

Exploring the Financial and Time Management Strategies of Parents of Children with Autism Spectrum Disorder (ASD)

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Abstract

This study aims to explore the experiences of parents with children who have Autism Spectrum Disorder (ASD) in two crucial areas that influence caregiving: financial strategy and time management. This qualitative study uses a phenomenological approach and involves in-depth interviews with five primary caregivers, specifically mothers or fathers. The informants, who are parents, have at least seven years of experience caring for children with autism, aged between 30 and 50 years, are currently employed, and reside in Selangor. The findings identified four main themes in financial strategies: selecting care centres within financial means, taking on additional work, utilizing government assistance programs, and practicing prudent budgeting. Meanwhile, three themes for time management strategies practiced by parents of children with ASD were alternating work schedules between spouses, organizing priorities between work and caring for ASD children, and prioritizing the routine needs of ASD children to ensure quality care after working hours. The findings of this study demonstrate how financial strategies and time management practices adopted by parents with ASD children can influence the quality of caregiving and their daily lives. The goal of this study is to help parents of children with ASD deal with difficult time and money management problems by offering them better advice.

Keywords: Autism Spectrum Disorder (ASD), Financial Planning, Time Management, Experiences

Introduction

Parenting children with Autism Spectrum Disorder (ASD) is a critical journey of life for parents (Bujang, Jima'ain & Saari, 2020), particularly those in nations with fewer service resources (Papadopoulos, 2021). Although all parents stated that they are uncertain about their children's future, they still strive to make the best plans to support their children's development (Ying & Mohamed, 2023). Out of all the different problems that parents encounter, financial and work-related is arguably the biggest. According to a study by

Marsack-Topolewski & Samuel (2024), one of the main challenges parents of children with ASD confront is managing caregiving responsibilities while also juggling work duties. Typically, the money needed to address the demands of special needs children is greater than the parent's monthly income. (Sazlina et al., 2018). Studies have shown that the high costs associated with obtaining the necessary training to become a skilled practitioner in administering early interventions contribute to the high treatment fees, which is why the treatment for children with autism is expensive (Han, Wan Sulaiman & Ahmad Badayai, 2024). Therapies, medications, and treatments are also more complex and costly, while families often have to change their routines, even modifying their homes, further contributing to their expenses. Befkadu et al. (2022), claim that parents of children with ASD experience stress at home and in their daily lives, which leads to an imbalance between their income and the requirements and expectations of their children.

Parents are forced to juggle these costs and a steady income enough to sustain their families. Due to this situation, parents may experience financial stress and poor mental health, and due to this, their caregiving of a child with ASD can be affected. Parents of children with ASD reported slightly lower life satisfaction and well-being (Landon, Shepherd & Goedeke, 2018). Information from a stepwise linear regression revealed three drivers of this reduced well-being: caregiver health problems, caregiver acknowledgment, and financial hardship. Parents who have children with ASD experience more stress than parents of children without ASD (Muhammad Haziq & Nurul Akma, 2019; Siti Marziah & Nor Shahirah, 2018; Mohd Suhaimi & Nur Natasha, 2018), and they have poorer physical health, psychological well-being and social functioning compared to parents of children without ASD (Turnage & Conner, 2022).

The challenges accompanying parenting a child with ASD may hinder parents' career progression or even their capacity to concentrate on their career advancement. Ozdemir & Koç (2023) shared that parents of a child with ASD have difficulty focusing on their work, particularly with their child's diagnoses. According to Liao & Li (2020) research on parents with children with autism, they are subject to more adverse job outcomes and financial burdens, with mothers facing the most tremendous burdens. Parents of children diagnosed with ASD also experience further challenges at work and productivity in the workplace (Lynch et al., 2023). They become tired of managing daily activities and have to work and take care of other responsibilities (Kartini et al., 2019).

