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ORIGINAL ARTICLE

Experiences of Parental Caregivers of Adults with Autism in Navigating the World of Employment

Christina N. Marsack-Topolewski[1] · **Preethy S. Samuel**[2]

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Abstract

Purpose Caregiving often presents challenges for parents, particularly for parents of loved ones with disabilities or health challenges, who need and/or want to be employed. This study describes the employment experiences of aging parents as they continue to balance engagement in the paid workforce with the ongoing provision of care for their *adult* children with autism spectrum disorder (ASD). The purpose of this study was to examine the lived experiences of parents of adult children with ASD in the context of balancing career and caregiving responsibilities.

Methods The current study uses a qualitative phenomenological research approach to describe the lived experiences of 51 parents who were caring for an adult child with ASD. The parents participated in telephone interviews to obtain information about their career experiences while providing care and support to their adult children with ASD.

Results Three caregiving themes emerged including: (a) difficulty balancing caregiving with work responsibilities, (b) reasons for working, not working, or working intermittently, and (c) work as an escape or wanting to work more.

Conclusion As more individuals with ASD reach adulthood, often relying to varying extents on their families for daily support, parental employment will continue to be impacted as they juggle their career with caregiving responsibilities. Economically, one or more family members typically need to work to sustain the family's needs and employment support should be considered. As a society, families often need to make choices even with an adult child with ASD of who will work, how, and when.

Keywords Caregivers · Employment · Adults with autism · Career · Employee caregivers · Qualitative research

Despite the joys and rewards of raising children, parenting is associated with many challenges (Barroso et al., 2018; Bekhet & Matel-Anderson, 2017; Foody et al., 2014; Waizbard-Bartov et al., 2019). Parents caring for loved ones with disabilities may face unique circumstances in many facets of their lives (Myers et al., 2009; DePape & Lindsay, 2015). In the United States and worldwide, an estimated 1 in 36 children is diagnosed with autism spectrum disorder (ASD), with impairments ranging from minimal to severe (Centers for Disease Control and Prevention, 2023; Fombonne, 2020). Within the past two decades, the reported incidence of ASD has increased 269% (Nevison et al., 2018; Van Naarden Braun et al., 2015). Recent estimates from Dietz et al. (2020) indicated that nearly 5.5 million adults are diagnosed with ASD in the United States. This condition is associated with varying manifestations that affect social, communication, developmental, and behavioral functioning across multiple contexts and settings (e.g., school, work, home environment; Leung et al., 2018). While ASD

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✉ Christina N. Marsack-Topolewski
cmarsack@emich.edu

[1] School of Social Work, Eastern Michigan University, 206H Everett L. Marshall Building, Ypsilanti, Ypsilanti, MI 48197, USA

[2] College of Pharmacy and Health Sciences, Wayne State University, 259 Mack Avenue, Detroit, MI 48201, USA

typically presents in early childhood, individuals with this disorder are impacted across their lifespan (Chamak & Bonniau, 2016).

Predominant literature focuses on children and adolescents with ASD and their younger parents (Ackert et al., 2018; Callander & Lindsay, 2018), although these parents typically provide ongoing care for their children into adulthood (Dillenburger & McKerr, 2011; Seltzer et al., 2011). Even as adults, individuals with ASD may require a substantial amount of time and support from their parental caregivers (Pozo & Sarriá, 2015; Sonido et al., 2022). Responsibilities often present challenges for parents who need and/or want to be employed when compared to the general population of parents whose adult children have *launched*. This study explores employment experiences of aging parents as they continue to balance paid work and provide care and support to their *adult* children with ASD.

Impacts of Caregiving

Caring for an adult child with ASD can vary from requiring minimal practical and/or financial assistance to providing round-the-clock support to attend to the physical, verbal, and practical needs (Marsack-Topolewski & Maragakis, 2021; Smith et al., 2012). As children with this condition transition into adolescence and adulthood, their caregiving needs may change, with many remaining dependent on their parental caregivers who often had few available options for support and experienced challenges in maintaining employment (Banda et al., 2022; Marsack-Topolewski & Weisz, 2020; Chamak & Bonniau, 2016). Decreased formal service options combined with shrinking available social networks may further compound one's caregiving responsibilities, particularly for those needing or wishing to maintain part- or full-time employment (Turcotte et al., 2016). Although care needs vary among individuals with ASD, parental caregivers often experience stress, caregiver burden, and time demands that affect their ability to maintain productive employment (Marsack-Topolewski & Weisz, 2020; Myers et al., 2009).

