% no)
Reduced hours to care for child (Because of COVID-19?)	23% no, 77% yes (78% no)
Altered work schedule to care for child (Because of COVID-19?)	9% no, 91% yes (80% no)
Child with SHCN	
Child with SHCN's Age (years)	$M = 8.79, SD = 4.76$
Diagnosis	Autism Spectrum Disorder/Sensory Processing Disorder (23%), ADHD (11%), chronic physical illnesses (9%), developmental disorders (9%), motor/muscular disabilities (9%), epilepsy/seizure disorders (7%), psychological disorders (7%), genetic/chromosomal disorder (6%), hearing/visual impairment (5%), brain damage (3%), intellectual/learning disabilities (3%), behavioral disorders (3%), physical deformity (3%), severe allergies (1%), FASD (1%), Tourette syndrome (1%), failure to thrive (< 1%)
Level of required assistance with daily activities	3% none, 59% some, 38% complete assistance
Required medical procedures	38% never, 38% monthly, 8% weekly, 14% daily
Participation in age-appropriate activities	19% similar to well-child, 49% some, 31% none

Note. $N = 150$

specialneedsparenting, etc.). Information about the purpose and procedure was provided on these sites. Due to the smaller size of this population, a snowball sampling technique was utilized to gain accessibility to this group and to maximize sample size. Participants gave consent to participate prior to starting the survey, which was housed in Qualtrics. The informed consent page stated their participation was voluntary and assured the confidentiality and anonymity of their responses. The survey contained demographic questions, as well as items measuring caregiver burden, organizational work-family culture, and work-life balance. Notably, data were collected during the COVID-19 pandemic. Considering the adjustments likely made by the current study participants, work-life balance

was measured both pre-COVID-19 and during COVID-19 by requesting participants to answer those items twice (i.e., reflect on previous, pre-COVID-19, levels and respond based on current levels of work-life balance during the pandemic).

Measures

Caregiver Burden

The 12-item Adapted Zarit Interview (ZBI) was used to assess caregiver burden (Bedard et al., 2001). This measure was developed as a shortened alternative to the original 22-item ZBI. Bedard et al. (2001) conducted a principal

component analysis with varimax rotation and item-total correlations to develop this shortened version. The findings in Bedard et al.'s study revealed similar results to the original ZBI, thus indicating acceptability of use for this adapted version. Each question was responded to on a 5-point scale ranging from 0 (*never*) to 4 (*nearly always*). Scores are summed to range from 0 to 48, in which higher scores represent higher levels of caregiver burden. Sample items include, "Do you feel that you don't have enough time for yourself because of the time you spend with the person for whom you are providing care?" and "Do you feel stressed between caring for this person and trying to meet other responsibilities (work, family)?" A Cronbach's α of 0.85 was found in the current study.

Organizational Work-Family Culture

The 20-item Work-Family Culture Scale was used to evaluate organizational work-family culture (Thompson et al., 1999). Participants responded on a 7-point scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). A Cronbach's α of 0.94 was found for the overall measure in the current study. In the original study in which this measure was developed, Thompson et al. (1999) conducted a principal component analysis with equamax rotation, with three factors being the most supported based on their criteria: managerial support (Cronbach's $\alpha = 0.93$), career consequences (Cronbach's $\alpha = 0.88$), and organizational time demands (Cronbach's $\alpha = 0.83$). Scores across each factor were composited to develop a total average score. Sample items include, "Employees are often expected to take work home at night and/or on weekends" and "To turn down a promotion or transfer for family related reasons will seriously hurt one's career in my work organization." Higher scores indicated a more supportive work-family culture within the organization.

Work-life Balance

Brough et al. (2014)'s 4-item Work-Life Balance Measure was used to assess work-life balance. Participants responded on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*), with higher scores indicating a higher level of work-life balance. Sample items include "I currently have a good balance between the time I spend at work and the time I have available for non-work activities" and "I have difficulty balancing my work and non-work activities." A Cronbach's α of 0.94 was obtained before COVID-19 and 0.90 during COVID-19. Brough et al. (2014) reported this measure to have "a good fit overall" with CFI = 0.99, RMSEA ranging from 0.02 to 0.07, SRMR ranging from 0.01 to 0.03, and TLI ranging from 0.97 to 0.99.