Treatment sessions are conducted in therapy centers, and getting them there is time-consuming for working-class parents of children with ASD (Nur Farahana & Manisah, 2020). Enabling parents who are employed are constrained in spending time with their ASD children to be able to carry out activities related to ASD (Nurdiyana et al., 2021). Due to the imposition of continuous attention, exceptional care, and frequent medical appointments with doctors, parents struggle to balance their work and caring responsibilities. Consequently, their workplace planning is reduced, time frameworks are disorganized, and some parents need to quit their jobs to take care of their ASD children. On the other hand, mothers who choose to stay out of work to take care of their children diagnosed with autism spectrum disorder (ASD) are experiencing symptoms of depression, according to a study conducted by Benson (2021). This situation indicates the financial difficulties that parents of children with ASD are presented with, in addition to the time management stigma parents with complex work commitments find themselves in.

Since children with ASD require ongoing care and specialized therapy, which frequently entails frequent medical appointments, parents may find it challenging to balance their careers. To offer full-time care may necessitate reduced work hours, more flexible work schedules, or, in the worst situations, one parent quit their job entirely. The inability to securely put a roof over their heads, the potential loss of income, reduced opportunities for career advancement, and the lingering threat of being evicted can compound the financial pressure these families face, according to a recent study by Benson (2021), mothers who quit their jobs to take care of their children with ASD experience more depressive symptoms.

Hence, it can be said that parents of children with ASD are often caught up in the ring of severely vast financial or occupational demands of their children. Still, they do their best to take care of their children. Therefore, this study aims to investigate the financial management strategies and time allocation strategies of parents making up the primary caregivers of children with ASD.

Literature Review

The majority of studies on caregiving experiences indicate that most parents experience difficulties in caring for children with ASD (Bujang, Jima'ain & Saari, 2020). Mothers of children with ASD experience significantly higher levels of burnout than fathers, while fathers experience higher degrees of depression than mothers (Kütük et al., 2021). Higher rates of paternal depression, children having speech problems, and children attending special education services were all associated with maternal depression. Mothers of individuals with ASD also had higher care burden, anxiety, sleep quality, and HRQOL (health-related quality of life) ($p < 0.05$) (Soytaç, Kahraman ve Genç, 2022).

Their quality of life is ultimately impacted by the responsibilities and challenges of raising autistic children, which frequently come before caregivers become involved in their desires and aspirations (Davy, Unwin, Barbaro, & Dissanayake, 2022). Household income is among the five main factors contributing to extreme exhaustion among parents of children with autism, alongside living space environment, the behavior of autistic children, and acceptance of the child with autism (Zulkefli, Mohamad Aun & Sarnon, 2024). Time management is another crucial area of life for parents of children with ASD. Some parents (45.5%) had to adapt their work hours, change from full-time to part-time jobs, take unpaid leave, and/or live away from their families because of their employment (Kartini et al., 2018).

According to the research of Ozdemir and Koç (2023), the career adaptability of parents with children with ASD is defined as the stabling four main factors, which are (i) concern, (ii) control, (iii) curiosity, and (iv) confidence. A subtheme of concern included themes of planning and future planning. The control subtheme emphasized the importance of working for their children's future and featured themes mostly about decision-making processes and participant traits (such as perseverance and consideration). The subtheme of curiosity emerged from their interest in and self-assessment of their career, which articulated their opinions on seeking career options. The confidence subtheme encompassed workplace difficulties, job expectations, coping strategies, and career support. In their working lives after the ASD diagnosis, participants often highlighted pinching realities that they faced.

Saptyasari (2020) suggests that such adjustment of roles by married couples has dynamic features when they try to meet the emotional, financial, energy, and time necessities of their children with ASD. Each respondent modified role-sharing arrangements to meet these needs, investing entirely in shared responsibilities. They had a "grief period" upon discovering that their child had ASD, followed by a peak in adapting their personal and professional lives. The study showcases the need to look towards the future, work hard, make career/life choices, and discover career paths with expectations like earning money now and more flexibility in the future. Coping skills, postponed career goals, future career plans, or less self-exploration were underlying strategies implemented toward married couples. To meet these high demands, parents must master skills related to their career and time management to minimize stress and thus indirectly improve the quality of care rendered to the child with ASD. Although Razuan, Aun, and Fazree (2023) study indicates that most caregivers of children with ASD have knowledge about autism and experience moderate levels of stress. However, this does not imply that caregivers of children with autism do not feel stressed when managing and raising them, as previous studies have shown that parents of children with autism experience higher levels of stress compared to those with typically developing children.