Caregiving and Employment

For many people, employment provides a sense of financial security, as well as independence, personal fulfillment, and social engagement (Repetti & Wang, 2014). In the United States, the cost of caregiving is often assumed by family caregivers, resulting in an estimated loss of over 650,000 jobs, with nearly 800,000 caregivers experiencing workplace absences due to their caregiving demands (White et al., 2021). The total impact of providing care through both direct and indirect channels has been estimated to total $264 billion in economic loss for both families and society (White et al., 2021). Juggling caregiving and employment responsibilities can be challenging for parents in general, but can be magnified in intensity for parents caring for children with ASD (Watson et al., 2021). Many caregivers across the continuum of their children's lives often need to forego, change, decrease, and/or leave their employment simply to provide the necessary level of care to their loved ones with ASD (Cidav et al., 2012; Stoner & Stoner, 2016). According to Montes and Halterman (2008) and supported by Houser et al. (2014), parents are 4 to 7 times more likely to quit their jobs to provide care for their child with ASD. Providing daily care and support and balancing family caregiving needs with work-related responsibilities can pose strains on one's ability to be actively employed in the workforce (Banda et al., 2022; Callander et al., 2016).

Parents of adults with ASD frequently struggle to balance job, family, and caregiving responsibilities; often resulting in barriers for caregivers to meet their educational and employment aspirations (Bainbridge & Broady, 2017; Bauer & Sousa-Poza, 2015). Research has found that parents, particularly mothers of children with ASD, have trouble finding jobs that meet their employment and family needs (Stoner & Stoner, 2016). Some parents feel pressure to forego paid employment and give up on their professional and academic goals (Schofield et al., 2019; Stoner & Stoner, 2016). Other parents might discover that their jobs provide a source of respite from the ongoing demands of caregiving (Joseph & Joseph, 2019). While many studies have examined experiences of parents of younger children with ASD (Callander & Lindsay, 2018), a paucity of research has been found that investigated the lived experiences of aging parental caregivers of adult children with ASD in the context of their employment experiences.

Problem Statement

The purpose of this qualitative phenomenological study is to examine the lived experiences of parents of adult children with ASD who are balancing employment in addition to their caregiving responsibilities. The research question developed for this study includes: What are the lived experiences of parents who are simultaneously providing care for their adult children with ASD and are or have been employed?

Methods

Recruitment

Following Institutional Review Board (IRB) approval from Wayne State University, the principal investigator (PI) contacted local, statewide, and national organizations of autism groups, as well as practitioners who interacted with adults with ASD and their parents, to support recruitment efforts. These organizations distributed study informational material and a link to the online survey on their websites, newsletters, and/or via email to encourage member involvement. Potential participants also were contacted directly through recruitment attempts (e.g., autism support groups, snowball sampling).

The qualitative portion of this study comes from a larger quantitative survey that assessed caregiver burden and quality of life. To be eligible to participate in this study, parents had to be at least 50 years of age and have an adult child (minimum of 18 years old) diagnosed with ASD as stated by parent self-report. This survey was completed by 320 parents. After completing a web-based survey, 186 parents agreed to take part in semi-structured interviews (Marsack-Topolewski & Church, 2019). A random sample of 51 parents (27.4%) was selected to participate in follow-up interviews. The qualitative portion of this study was closed following the completion of the 51 interviews. The researchers were confident that data saturation had been achieved and included representative perspectives of caregiving experiences for adults with ASD. The PI scheduled the one-on-one interviews. All interviews were recorded following participant consent.