Data Analysis

All analyses were conducted using SPSS 27. Pearson correlations were computed between caregiver burden, work-life balance, and organizational work-family culture, as well as the three factors of organizational work-family culture (i.e., managerial support, organizational time demands, and career consequences). H1 and H2 were tested with the correlation analysis. Organizational work-family culture (and its three factors) was investigated as a moderator of the relationship between caregiver burden and work-life balance (H3). All variables were first standardized. Multiple regression was employed to test caregiver burden and the three organizational work-family culture components as predictors of work-life balance. Three interaction terms were also created: Caregiver Burden X Managerial Support, Caregiver Burden X Career Consequences, and Caregiver Burden X Organizational Time Demands. PROCESS (Hayes, 2018) was employed to evaluate the moderating effects of total organizational work-family culture and each of three subscales of organizational work-family culture before and during COVID-19.

Results

Bivariate correlations between caregiver burden, organizational work-family culture, and work-life balance during and before the COVID-19 pandemic are presented in Table 2. Caregiver burden was negatively related to work-life balance for both during and before COVID-19, $r = -0.45$, 95% CI $[-0.60 -0.27]$, $p < 0.001$. Additionally, H1 was supported, as caregiver burden was negatively related to organizational work-family culture, $r = -0.28$, 95% CI $[-0.42 -0.13]$, $p < 0.001$ and managerial support, $r = -0.22$, 95% CI $[-0.37 -0.06]$, $p = 0.006$ and positively related to career consequences, $r = 0.30$, 95% CI $[0.15 0.44]$, $p < 0.001$ and organizational time demands, $r = 0.27$, 95% CI $[0.12 0.41]$, $p = 0.001$. A multiple regression predicting caregiver burden from the three components of organizational work-family culture was significant, $R = 0.31$, $F(3, 146) = 5.24$, $p = 0.002$. Due to redundancy among the predictors, none of the unique effects were significant.

H2 was also supported, as organizational work-family culture was positively related to work-life balance for both before and during COVID-19. During COVID-19, $r = 0.52$, 95% CI $[0.39 0.63]$, $p < 0.001$. Before COVID-19, $r = 0.33$, 95% CI $[0.18 0.47]$, $p < 0.001$. Managerial support was positively related to work-life balance both during and before COVID-19. During COVID-19, $r = 0.47$, 95% CI $[0.34 0.59]$, $p < 0.001$. Before COVID-19, $r = 0.27$, 95% CI $[0.12 0.41]$, $p = 0.001$. Career consequences were negatively related to

Table 2 Descriptive statistics and intercorrelations

Variable	1	2	3	4	5	6	7
1. CB	(0.85)						
2. WFC – Total	–0.28**	(0.94)					
3. WFC – MS	–0.22*	0.94**	(0.93)				
4. WFC – TD	0.27**	–0.83**	–0.65**	(0.83)			
5. WFC – CC	0.30**	–0.84**	–0.65**	0.68**	(0.88)		
6. WLB1	–0.45**	0.52**	0.47**	–0.45**	–0.46**	(0.90)	
7. WLB2	–0.45**	0.33**	0.27**	–0.30**	–0.32**	0.55**	(0.94)
Range	8 – 43	1.05 – 6.90	1.09 – 6.82	1.00 – 7.00	1.00 – 7.00	1.00 – 5.00	1.00 – 5.00
Mean	26.75	4.26	4.35	3.82	3.87	2.56	2.73
SD	7.58	1.27	1.35	1.58	1.47	0.96	0.98

Note. $N = 150$. *CB* caregiver burden, *WFC – total* work-family culture total score, *WFC – MS* work-family culture managerial support, *WFC – TD* work-family culture time demands, *WFC – CC* work-family culture career consequences, *WLB1* work-life balance during COVID-19, *WLB2* work-life balance before COVID-19

* $p < 0.01$, ** $p < 0.001$

work-life balance both during and before COVID-19. During COVID-19, $r = -0.46$, 95% CI $[-0.58 -0.32]$, $p < 0.001$. Before COVID-19, $r = -0.32$, 95% CI $[-0.46 -0.17]$, $p < 0.001$. Organizational time demands were negatively related to work-life balance both during and before COVID-19. During COVID-19, $r = -0.45$, 95% CI $[-0.57 -0.31]$, $p < 0.001$. Before COVID-19, $r = -0.30$, 95% CI $[-0.44 -0.15]$, $p < 0.001$. Benjamini-Hochberg's linear step-up procedure was applied to all 21 correlations in Table 2. The adjusted critical values of p ranged from 0.05 to 0.00238. Details on this analysis are available by request to the first author. With the false discovery rate set at 0.05, all the correlations remained significant beyond the 0.05 level.

A multiple regression predicting work-life balance during COVID-19 from the three components of organizational work-family culture was significant, $R = 0.52$, $F(3, 146) = 18.09$, $p < 0.001$. Only the managerial support predictor had a significant effect, $\beta = 0.23$. A multiple regression predicting work-life balance before COVID-19 from the three components of organizational work-family culture was also significant, $R = 0.34$, $F(3, 146) = 6.51$, $p < 0.001$. Due to redundancy, none of the predictors had significant unique effects.