When connected to theory, the financial and time management aspects can be explained through the lens of the ecological systems theory first proposed by Urie Bronfenbrenner (1979). Bronfenbrenner also focused on how different systems in the macroenvironment, the exosystem, and the microsystem develop and interact with individuals. At the microsystem level, the family unit is the most intimate setting that impacts individuals—in this case, the ASD child. For parents of children with ASD, the microsystem encompasses family financial means, work status, and support networks. In this system, parents feel the costs of therapy, medical treatments, and special education. How flexible work arrangements or shortened workdays are handled also impacts the family's financial security, the process of family growth, and the professional advancement of the parents. At the mesosystem level, it illustrates the interaction of the family's financial situation with other systems such as healthcare, education, and community services. This shows how financial strain indirectly restricts access to services and support that are essential for children, nurturing a feedback loop in which financial resources directly correlate with the quality and availability of care and support available to children with ASD. The macrosystem level involves broader cultural values, economic conditions, and government policies. When this is applied to raising children with ASD, the macrosystem involves considerations such as funding for research on ASD, disability benefits, tax policies related to medical expenses, and employment laws around parental leave and accommodations.

Methodology

This study employed a qualitative design with a phenomenological approach. Hence, this is useful for exploring in-depth how working parents perform financial and time management strategies while managing their children with ASD. The sampling method used was purposive sampling. It involved interviewing the primary caregivers of children diagnosed with autism spectrum disorder (ASD)—and these were mothers or fathers. Five informants met the criteria: aged between 30 and 45 years, employed, living in Selangor, and having at least one child diagnosed with ASD who has been under their care for more than 7 years. The study data were collected using in-depth interview techniques with semi-structured questions. The data collected were subsequently analyzed by thematic analysis. In the open coding phase,

the researcher selected significant phrases to later select for selective coding, which became the main themes.

Results

Socio-Demographic Profile of Study

A sample of 9 informants (mothers or fathers) who take care of children with ASD were successfully interviewed. The demographic analysis also stated that all informants had a steady job, and as such, the families showed they could fulfill the needs of the children with ASD. Mrs Asnidah is a nurse and lives with her 15-year-old autistic son and two daughters. Mrs Tasya, who manages a Petronas gas station, does her best to juggle her work demands with those of her autistic son and daughter. Using a lower income, Mrs Kina, a police officer, lives with her 9-year-old autistic son. Mr Danish is an online trader with a higher monthly income and two children, including a 10-year-old autistic son. Mrs Emelia is a school counselor who caters to the needs of her 16-year-old autistic son while working. These income levels in each case are different; the income of each individual is different, showing how the other parent has worked with the ASD children.

Table 1.1

Demographics of Informants

Informant	Age	Ethnicity	Occupation	Income	Age of ASD children
Mrs. Asnidah	39	Malay	Nurse	RM 3,600	15
Mrs. Tasya	36	Malay	Manager	RM 4,000	7
Mrs. Kina	40	Malay	Police	RM 4,000	9
Mr. Danish	38	Chinese	Businessman	RM 5,000	10
Mrs. Emelia	36	Malay	Teacher	RM 4,500	16

Financial Strategies

The financial burden on parents with children with ASD is enormous. Despite facing high costs, these parents remain committed to providing their children with the best care and education. The analysis revealed four main financial strategies practiced by the informants in managing finances for the care and education of ASD children. Four financial strategies were identified from the data interview as practiced by the informants in managing finances for the care and education of children with ASD. These four strategies include selecting care centers within financial means, taking on additional work, utilizing government assistance programs, and practicing prudent budgeting.

Selecting Care Centers Within Financial Means

All informants prioritized their children's education, ensuring no child was sent to a care center without proper education, even though they knew their child was not like typical children. When selecting care centers, all informants adjusted according to their financial capabilities without compromising the quality of care and education. For all informants, choosing a care center based on financial capacity did not mean looking for the cheapest option; instead, they emphasized quality aligned with their finances and the specific needs, particularly the temperament, of their ASD child.

According to Mrs Asnidah, her child could not be sent to a different special school even though the annual fee was much cheaper than the current school. This was because only the teachers at the current school could handle her child's recurring tantrums.

"I wanted to send my child to another special school that isn't as expensive, but only the teachers at this school understand my child. I feel like I can't choose to send him elsewhere."

