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Navigating lifelong care: experiences of mothers caring for adult offspring with autism spectrum disorder

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Abstract

Background: Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition that often requires intensive parental caregiving. While research has focused on children with ASD, experiences of parents caring for adult offspring remain underexplored.

Aim: This study aimed to explore parents' experiences of caring for their adult child with ASD.

Methods: A qualitative study was conducted with ten mothers using in-depth semi-structured interviews. Data were analyzed through reflexive thematic analysis to identify key patterns and themes in participants' experiences.

Results: Five main themes emerged: Non-Transferable Caregiving, Reduction of the Supportive Social Network, Neglect of Self-Care, Fear for the Child's Future, and Persistent Need for Advocacy. Mothers described intensive, enduring caregiving roles, social isolation, limited self-care, and significant concerns about future support and services. Advocacy served as a coping mechanism and a means to influence systemic support.

Conclusion: Mothers of adult children with ASD face substantial, ongoing caregiving burdens. Improved formal support, respite services, and professional preparedness are essential to enhance both caregiver well-being and the quality of life of adults with ASD.

Keywords: Adult care; Autism Spectrum Disorder; Caregiving burden; Mothers; Qualitative study; Thematic analysis

Introduction

Autism Spectrum Disorder (ASD), as defined by the DSM-5, is an overarching term for neurodevelopmental disorders characterized by impairments in communication and social interaction, stereotyped behaviors, and atypical sensory processing. In addition to these core features, individuals with ASD often experience comorbid mental disorders, which further reduce the quality of life of both the affected child and the family (Ostatníková et al., 2022). Intellectual disability is present in approximately 30% of individuals with ASD (Fodstad et al., 2020).

ASD represents one of the fastest-growing neurodevelopmental conditions in the United States (Ardhanareeswaran and Volkmar, 2015). Current global estimates indicate that approximately one in 100 children is diagnosed with ASD (Zeidan et al., 2022). A study by the US Centers for Disease Control and Prevention reported a prevalence of ASD in one out of 31 children at age eight, based on research conducted in 16 selected US cities (Shaw et al., 2025). Systematic monitoring of ASD prevalence in Slovakia is currently lacking. According to the Ministry of Health, prevalence is assumed to be similar to other European countries, which corresponds to an estimated 32,000 individuals with ASD in Slovakia (Antalová et al., 2025). Research on parents of young adults with ASD remains limited compared to the broader literature on parents of children under 18 years of age (Marsack and Perry, 2018).

Caring for a young adult with ASD can pose substantial challenges for parents. The needs of parents change over time, but more importantly, the needs of young adults with ASD evolve, particularly regarding independence, employment, and living arrangements (Cidav et al., 2012). Following the transition to adulthood, the availability and accessibility of support services often decrease, placing a greater burden on families (Anderson et al., 2018). Płatos and Pisula (2019) confirmed that one of the main challenges is the financial inaccessibility of services, or in some cases, their complete absence. Consequently, caregiving responsibilities often remain with the parents into adulthood.

When continuous home care is needed, one parent – usually the mother – often becomes the primary caregiver, which can limit or end their participation in the workforce (Stoner and Stoner, 2016). The financial burden of caring for a young adult with ASD, together with reduced family income, is a major negative aspect of caregiving (Banda et al., 2022; D'Arcy et al., 2024).

Prolonged caregiving for adult children with ASD is linked to lower family quality of life (Boehm et al., 2015), greater emotional exhaustion, and poorer parental mental health

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(Bourke-Taylor et al., 2022). Caregivers often report depression, anxiety, and stress (Herrema et al., 2017); for example, mothers of adolescents and young adults with ASD experience more days with stressful events than mothers of children without disabilities (Smith et al., 2010).

Marsack-Topolewski and Church (2019) found that although parents experience developmental, emotional, time, and financial burdens, developmental and financial burdens most strongly reduce quality of life. Later studies also highlight the significant impact of developmental and emotional burdens on parents of children with ASD (Samuel et al., 2025).

Other factors influencing parental quality of life include challenging behaviors, adaptive functioning, and the severity of the young adult's ASD diagnosis (Rattaz et al., 2017; Turnage and Conner, 2022). Uncertainty regarding the young adult's future represents another important source of stress (Herrema et al., 2017). Parental age and the natural aging process further affect caregiving; as parents lose functional abilities, they may struggle to provide continuous care. The demands of caregiving increase, fatigue accumulates, and parents contemplate future support for their child when they are no longer able to provide care (Blacher et al., 2010; Hare et al., 2004).