Sample

The initial study collected demographic information on the parents and their adult autistic children; however, no additional demographic information was obtained from the interviewed parents to assure confidentiality of their qualitative interview responses. Since the 51 interviewed parents participated in the larger study, their personal characteristics were presumed to be similar to the demographic information of the parent study. The majority of the 51 parents who were interviewed were 46 (90.2%) were mothers. From the parent study, participants ranged in age from 50 to above 70 years, with most between 50 and 59 years of age ($n=212$, 66.3%). The educational levels of most of the participants included (bachelor's degrees ($n=100$, 31.3%); master's degrees ($n=90$, 28.1)-, and doctorate/professional degree ($n=33$, 10.3%).

Parents were living in suburban and rural parts of the United States. Most parents had at least one additional child, and several reported having a second child with an ASD diagnosis or other long-term illness. To protect the respondents' privacy, all names and other identifying information were removed from the recordings and transcriptions of the interviews. Although an attempt was made to recruit participants from organizations that were likely to include racially and ethnically diverse parents, most parents were Non-Hispanic White ($n=289$, 90.2%). Most participants were married ($n=252$, 79.2%) and their annual family incomes ranged from less than US$20,000 to more than US$100,000.

The adult children with ASD ranged in age from 18 to 44, with the majority being emerging adults in their 20s. Ten parents had an adult daughter with ASD, while 41 parents had adult sons with the disorder. These demographics were in line with research showing that men are diagnosed with ASD about four times more frequently than women (Christensen, 2016). Most of the adult children were enrolled in public schools or had recently graduated from them. The parents indicated that their adult children's capacity for social interaction, communication, doing daily tasks, and employment varied.

Procedure

The current study uses a qualitative phenomenological research approach to explore the lived experiences of parents who were either currently working or had tried to work while caring for adult children with ASD. Prior to conducting the present study, professionals (i.e., school social worker, teacher consultants, special education teacher, school psychologist, speech pathologist, and transition coordinator) who work with people with ASD and other developmental disabilities were consulted regarding the readability and relevance of the interview questions. Professionals offered feedback on the interview questions, which the PI used to enhance their readability and relevance, as well as ensure the credibility of the interview questions. Minor changes were made to wording based on the feedback derived. Over a two-month period, the PI conducted interviews over the phone, with one interview taking place in person. A script including nine open-ended semi-structured questions was used to guide the interview process. The purpose of the questions was to learn more about the parents' experiences with raising an adult child with ASD. The participants' challenges with working and providing care to their adult child with ASD were the main topics of the interviews. While parents were not asked direct questions regarding their employment experiences and perceptions of employment while caring for an adult child with autism, comments and discussion points regarding their experiences in these topical areas

Table 1 Sample characteristics: parents' demographics (N 320)

Parent Characteristics	*N*	%
Parents' age		
50 to 59	212	66.3
60 to 69	95	29.7
70 and over	13	4.0
Gender of parent completing survey		
Male	57	18.0
Female	259	82.0
Missing 4		
Ethnicity		
African American/Black	5	1.6
American Indian/Alaskan Native	1	0.3
Caucasian/White	289	90.9
Hispanic	12	3.8
Multiethnic	6	1.9
Other	5	1.5
Missing 2		
Marital status		
Single, never married	6	1.9
Married	252	79.2
Divorced	41	12.9
Widowed	11	3.5
Co-habiting	2	0.6
Separated	6	1.9
Missing 2		
Educational level of respondent		
Less than high school	1	0.3
High school/GED	10	3.1
Some college	42	13.1
Associates degree/technical school	44	13.8
Bachelor's degree	100	31.3
Master's degree	90	28.1
Doctorate/professional degree	33	10.3
Annual Family Income		
Less than $20,000	14	4.5
$20,001 to $40,000	24	7.7
$40,001 to $60,000	42	13.4
$60,001 to $80,000	45	14.4
$80,001 to $100,000	37	11.8
More than $100,000	103	32.9
I would prefer not to respond	48	15.3
Missing 7		
Living Arrangement of Adult Child with ASD		
Live independently	22	6.9
Live independently with support	35	10.9
Live in group home	14	4.4
Live with parents	249	77.8

emerged. At the end of the interview, each interviewee was given a $20 gift card.