As for H3, we posited that the negative relationship between caregiver burden and work-life balance would be stronger when level of organizational work-family culture is lower. Such a hypothesis is appropriately tested by including an interaction term in the regression model (Hayes, 2018). As shown in Table 3, a multiple regression predicting work-life balance from both caregiver burden and work-family culture with the before COVID-19 data was significant, $R = 0.49$, with both predictors having significant unique effects. Adding the interaction between caregiver burden and work-family culture significantly increased R to 0.52, $F(1, 146) = 6.35$, $p = 0.013$. Looking at the plot of the simple slopes (Fig. 1),

Table 3 Predicting work-life balance before COVID-19 from caregiver burden and work-family culture

Variable	Zero-Order r			β	sr^2
	CB	WFC	WLB2		
CB	(0.85)	–0.28**	–0.45**	–0.38**	–0.37
WFC		(0.94)	0.33**	0.22*	0.21
WLB2			(0.94)		
M	26.75	4.26	2.73		
SD	7.58	1.27	0.98	$R^2 = 0.27**$	

Note. $N = 150$. Entries on the main diagonal are Cronbach's alphas. *CB* caregiver burden, *WFC* work-family culture, *WLB2* work-life balance before COVID-19

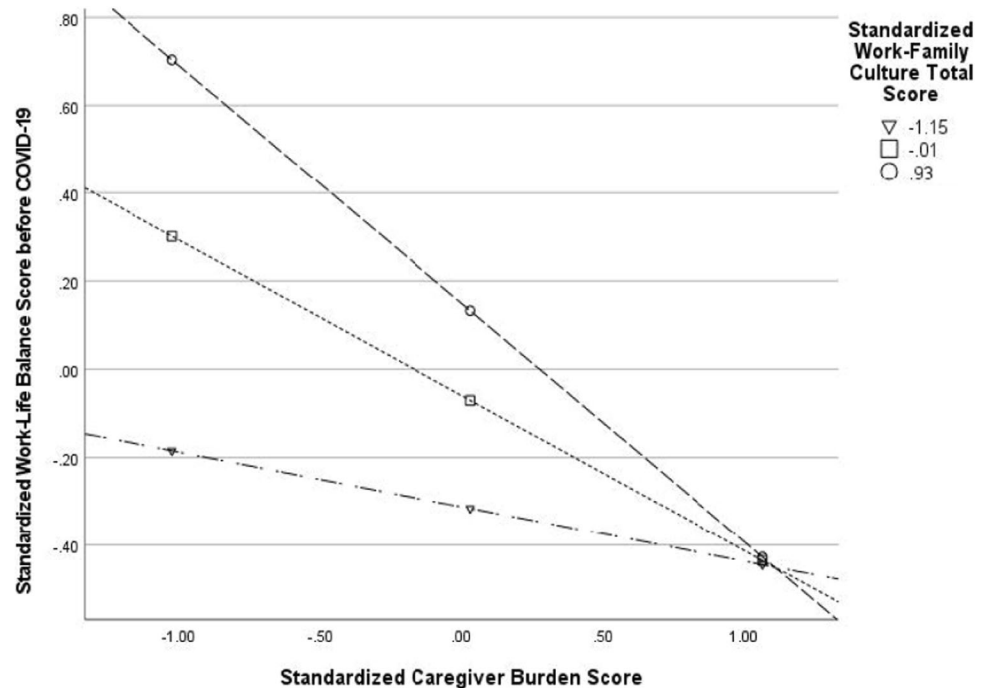
* $p < 0.01$, ** $p < 0.001$

work-life balance dropped less rapidly with increasing caregiver burden when work-family culture was low (1.15 SD below the mean) than when it was near the median (-0.01 SD), and less rapidly when it was near the median than when it was high (0.93 SD above the mean). Although this interaction effect was statistically significant, it was not large, increasing the R^2 by 0.03. Multiple regression analysis with the during COVID-19 data indicated that the interaction between caregiver burden and work-family culture fell well short of statistical significance, $\Delta R^2 = 0.01$, $F(1, 146) = 1.39$, $p = 0.240$. Caregiver burden ($\beta = -0.32$) and work-family culture ($\beta = 0.43$) did have significant unique effects ($p < 0.001$).