(Mrs Asnidah)

She prioritized providing the best education for her child, even though she admitted that the tuition fees were relatively high.

"We enrolled him in a school for special needs children, about RM28,000 a year. That's not including books, food, or supplies for school use. It's costly, but we have no choice. We want the best for our child."

(Mrs Asnidah)

For Mrs Kina, she tried her best to ensure her child received the best education by combining private and government schooling. She sent her child to a private Early Intervention Programme (EIP) and also to the government-run Program Pemulihan Dalam Komuniti (PDK) under the Department of Social Welfare (JKM), along with a transitional therapy class under the Program Bantuan Didik Anak Istimewa Selangor (ANIS).

"He goes to EIP, then to the PDK program under JKM, and then another transitional therapy class under Selangor's ANIS program. EIP is private, so it's a different type of therapy center that is three hours long."

(Mrs Kina)

Mrs Kina also enrolled her child in a free government special school to reduce education costs, as she found the cost of private Early Intervention Program (EIP) classes to be RM1,600 per month.

Mrs Tasya, on the other hand, sent her child to the government-run PDK program because it was close to home, reduced costs, and provided a satisfying experience with many improvements observed in her child.

"After completing the PDK program, I registered him in PPKI at Taman Maluri. It's close to home, so it saves money, and I noticed many behavioral improvements—less tantrums and better manners."

(Mrs Tasya)

Mr Danish also tried to enroll his child in a government school to reduce expenses, but he was told he was not eligible for assistance.

"I also tried for government programs. I always heard about this PPKI and other assistance programs, but I'm not eligible for anything just because of my income statement."

(Mr Danish)

Taking on Additional Work

The study found some informants engaged in side jobs to supplement their primary income. This was necessary due to the higher costs of raising ASD children, including expenses for

special education, therapy, medical treatments, and other support services. The high costs led Mrs. Asnidah to abandon her plan of quitting her job to spend more time with her child, as her husband discouraged it due to the inability to cover the high costs of ASD care and education with only his income.

"I used to think about quitting my job because of the work burden and managing my child. Sometimes, I thought if I stopped working, I could spend more time with my child. But then my husband reminded me, 'If you quit, how will we pay for school fees or buy his supplies?'"

(Mrs Asnidah)

Additionally, to send her child to school, Mrs Asnidah had to bear additional expenses such as books, meals, and activities specifically for autistic students.

All five informants reported having unstable financial situations after the arrival of an autistic child in their family. Therefore, parents could not rely on a single source of income. They had to work side jobs to earn additional income.

Mrs Tasya, a manager at a Petronas gas station, revealed that her manager's salary was insufficient to cover high expenses. She persisted and started using social media platforms like TikTok to earn extra income, albeit modestly, while her husband took up a part-time job as a delivery rider.

"Currently, TikTok is providing me with part-time income. I just started it, and sometimes I do reviews that earn me around RM20 to RM50. Online jobs are okay for me, too. I even worked as a promoter once, earning around RM100. My husband also does delivery jobs as a rider. A Petronas manager's salary alone is not stable enough to run the family."

(Mrs Tasya)

Similarly, Mrs Kina also earned additional income through TikTok to reduce her financial burden. Her police salary was insufficient to manage her child's expenses, and she solely relied on TikTok earnings to cover the costs for her child.

"I now just think about making money. TikTok content allows me to earn money, so I do it because, honestly, my entire salary goes to commitments. I only rely on TikTok earnings to spend on outings with my child, like meals or relaxation. My police salary is completely used up for house expenses, bills, and cars. There's nothing left for me."

(Mrs Kina)

"I started TikTok out of desperation because I was running out of money. I thought, 'How will I manage?' So, I started TikTok. Now, it's my main job."

(Mrs Kina)

Additionally, Mr Danish frequently took his child to private hospitals due to long waiting times at public hospitals, and he also worked side jobs. He had to sell clothes at night markets to increase his income because his monthly business income of RM2,500 was only enough to cover his child's school fees. He stated that he couldn't rely on a single income source to support his family after the arrival of an autistic child.

"My business also went down for a while, and it's hard to manage with just one source of income. So I started working at the night market for extra income. I just sell some clothes to survive."