A professional transcriptionist transcribed the interviews. The PI used member checking with 10 study participants to validate interpretations. Using Atlas.ti 7 software, the interviews were coded for analysis once transcription accuracy was confirmed. The PI and co-investigator independently coded the interview responses before comparing their findings. Line-by-line analysis was a component of the phenomenological approach to creating initial codes and subthemes. They applied bracketing, as recommended by Creswell and Poth (2018), to ensure that the coders were conscious of any potential biases they might have when coding. The investigators were able to identify trends in the data using this coding method. Aligned with Saldaña's (2016) recommendations regarding coding, codes were collapsed and combined to improve the themes and patterns.

Findings

Each of the parental caregivers included in this research discussed their lived experiences with employment while providing care for their adult children with ASD. Through thematic analysis of the transcribed interviews, three overarching themes emerged related to employment among parents of adult children with ASD. Specifically, the themes regarding caregiver employment include the following: (a) difficulty balancing caregiving with work responsibilities, (b) reasons for working, not working, or working intermittently, and (c) work as an escape or wanting to work more. Descriptions of each of the emerging themes, including quotes from participants, provide an explanation of the association between caregiving for an adult child with ASD and experiences with employment. The confidentiality of participants is maintained using pseudonyms.

Difficulty Balancing Caregiving with Work Responsibilities

Many parental caregivers shared comments regarding their challenges associated with balancing their careers with caregiving. Depending on the severity of their adult children's ASD and/or time associated with providing care, parents discussed having to take time away from work to address situations that required their immediate attention. Some parents reported difficulties when they had to stop working to take telephone calls involving their adult children's behavior at school, ability to socially navigate in the community, or at their work.

One mother, Veronica, expressed her frustration and challenges when her son requires immediate attention while she is working. For example, her son calls frequently because he gets lost and relies on her for assistance. Veronica commented that she must tell her son constantly that:

> You know, I can't come and get you. So, you're going to have to ask for directions… and he made it home. I mean, there's lots of little things that come up through the day constantly and it's like ok, I'm at work. I'm trying to do my job and then this type of situation happens.

While she feels her supervisor is somewhat tolerant of these frequent interruptions, Veronica finds it very challenging to do her job, illustrating that her colleagues do not fully understand why an adult child needs so much support.

Like Veronica's experiences, other caregivers discussed feeling the pressure of having to work in settings that were not conducive to their caregiving demands. For example, one mother (Breanna) discussed the challenges of working in the same school district her adult son with ASD was attending. She shared "… one of my bosses was getting angry with me because I was fighting for things for my son. So, I had to kind of be careful about what I asked for." Ultimately, she decided to take a step back in her advocacy role as a parent due to her need to maintain her employment. She alluded to being pressured to maintain a non-conflictual work environment while knowing that her son deserved more educational support. Ultimately, she made the choice to defer advocating for her son educationally, knowing she needed to maintain her employment for the betterment of her family.

Another parent, Camilla, talked about receiving frequent calls from her adult son, Sam, who required immediate support while she was at work. She perceived these interruptions as tremendously stressful.

> I'd get phone calls. He was at the local restaurant and having a meltdown. Sam drives his own vehicle and he hit a sign that had the prices of the fast food restaurant. The manager told him that he had to pay for it [the sign with prices] and he just flipped out. They had to call the police.

Camilla went on to explain how all of this was happening while she was in the middle of a time sensitive work project. "Those kinds of things… they're just so stressful and so difficult to keep a regular eight-to-five job when you have to leave so much."

Despite the specific experiences shared by parents of adult children, in essence, their stories and examples resonated with personal challenges while balancing both caregiving and work responsibilities. Supporting practical, everyday needs of an adult child with ASD, while navigating work responsibilities, can be difficult. Having to tend to the immediate needs of an adult with ASD with little or no notice often takes parents away from work psychologically or even physically and can result in stress and disruptions for those trying to maintain employment.