Discussion

Primary caregivers of children with SHCN experience an increase in responsibilities compared to caregivers of

Fig. 1 Total work-family culture score as a moderator between caregiver burden and work-life balance before COVID-19



typically developing children, including additional medical care needs, assistance with daily tasks, and financial obligations (Javalkar et al., 2017). These responsibilities, stress, and concerns often lead to higher caregiver burden which, in turn, is associated with increased psychological and physical health issues (Caicedo, 2014). Caregiver burden is also related to decreases in work-life balance for employed caregivers of children with SHCN. These caregivers are placed in a position where they attempt to balance the priorities of their career with those of their child. A proposed solution is the implementation of a supportive organizational work-family culture that assists caregivers with children with SHCN to efficiently balance their family and work responsibilities.

In general, employed caregivers of children with SHCN are vastly understudied and leave a vulnerable population without research-based interventions for support. Thus, this study has filled a major gap in the literature by applying the concept of organizational work-family culture to employed caregivers of children with SHCN. Furthermore, organizational work-family culture and its facets were examined as potential moderators of the relationship between caregiver burden and work-life balance. Organizations with a culture of organizational work-family managerial support and reduced time demands can benefit employers and their employed caregivers. Caregivers with increased caregiver burden may experience improved work-life balance, allowing them to maintain a career and care for their family. Employees with better work-life balance can also provide effective contributions to the organization.

Study findings supported that, as caregivers' amount of caregiver burden increased, their work-life balance decreased. This result reflects the increase in responsibilities and time demands these caregivers face, which can interfere with work obligations. As explained by the Pearlin Stress Process Model, primary stress factors when caring for a child with SHCN and the secondary stress factor of employment lead to resulting tensions between these roles (Pearlin et al., 1990). Competing roles of being a caregiver and the resulting caregiver burden competes with work-related tasks, thereby decreasing work-life balance.

Next, the relationship between caregiver burden and organizational work-family culture, including each facet, were investigated. All these relationships were significant in the hypothesized directions. As caregiver burden increased, overall organizational work-family culture and managerial support decreased, while career consequences and time demands increased. These findings suggest organizations with an implemented, supportive work-family culture could be associated with less caregiver burden.

We also tested the associations between organizational work-family culture and its facets with work-life balance. All these relationships were significant in the hypothesized directions for both during and before COVID-19. Career consequences and time demands were negatively related to work-life balance, while overall work-family culture and managerial support were positively related to it. A supportive organizational work-family culture, including a supportive manager, can be viewed as resources within the Pearlin Stress Process Model, which intervene between

stressors of caring for children with SHCN and the outcome of the stressor (i.e., work-life balance) (Pearlin et al., 1990). Thus, our findings indicate that as organizational work-family culture (including its facets) improves, work-life balance enhances.

In the final hypothesis, organizational work-family culture was examined as a moderator between caregiver burden and work-life balance. Total organizational work-family culture, managerial support, and time demands were significant moderators, but only before COVID-19. These results suggest organizations with more effective work-family culture practices via managerial support and balanced time expectations were beneficial in supporting caregivers with children with SHCN through enhancing their work-life balance before the pandemic. None were significant when considering work-life balance during COVID-19. Perhaps managerial support and an understanding of time demands for employees with families has not been a sufficient method of support without some other supplementation during the pandemic. Furthermore, career consequences were not a significant moderator during or before COVID-19. Promoting managerial support and decreasing stringent time demands (e.g., more flexibility in work scheduling) may directly benefit the work-life balance of employed caregivers of children with SHCN who are experiencing caregiver burden. For instance, managerial support involves an understanding manager who permits changes to be made for employees to better accommodate their family obligations. Similarly, time demands create competition between caregiving and work responsibilities. Thus, improvements in this area promote a better work-life balance for caregivers who have an increase in caregiver burden. These findings support previous research regarding employment time demands, such that employer-provided benefits (e.g., flexible work arrangements and leaves of absence) permit the caregiver to balance time demands more effectively between work and childcare obligations. Conversely, addressing career consequences for adjusting care for one's family is less beneficial for encouraging work-life balance and more of a result of shifts in commitments towards these responsibilities. Overall, this study provides overarching support for time demand balance and managerial support as conceptual interventions. This is significant by adding to the dearth of research for this population and applying the aforementioned concepts to employed primary caregivers of at least one child with SHCN.