(Mr Danish)

"My monthly payment for his school fees is RM2,500, but I've seen the progress and think it's the best. I always plan my finances no matter how much I struggle so I can provide the best for him."

(Mr Danish)

Utilizing government assistance programs

As an alternative to meeting the needs of their ASD children, some informants chose to take advantage of government assistance programs such as the Program Pemulihan Khas dalam Komuniti (PDK) under the Social Welfare Department and NASOM (The National Autism Society of Malaysia), which offer financial aid and free or lower-cost services. Parents like Tasya, Kina, and Emelia opted for government-subsidized programs or organizations like NASOM to reduce the cost of their children's education.

"I decided to send my child to NASOM because first, it's affordable, and my salary isn't much. NASOM doesn't charge high fees, and they also provide reports."

(Mrs Emelia)

Mrs Kina emphasized the effectiveness of government programs in improving her child's behavior and skills, countering the perception that such programs are ineffective. With this assistance, parents can reduce their financial burden while ensuring their children receive the necessary education and therapy.

"I suggest all parents join free autism programs if they can't afford private ones... Many people think government programs are ineffective, but I've seen changes in my child's behavior... my child can now speak. Isn't that interesting?"

(Mrs Kina)

Some parents, like Tasya and Kina, benefited from government assistance programs that provide financial aid, such as monthly allowances from the Program Pemulihan Khas dalam Komuniti (PDK) under the Social Welfare Department.

"I sent my child to PDK under JKM, and it's been great. You even get a monthly allowance of RM150. PDK doesn't have fees like tuition."

(Mrs Tasya)

"PDK has records, their reports are like a progress card. It's very easy to track the child's development. Plus, PDK is free, and we get RM150 monthly allowance... it's really worth it."

(Mrs Kina)

Mrs Emelia shared her hopes and progress observed in her child through the program.

"We saw that he started making eye contact, which I had always hoped for. Then he began following instructions, and he could even do things we hadn't taught him. For example, he wipes the table and picks up rice after eating."

(Mrs Emelia)

Practicing Prudent Budgeting

Adjusting budgets and practicing careful spending are critical strategies for parents of ASD children to manage their finances effectively. This practice helps families prioritize expenses, adapt to their child's unique needs, and cover essential costs without incurring unnecessary debt.

Parents like Mrs Asnidah adopt meticulous budgeting to manage the high costs of their child's unique needs, such as diapers and specialized dietary requirements.

"Even baby diapers are now expensive. If the diaper size is large, the price is even higher. Yes, large-sized diapers cost twenty ringgit for ten pieces. He can use five diapers daily, which means RM10 a day – that's a significant amount for us. Our income has decreased, and the cost of goods has increased. Maybe for other parents, this seems small, but for us, ten ringgit daily is a big deal."

(Mrs Asnidah)

Mrs Asnidah also stated that she has to make daily spending plans and be frugal every month to buy her child's necessities. Despite her financial struggles, she prioritizes her child's needs.

"I have to budget every day for this. If it's between my child and money, I choose my child. It's okay; money can be earned as long as my special child gets what he needs."

(Mrs Asnidah)

Mrs Tasya also tried to reduce the cost of her child's disposable diapers by purchasing them online. Unfortunately, the prices were still high for her

"We have a problem when it comes to buying his diapers. He's big now, so he needs size XL, but now he has to wear size 3XL, and 3XL diapers aren't available here... so I have to buy them online, and that's quite expensive for me."

(Mrs Tasya)

Mrs Tasya mentioned that she strongly hopes to assist her child with diapers because he frequently uses them, which increases the cost of living.

"If you ask me, I would say we need assistance for his diapers. Just for diapers alone, in a month, it can become... especially now that he's bigger. His bowel movements and everything else... it happens more frequently, and we can't afford it."

(Mrs Tasya)

Mr Danish, on the other hand, spends a significant amount on toys tailored to develop his child's motor skills. For him, these toys are essential for his child. He explained that the toys need to be custom-designed to suit his child's fine motor skills, so he spends RM300 a month on them.

"I usually spend a lot on his toys, and I always customize them according to his interests. I accumulate around RM300 per month for his toys."