Reasons for Working, Not Working, or Working Intermittently

Becoming a parent generally requires navigating new responsibilities and recalibrating one's life to adapt to new roles. For parents of children with disabilities, caregiving is generally lifelong and continues as their child moves from childhood to adolescence and then into adulthood (Dillenburger & McKerr, 2011; Seltzer et al., 2011). While caregiving can be very different for each caregiver of an adult child with ASD, most parents assume lifelong roles providing emotional, social, financial, and physical support, which may influence their career pathways in unexpected or unplanned ways.

Caregivers often must navigate how and where they will work, as well as when they can work. Over time, they often try to adapt their work schedules to match their dynamically evolving caregiving responsibilities. Some parents realize that for various reasons, they may be unable to work in the same way or may choose to work in some capacity. Parents in the present study discussed reasons for working, not working, or working intermittently throughout their traditional work years.

For example, Bill shared that his wife, Margaret, was unable to work due to the caregiving demands and responsibilities to meet her son's needs.

> She can't work because she never, you know, she could never hold a job because of always being called by the school or whatever because of the trouble he was getting in. There was no daycare that could handle him or anything like that. So, she is home. I'm going to say, 70% of her day, every single day, revolves around cleaning up after him, taking care of him, making sure he's taking his meds, scheduling staff, everything else. 70%. She has a full-time job doing that.

Bill described the care Margaret provides as a "full-time job," making even part-time work for pay outside the home difficult, thus influencing her ability to have a career.

Similarly, Anna described that her work responsibilities made it difficult for her to provide care for her son, causing her to choose to invest in her life role as a mother instead of her career. She stated, "Well in the past it was hard, I had to quit my job. I quit my career and we struggled because a lot of people don't realize that you have this job, but you have physical therapy, speech therapy appointments, oh my God I mean… I mean massive medical bills." She talked about the expenses associated with her son's treatments and therapies (e.g., speech therapy, sensory integration therapy) when he was initially diagnosed. Anna reflected that she considered herself lucky that her husband's work provided discretionary funds to pay for out-of-pocket medical treatments without her having to hold either a full- or part-time job. She reflected on the many appointments and responsibilities that would have been very challenging to make had she been working outside of the home.

Another mother, Susanna, talked about giving up her career, but as a family not being financially impacted. She shared, "I'm so happy, you know, for my husband and I, we're pretty well off, and so money is not the issue. I had to give up my career as a television producer. When he was in high school, it was very hard. I mean, I had to give up my career, and I did because I love my son and I have two other children and it was hard." She described early on not having a diagnosis for her son. When the family eventually received her son's diagnosis, she reflected that they didn't know about Asperger's and didn't know what "problems" were associated with this condition. Like Bill, she talked about how no daycare would accept her son, so she felt forced to leave her full-time job. While Susanna emphasized that her family was not adversely impacted by her not working, she did wonder what her life would have been like, stating:

> And I think to myself as a television producer up and coming, 'Oh, my God,' I was just rising in my career. I thought, wow. I wonder what would have been different in my life had I been able to go on and do that, but I worked with a television crew that traveled. There was no way that I could do that.

This quote illustrates her loss of her career identity as a "television producer" as she could not figure out a way to keep a job that required traveling. Although Susanna indicated that finances were not a problem when she had to quit, she did reflect on turning 60 next week and realizing that her social security timeline with a major drop off in benefits from her decision to quit the paid workforce.

Other parents talked about having to take pauses throughout their work lives and then coming back to paid employment when care demands of their child with ASD became more manageable. For example, Olivia stated: "And sometimes I didn't work at all over the years, so you have to see the loss of income. I would do some freelance stuff, but I didn't have a regular job for a lot of the time too." Another mother, Patsy, talked about having to take a lot of time off due to her son's escalating maladaptive behaviors. For example, "I always worked, until I had to take a lot of time off work to deal with Joe who was having problems in school or meltdowns at home. I had to leave my job and things like that." Another mother, Naomie, discussed leaving their profession or foregoing work altogether. Jessica was an entrepreneur and owned her own business. However, to provide care for her adult daughter with ASD, she was forced to sell her business. She stated that she sold the company when her second daughter was diagnosed, and now her income is extremely modest. In sum, many parents talked about the reasons they worked, the problems they faced at work, and the things that kept them from working every day. Many families experienced financial consequences or challenges as a result of being unable to work consistently or intermittently.