Study Limitations

One limitation is a lack of diversity in terms of the sample; it is unknown if the study findings could be replicated with other populations in terms of gender, race/ethnicity, marital

status, income, and level of education. Given that the sample for the current study is largely married, White, mothers with a higher education and a middle- to-upper class income, it is questionable what the results would be for other populations. For instance, in comparison to professional level jobs, low-income workers typically have jobs with irregular hours, working hours assigned on short notice, and less access to formal support, such as onsite childcare and flextime (Bromer & Henly, 2009; Swanberg et al., 2008). Additionally, individuals of racial minorities are disproportionately low-income workers compared to White workers, and experience disparities in access to employment benefits, including health insurance and paid family and medical leave (Bartel et al., 2019; Semyonov et al., 2010). For low-income and racial minority groups, a lack of access to employment benefits to effectively care for a child with SHCN would most likely influence the results and effectiveness of organizational work-family culture, such that a facilitative work-family culture would be far less prevalent among these populations.

Another limitation is the use of self-report, including reflection before the COVID-19 pandemic and during, which is associated with critiques regarding response bias, sampling bias, validity, and objectivity (Haefel & Howard, 2010). Moreover, when reflecting before the pandemic, participants had the benefit of a hindsight view of experiences before undergoing the implications of the pandemic, furthering the bias of their own experiences. However, given the Cronbach's alphas were well above what is considered an acceptable value (i.e., 0.70), the study measures demonstrated sufficient levels of reliability. Also, the scale items rely on the individual's perceptions of their personal experiences as an employee and as a primary caregiver. Personal bias is therefore helpful in determining one's own experiences in these situations (Spector, 1994).

The use of a cross-sectional design might be a limitation due to the inability to make causal inferences. It is often suggested longitudinal designs can provide results in which causal inferences can be made (Spector, 2019). However, improvements can be implemented into cross-sectional designs to enhance the inferences, including determining covariation among measures, implementing temporal precedence, using control variables, and utilizing experimental approaches in the design (Spector, 2019). In this study, covariances were investigated among the measures. Also, participants were primed to consider their work-life balance before and during COVID-19 (temporal precedence) due to anticipation of changes in this measure upon reflection of the pandemic.

Additionally, convenience sampling was utilized in the current study as a method for recruiting participants. Convenience sampling is often recognized within research as lacking generalizability in comparison to probability

samples (Jager et al., 2017). However, it is more cost-effective and continues to be the more common approach in developmental science research than probability sampling. As an alternative, homogenous (contrariwise to heterogeneous) convenience sampling is recommended. With this method, intentional constraints are placed upon the selected population (Jager et al., 2017). In the current study, it is possible that the specificity of the population regarding requirements for inclusion (i.e., previous or current employment with at least one child with SHCN), might mitigate some of the issues with convenience sampling.

Lastly, the use of social media as a recruitment source could be a limitation due to the lack of available response rate because it is unknown how many individuals viewed the posts as a potential number of participants. Also, accessibility to the social media site requires a computer or smart device and internet connection, as well as digital literacy, therefore, individuals without access to this technology or digital literacy would be excluded from the study. Finally, the use of social media recruitment techniques suggests those who were part of these groups or seeking these pages are pursuing assistance in the form of programs, advocates, and peers in similar situations. Therefore, the generalizability of the findings may be limited to families that are active on these social media sites and support groups. Nonetheless, this method was the most feasible given the presence of the COVID-19 pandemic during data collection. In-person recruitment methods (e.g., visiting schools, hospitals, and other organizations) would have violated social distancing and stay-at-home orders.

Organizational Implications and Future Directions

Our results demonstrate the importance of applying a culture that supports the needs of employees with children with SHCN in various organizations. Programs, policies, and practices should include managerial support and flexibility with organizational time demands. For example, managers can receive training to provide background information on children with SHCN and the various stressors these families face. Additionally, training could include tactics for permitting flexible work schedules, remote work, or other programs and policies to support these families in balancing their work and family obligations. An important first step is for employers to survey current employees to research what is most beneficial for their organization and its employed caregivers.

Future researchers could investigate the lack of significance of career consequences as a moderator of the relationship between caregiver burden and work-life balance. It is unclear why only managerial support and time demands were significant moderators. Furthermore, although our aim was to examine overall parental burden

and stress related to chronic health conditions, future researchers may examine how specific childhood health conditions influence caregiver burden/stress, which may subsequently influence the moderation effects. Other researchers might examine various populations' experiences with these issues, including single parents, dual-earner families, racial and ethnic minority groups, foster parents, low-income households, etc. Other future directions include organizational work-family culture in various industries, such as healthcare, manufacturing, hospitality, etc. to see if there are variations in how an organization can implement such a strategy. Lastly, organizational work-family culture was not a significant moderator for work-life balance during COVID-19. Future researchers may seek out other solutions to support families during societal and economic downturns, such as the COVID-19 pandemic, and how organizations can effectively support these families during such challenging times.

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Compliance with ethical standards

Conflict of interest The authors declare no competing interests.

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