(Mr Danish)

In addition, Mr Danish noted that the cost of his child's diapers is also high. He spends about RM500 a month solely on disposable diapers. He stated that while his child is being trained to use the toilet properly, success has not been achieved yet.

"I usually spend around five hundred ringgit per month just to buy diapers for him. I see that he can pee or poop easily at school, but when he's at home, we still need to put him in diapers."

(Mr Danish)

Time Management Strategies

The findings of this study revealed that three time management strategies were implemented, namely (i) alternating work shifts between spouses, (ii) arranging work needs and ASD giving, and (iii) Prioritizing ASD needs for quality care after work.

Alternating work shifts between spouses

Mrs Asnidah, who works as a hospital nurse, and her husband, who also works at the hospital, ensure they choose different shifts so that one of them is always available to care for their ASD child.

According to Mrs Asnidah, she plans her time to work and care for her ASD child at home so that her child can be appropriately managed. She works a 10-hour shift from evening to night at the hospital, spending 8 hours with her family. Thus, Mrs Asnidah has been responsible for caring for her child from morning until noon. She stated that her choice to work the evening-to-night shift was appropriate because it allowed her to manage her child, who often displays tantrum behavior in the morning. Meanwhile, her husband works morning shifts as a nurse from morning until noon.

"For my work schedule, I always take evening and night shifts because there's no problem with caregivers during that time. At the hospital, it's 10 hours of work, from evening to night, while my husband works morning to noon. We take turns looking after our child. Sometimes it's exhausting."

(Mrs Asnidah)

Mrs. Asnidah also mentioned that she never considered quitting her job after managing to divide her time between work and caregiving. This arrangement made it easier for the parents and allowed Mrs. Asnidah to care for her child without feeling overwhelmed.

"I don't think about quitting my job anymore. If the time is arranged properly, it's manageable to care for my child. It reduces stress, and there's no need to feel overwhelmed."

(Mrs Asnidah)

According to Mr. Danish, he and his spouse had to take turns taking care of their child and working. They alternately spend time with their child, engaging in activities like playing with plasticine and gym balls to improve fine motor skills. This time-sharing arrangement has improved his child's fine motor skills, enabling him to handle noodles and rice independently.

"I handle the time when my wife works, and when I'm working, she handles the kids. We take turns managing the kids."

(Mr Danish)

The progress of Mr Danish's ASD child motivated him to continue managing his time wisely to care for his child. He explained the link between the time spent and the progress achieved by his child:

"If you see, play therapy in private is really expensive, and it's just a few hours but costs so much. The things they use, like gym balls, plasticine, clay, and slime, are DIY materials that we can create ourselves. So, why not make them at home? We spend time with our kids daily, almost every day, taking turns. For example, today, we'll play with slime, and he plays with slime, and you can see the progress in his skills. Before, he couldn't, but now, after these activities, he can touch noodles, touch rice, and even eat the rice. So, these activities with your kids are really beneficial."

(Mr Danish)

For Mr Danish, managing time with his child is challenging, but alternating caregiving between parents helps save therapy costs and provides deeper insights into the child's behavior. He expressed that parents who allocate time for their children can better understand their weaknesses and harness their strengths.

"I also try my best, but it's really tiring. You either take turns with your wife or rely on expensive therapists, but it's costly. Spending time with them through activities helps you understand your child more deeply. You can see their issues and find solutions. There are so many activities you can search for on Google and do with them. You just have to be there for them."

(Mr Danish)

Arranging work and caregiving need

Informants like Mrs. Tasya shared many time management experiences by listing work tasks and essential activities with her child to ensure she balances her responsibilities as an employee and a mother who understands her child's needs well.

"PPKI focuses on him every Monday to Friday... Genius Kurnia every Wednesday and Thursday; they will call me... so I'm relieved there are two classes in one day. I also have to manage if I need to send my child to PPKI and Genius Kurnia. If there are too many classes in one day, he loses interest, and he doesn't feel like going to school. It doesn't feel good for him. I will skip the PPKI morning class if I need to send him to Genius."

(Mrs Tasya)

According to Mrs Tasya, she divides her time between work and caring for her child by completing her employer's essential tasks first, then listing activities she needs to do with her

child. She never misses the chance to manage her child because he requires more attention and support from his parents.