Work as an Escape or Wanting to Work More

For many caregivers, work can provide a sense of normalcy, a schedule, and some may even say respite or retreat from the relentless caregiving demands associated with caring for a loved one with ASD. While parents described a myriad of reasons for working or not working, including the challenges of balancing work with caregiving obligations, other parents indicated that they used work as an escape from their responsibilities of caring for their adult children. In contrast, other parents who were unable to work a traditional 40-hour work week, discussed their desire to work more for various reasons (e.g., a sense of accomplishment, having something of one's own, getting out of the house). One mother, Sara, described the many caregiving obligations that she assumed when her husband retreated to work beyond his typical work day to avoid their caregiving responsibilities. She described the reality of having a child with a severe disability and associated caregiving demands were challenging for her husband to grapple with, instead using work as an escape. She said, "He [Sara's husband] hid because he didn't want to deal with a child with a disability. He couldn't deal with it. It was very painful…".

Other parents in the study also described work as being an escape for themselves and/or their spouses from the perceived challenging caregiving responsibilities. For example, even parents who work at home can have difficulty in maintaining a work schedule when providing care for an adult child with ASD. Sheila described taking a job as an accountant working from home during tax season each year. She talked about the perceived burden of balancing care for her son who was "severely" impaired with a dual diagnosis in ASD and Down syndrome with her work responsibilities. She also described the challenges she had navigating caregiving and work while her husband's job took him away from the home regularly for international travel. Sheila indicated that:

> I didn't know what to do and honestly, I thought I was ready to crack up. I mean I was really teetering on the edge of sanity because he [her son] would come home from school and if it was one of the nights that one of

> the paid caregivers didn't come, I would have to stop work immediately. When something happens and they [paid caregivers] can't watch him, I have to stop what I am doing and just sit there with him because that's what he does.

From year to year, Sheila does not always know if she will be able to return to her seasonal work as a professional tax accountant. Her caregiving situation is complicated by not knowing if she will be able to secure the right support for care from her home state. Sheila described the needs of her son as being quite complex due to his dual diagnosis and his need for psychiatric care, requiring an admittance into a psychiatric facility. Echoing many parents' voices in the present study - Sheila illustrated her deep want to continue her paid employment as work gave her something she enjoyed and an escape from the complex caregiving challenges of her son.

Jordan reflected back on needing to put the right supports in place to manage his son's [Patrick] complex conditions including ASD. He described the crisis he felt due to his son's disability and a host of other challenges and retreating to work. Jordan shared,

> And such crisis at home, my response was to do the thing I'm good at, which is go to work and I had the opportunity to work, so I thought, 'you know what, I'll if I make, I can work more, I can make more money, I can- that's my contribution, I can help a lot'. It's just, we [my wife and myself] lost sight of each other, like we were on either ends of a fox hole, throwing hand grenades and shooting in different directions and once in a while tossing each other some supplies. I mean, it was just such a battle, and I don't mean to be too dramatic, but it was like that.

Since that time, Jordan has been able to work with his wife to secure appropriate support and services for Patrick and works diligently to be a present and supportive father while balancing his very demanding career. Many parents, in the present study, described wanting to work or using work as an escape to avoid their relentless caregiving responsibilities and challenges.

Discussion

The purpose of this qualitative phenomenological study is to examine the lived experiences of parents of adult children with ASD who are balancing employment in addition to their caregiving responsibilities. Three themes emerged from the analysis of the parental caregivers' responses, including difficulty balancing caregiving with work responsibilities, (b) reasons for working, not working, or working intermittently, and (c) work as an escape or wanting to work more. Each of these themes is discussed along with relevant previous research.