"I work as a manager at Petronas, and if you ask how I divide my time, I make sure I list down all the important tasks to be done first, settle those, and then list the activities I need to do with my child. My husband finds it easier to handle. When I return from work, I make sure to manage him completely. My Adam is special; he needs a lot of attention. If I don't engage with him after work, there won't be any changes."

(Mrs Tasya)

Mrs Tasya is fortunate to have an understanding employer who knows her child needs extra attention. Her employer is accommodating when Mrs. Tasya cannot complete work on time due to managing her ASD child.

"They are very understanding, and my boss knows if my work is delayed slightly, it's because I'm handling my child. But my boss understands, and it's not like the delay happens often. One time, even a file was delayed, but they understood."

(Mrs Tasya)

Mrs Kina had to adjust her work schedule to avoid disciplinary actions because her child's needs interrupted her work hours. Her child also requires specific foods as part of his daily routine whenever they leave the house. Her child must always eat at the same restaurant and sit in the same spot. Even though Mrs Kina considers eating elsewhere, her child insists on going to the same restaurant. To meet his needs, Mrs Kina and her husband adjust their work schedules and time for their ASD child.

"As he got older, he became a picky eater; he only wants one type of food every day. The same food every day... he needs to follow the routine, the same restaurant. The same, over and over, he will sit in the same spot and drink the same drink."

(Mrs Kina)

"We wait for him to finish eating at that restaurant before we move on. Only then will he not disrupt our work. If he doesn't eat at the restaurant he knows, we can't move forward."

(Mrs Kina)

Prioritizing ASD needs for quality care after work

Children diagnosed with autism require consistent daily routines, continuous attention, and support from their parents. Informants provided quality attention and support by helping their children avoid tantrums first. Using the time after work allows them to meet their children's needs while maintaining balance in daily life.

All informants try to spend time with their children according to their needs. They agree that children diagnosed with autism need consistent routines that should not be disrupted. According to Mrs Tasya, her child has a daily eating routine where she must provide rice, chicken, eggs, and French fries daily. She added that if she cannot fulfill his routine, her child will have a tantrum until they meet his daily food requirements.

"He only likes this food... rice with chicken and eggs every day. He starts having tantrums if we give him anything else. Rice, chicken, eggs, and nuggets are essential. Whether we like it or not, we have to buy them."

(Mrs Tasya)

Therefore, Mrs Tasya ensures her child's needs are met before spending quality time with him after work, giving him the attention and support he needs. This contributes to his development: *"When we give him attention, his improvement now is that he can eat nuggets and fries, just like that."*

Mr Danish shared that his home has a small, dedicated space for his children, especially his ASD child. This space is designed to help him and his wife spend time with their child quickly after work. He added that children diagnosed with ASD need more parental attention to help them become aware of the real world.

"We have this one corner just for the kids at home so my son can play with blocks, trains, and trucks peacefully. We have to be with them so they don't remain in their own world because autistic kids often retreat into their world. We have to bring them into reality, and that means being with them when they play. If we don't guide them, there's no progress. We want our kids to be normal, but they're extraordinary, so we need to treat them extraordinarily."

(Mr Danish)

Mrs Asnidah and her husband must buy her child-specific curry noodles and bread daily to avoid disrupting his routine. If they fail, her child exhibits self-harming tantrums. When her child is calm in the morning, Mrs Asnidah can give better attention and spend more quality time with him after returning from work that day.

"Every day, we have to buy curry noodles with bread for him to eat. If not, it's chaos—he'll start throwing tantrums. Breakfast without his favorite bread will turn the morning into a battle. Curry noodles and bread are his daily routine. For children with autism, any disruption to their routine can't be negotiated. When he's calm, it's easier to engage and spend time with him after work."

(Mrs Asnidah)

Discussion

This study involves the perspectives of parents of children with ASD, which can be linked to the Ecological Systems Theory. The findings show that the financial and occupational challenges faced by parents of children with ASD are not isolated issues but are influenced by the complex interaction between parents and their surrounding systems. Although parents shared similar emotional experience, they seem to face different challenges in their parental roles (Nur Amira and Mohd Syazwan Zainal, 2024).