Not surprisingly, many parents (Veronica, Breanna, Camilla) discussed the challenge of juggling caregiving and career. Although many might assume that demands get easier as children grow older, this is often not the case for children with ASD aging into adolescence and adulthood. The caregiving realities and responsibilities often change as children with ASD transition into adulthood. Services and support available during childhood (e.g., therapy, public education, social work) typically end, with parents often tasked with searching and navigating for adult-based disability support (Turcotte et al., 2016; Schott et al., 2021). A "black hole" or "services cliff" has been described as the point at which the landscape of support and services for people with ASD declines dramatically after they reach adulthood (Roux et al., 2017). This service decline impacts not only adults with ASD, but their family members. Professionals should be aware of the unique support needs of adults with ASD and their caregivers (Elias & White, 2018; Turcotte et al., 2016).

Given the diverse needs of individuals with ASD, many parents discussed challenges to remain in the paid workforce when support and outside care was not available. Some parents discussed additional layers of complication to working or the inability to work altogether due to the inability to find adequate support and help (e.g., care for their loved ones with ASD). Likewise, other parents also described perceived high demands (e.g., needing to take their loved one to frequent medical appointments) that made working nearly impossible. These findings aligned with research outcomes that provided evidence that parents of children with ASD experience greater challenges with employment, productivity, and financial problems in part due to the loss of income (Houser et al., 2014; Lynch et al., 2023).

For many new parents, there is an adjustment to parenting life, with typical day-to-day responsibilities and tasks changing drastically and suddenly with the birth of a child. Finding childcare and relevant support to coincide with a typically developing child's needs can be challenging and time consuming. However, for parents of children and adults with ASD, finding and navigating services can look and feel much different. For example, caregivers in the present study talked about the difficulties accessing some form of support or childcare and described challenges that superseded those with typically developing children. For parents unable to access childcare, keeping and maintaining employment was complicated if not perceived as impossible by caregivers in the present study. These findings coincide with previous research that indicated challenges with identifying care and support, with many families experiencing unmet needs (D'Arcy et al., 2023).

Finding and financing care can be costly for families of children with ASD across the lifespan. For families where one parent is unable to work outside of the home due to the severity of ASD and the corresponding care needs, this situation can have a financial impact. In the present study, some families discussed being somewhat insulated from financial challenges when one parent was unable to maintain employment due to the other parents' salary. However, most families were negatively impacted financially with only one income. Adverse financial implications associated with having a child or adult child with ASD have been well documented in the existing literature (Banda et al., 2022; D'Arcy et al., 2023; Dovgan et al., 2019; Rogge et al., 2019), with the present study's findings supporting their results.

Policy initiatives should include affordable care for all individuals needing care, including those with complex, special needs (Scales, 2021). Child care and care delivered to other populations (e.g., older adults, individuals with chronic illness) continues to pose challenges for caregivers who need to work (Bressan et al., 2020; Mollica et al., 2020). For families of individuals with ASD, finding care poses additional complexities due to the shortage of direct care workers and unique needs of each individual with ASD (Marsack-Topolewski & Weisz, 2020; Fleron et al., 2022). Policy efforts are important and needed now more than ever.

For parents who were unable to work or those who needed to work intermittently, some described a loss of identity and career advancement. Findings by D'Arcy et al. (2023) indicated that parents in their study "articulated a sense of loss in self, identity and career opportunities" (p. 7). Some parents of typically developing children may leave the workforce for extended time periods (e.g., many years) to raise their families and are then able to re-enter the workforce in some capacity. However, for parents of children with ASD, caregiving tasks remain into adulthood, preventing them from re-entering the employment setting.

In addition to financial benefits, career advancement, and a personal sense of identity that may result, in part, from being employed, many parents discussed respite and a break from the ongoing caregiving demands when they were able to work. Likewise, the concept of work as providing a "space for respite" was described by Joseph and Joseph (2019). Given the ongoing and sometimes mundane tasks that are associated with the provision of care, the notion that work provided caregivers with a place for and sense of respite is logical. Many caregivers in the present study described work serving as respite, with some referring to work as intellectual stimulation that is often missing in caregiving.