The results suggested that the financial and occupational difficulties of parents of children with ASD are not standalone phenomena and must be perceived through the complex interrelationship between both parents and their external contexts. The example given by the service provider, in which parents cooperatively make the most of the chances to enhance

their child's success, illustrates a positive interaction at both the mezzo and macro levels, where parents of the children successfully utilize the information and assistance that the government and non-governmental organizations with ASD jointly provide. At the macro level, government policies that are responsive to the needs of children with ASD, such as financial assistance, provide considerable assistance to parents in need. At the micro level, parents' career and time management can mediate the pressures they experience with the quality of care they provide for their children with ASD.

This can be understood as parents of children with ASD place their children's care high on their priority list and are willing to make financial arrangements to provide quality education for their children. All parents with children diagnosed with ASD have a unified goal in mind: To ensure the best care and education for their children. This commitment is addressed through their willingness to increase these expenses, such as choosing affordable and quality care centers, doing additional work to gain additional primary income, using available government assistance programs, and being frugal in spending (for the benefit of their family, primarily their children with ASD). These findings highlight that the quality of care is a priority for parents. It is crucial for care centers providing services for children with ASD to pay attention to parental expectations and also not to take advantage of their belief in quality services.

Get Active With Government Help One proactive step to dealing with the financial strain of raising children with ASD is to take advantage of government assistance. These programs aim to be helpful to families with special needs: They offer financial assistance, services, and resources to support the families in meeting their needs. In this study, parents relied on government programs to lower education spending. Others pieced together a mix of private and government programs to balance cost and quality and ensure their children's benefit. This means that parents need information, perseverance, and, in some cases, creativity to locate and obtain the necessary support. Some parents have also benefited from monthly allowances that alleviated financial pressure. Families who take advantage of these resources can then concentrate on the same goal: caring for their children with autism spectrum disorder (ASD). Mobility challenges of parents of children with ASD can motivate policymakers, healthcare providers, and employers to create more inclusive support systems that will provide the necessary incentive to families with children with ASD. Such systems are designed to alleviate financial strain and improve the well-being of kids and their guardians. In Malaysia, there is a wide range of assistance programs from the Government of Malaysia and the NGO & Corporate.

Parents were also willing to have extra jobs on top of their main ones. Working additional jobs is a frequently used strategy for parents of children with ASD; however, this is a substantial burden, as they need sufficient income to meet expenses but also a state of mind to focus on their work and their children with ASD. This approach highlights parents' ability to understand their children's individual needs and their commitment to finding the best educational and caregiving environment for them. Parents' involvement in extra work also illustrates the economic pressures of caring for children with ASD. This study highlights the co-joint strategies -- double income is needed to spread the high expenses that are associated with the care of the child with ASD (drawing on recent well-described results by Debbie Shinder et al. that show just how extensive the needs of these children), as a primary finding.

The lack of expenditure and considerations of the children with ASD in terms of time management, careful planning of the daily expenses, special care needs for their children, and utmost frugal budgeting are crucial towards the expenditure factor of ASD care. Some parents rotate caregiving duties, so someone is always with their children with ASD. The most successful working parents prioritize organizing tasks and activities. Many parents stress their children's routines, and the kids avoid behavioral issues to ensure quality care after work hours. They will change their lives to provide their children with ASD with consistent, familiar routines since they understand how important these are.

Flexible work-life balance policies are addresses of great importance. Programs that provide training to staff and support to parents of children with ASD in the workplace should also be expanded. These types of programs promote the values of diversity and inclusivity in society as a whole. A piece of research suggests that employees as well suffer the implications as done by Larson, J. (2022). Less motivated employees feel less productive or unable to quit their jobs, resulting in higher turnover costs. With increased prevalence rates of ASD, there's a growing population of parents raising children with autism who are also in the workforce—allowing organizations to help these parents through programs tailored for them.

In short, when it comes to caring for children with ASD, parents find ways to balance financial and time constraints with grit and determination. They utilize different tools to keep their children healthy and receive the best possible care education.

Conclusion

In summary, this study demonstrates the strategies the parents of children with ASD rely on to alleviate time and financial burdens. These results indicate the strength and resourcefulness of those parents in addressing their kids' needs in the face of enormous odds. This paper contributes to the broader literature on the economic cost of ASD to families and the need for policies and supportive programs that can help mitigate some of that cost.

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