Implications for Practice

As individuals with ASD exit juvenile services and support and enter adulthood, service options often decrease. Parental caregivers who were able to work while their children with ASD were in school, may find that providing care to their adult children negates their ability to work outside of the home. Parents who are employed should be supported through targeted and tailored services for both adults with ASD, as well as themselves. Employers should provide flexible work options to the extent possible (when needed) and understand that interruptions may occur during the workday. The interdependent relationship between employee and employer is important as parental caregivers can provide valuable services to their organization, with employers being supportive by helping decrease stress associated with caregiving and simultaneous work demands. Based on study findings, having supervisors and managers that understand the non-normative caregiving realities can be beneficial to employee caregivers. As such, employers should develop an understanding of the realities of caregiving for adults with ASD and provide support and empathy.

Government agencies should work with employers to help them develop policies that could include flexible work schedules, ability to work from home, and financial help with costs associated with providing outside care for the adult with ASD. The predominance of support available for individuals with ASD are offered for those in their childhood and adolescent years. Enlisting the assistance of a social worker can help employers understand the unique needs of employees who are also providing care for an adult with ASD. Adult children with ASD can benefit from the support provided to their parental caregivers from their employers. Programs and support should be developed and expanded to support the needs and preferences of adults with ASD and their family caregivers.

Hiring and training employees can be expensive and time consuming for businesses. To maintain employees who are qualified and experienced, employers need to be aware of their obligations beyond the workplace and be able to provide support for caregivers of adults with ASD. Providing flexible hours, ability to work from home when caregiving needs arise, and being understanding when the caregiver is interrupted during their work hours are ways that employers can provide needed support and maintain their workforce.

Study Limitations

Limitations of the present study should be acknowledged. Because most participants were found through ASD support groups and organizations, those who are not connected to these groups may have been inadvertently excluded.

Despite the use of snowball sampling strategies, it is doubtful that families who are more isolated or do not belong to a wider network would be included in the study. One possible limitation is that many parental caregivers employed may not be represented due to the combination of caregiving and employment responsibilities. Future studies should seek to recruit parental caregivers who are not connected with formal groups and organizations.

Another limitation is that information regarding the severity of the ASD for the adult children was not gathered. Most parents who participated in the interviews reported that their adult child(ren) had moderate or severe impairments. This element may also have influenced parental caregivers' ability to be employed. Additional research is needed that uses an ASD checklist to determine severity of ASD for adults whose caregivers are participating in research.

The sample was predominantly comprised of participants who were White, female, and had higher socioeconomic statuses. Additionally, families who had fewer financial resources may have faced various employment-related difficulties may have not been included in the sample. Future research should examine experiences of parental caregivers of adults with ASD with fewer financial resources, less education, and fewer employment opportunities (e.g., those living in rural areas).

Conclusion

As more individuals with ASD reach adulthood, often relying to varying extents on their families for daily support, parental employment will continue to be impacted as they juggle their career with caregiving responsibilities. Caregiver employment support should be considered because one or more family members typically need to work to sustain the family's financial needs. The findings of this study indicated three themes related to employment experiences of parents providing care to adult children with ASD. These three themes: (a) difficulty balancing caregiving with work responsibilities, (b) reasons for working, not working, or working intermittently, and (c) work as an escape or wanting to work more, were indicative of parents' trying to establish equilibrium between caregiving responsibilities and employment. As a society, families often need to make choices even with an adult child with ASD of who will work, how, and when.

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Declarations

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All procedures performed in this study involving human participants were in accordance with the ethical standards of Wayne State University's Institutional Review Board.

Informed Consent For the web-based study, the use of an electronic survey program precluded the use of an informed consent form. In its place an information sheet that required the participant to indicate that he/she agreed to participate was used. At the end of this web-based survey, participants were informed that a follow up interview would be conducted with interested participants. Participants could indicate whether they would be interested in sharing more information regarding their experiences. For participants interested in sharing more information, they were asked to select "yes" and leave their name and contact information. An email was sent to participants that indicated interest in participating in the follow up interview. In the email sent and in the interview script read at the beginning of the interviews, participants were notified that interviews could be recorded and that the recorder could be stopped at any time.

Competing Interests The author has no sources of competing interests or conflicts of interest.

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