Social support from family, friends, and the community is crucial, as it helps to reduce caregiving burden, alleviate stress, and decrease anxiety. With advancing age, informal support may decline, increasing the need for formal support, not only for the child but also for the parents themselves. Respite care is particularly important, as it can improve parental well-being, promote marital harmony, and support family stability (Harper et al., 2013; Whitmore, 2016). Intervention and educational programs also appear beneficial, as they can enhance parent–child relationships, increase parental knowledge, reduce stress, and assist in identifying risks of behavioral deterioration in the child (Smith et al., 2012).

Materials and methods

Given the limited research in this area, there is a need to address this knowledge gap. The aim of this study was to explore parents' experiences of caring for their adult child with autism. A qualitative research design was used to enable an in-depth understanding of this social reality. Qualitative methods allow participants to express their perspectives (Popper, 2008) and support rich interpretations of their experiences (Miles and Huberman, 1994).

The study is grounded in an ecological perspective, which views parents' experiences as shaped by interactions between individual circumstances and broader social and structural environments. Accordingly, the research considered multiple levels of influence, including individual (well-being), relational (family and social networks), community (services and support), and societal contexts (policy and awareness).

Reflexive thematic analysis (RTA) was employed to identify patterns of meaning within the data (Joy et al., 2023). This method was chosen for its flexibility across different research frameworks and its suitability for exploring lived experiences and social processes (Braun and Clarke, 2021).

Data were collected through semi-structured interviews with open-ended questions about parents' caregiving experiences. Interviews were audio-recorded, and data saturation was reached by the eighth interview, with two additional interviews confirming no new themes.

The study followed APA ethical principles. Participants provided informed consent, participation was voluntary, and confidentiality was ensured. Ethical approval was granted by the Faculty of Health Care and Social Work, Trnava University.

Participants

The study employed purposive criterion sampling to select participants who directly experienced the phenomenon under investigation. The target population consisted of parents (informal caregivers) of adult children with autism. Inclusion criteria were:

- Parent of a child with autism.
- Parent acts as an informal caregiver, defined by the Social Services Act no. 448/2008 as a person providing care in the home environment without professional service provision.
- A parent who has provided lifelong care for their child, from birth into adulthood.
- Child is over 18 years of age.
- Parent and child live in the same household.

The final sample comprised ten mothers, all informal caregivers of adults diagnosed with autism. Participants were recruited via a day care center providing services for adults with autism. Further details of the research sample are provided in Table 1.

Table 1. Descriptive characteristic of participants and their children

	Participant			Autistic adult		
	Parent	Age	Marital status	Gender	Age	Diagnosis
1.	Mother	42	Married	Daughter	19	ASD/ID*
2.	Mother	53	Single	Daughter	23	ASD/ID*
3.	Mother	54	Married	Son	34	ASD/ID*
4.	Mother	56	Married	Son	30	ASD/ID*
5.	Mother	52	Married	Daughter	30	ASD/ID*
6.	Mother	56	Married	Daughter	31	ASD/ID*
7.	Mother	59	Married	Daughter	37	ASD/ID*
8.	Mother	58	Married	Son	34	ASD/ID*
9.	Mother	43	Single	Son	19	ASD/ID*
10.	Mother	44	Single	Son	20	ASD/ID*

Note: * ASD/ID – Autism Spectrum Disorder / Intellectual Disability

Data analysis

All interviews were transcribed verbatim and analyzed using reflexive thematic analysis following Braun and Clarke's (2006, 2019) six phases. Our long-term engagement with this research informed the analytic process and enhanced interpretative sensitivity. In line with reflexive thematic analysis, this prior knowledge was acknowledged as shaping researchers' perspectives and was critically reflected on throughout.

We familiarized ourselves with the dataset through repeated readings and initial notes, then coded the entire dataset and organized codes into preliminary themes capturing broader patterns of meaning. These themes were reviewed and refined against coded extracts and the full dataset, then defined and named by clarifying their analytic focus. Finally, we produced the analytic account by integrating thematic interpretation with illustrative extracts and relevant literature.

The ecological perspective was also reflected in the analytical process. During coding and theme development, attention was given to interactions between personal experiences and contextual conditions, such as family relationships, social support, service availability, and structural barriers. This approach enabled themes to capture not only individual caregiving experiences but also relational, community, and systemic influences within participants' narratives.

Analytic rigour was supported through collaborative engagement, ongoing discussions among the research team, and critical reflection on analytic decisions. Credibility and trustworthiness were further enhanced through peer debriefing by two additional experts and member checking with participants.

Fig. 1. Ecological relationships among the main themes in parenting adults with ASD

Results and discussion

Interpreting the themes through an ecological lens allowed us to understand parents' experiences as shaped by interconnected personal, relational, and structural context (Fig. 1). The themes therefore reflect not only individual caregiving practices but also broader processes such as social isolation, service limitations, and systemic advocacy demands that influence families' everyday realities.

Through thematic analysis, we identified five main themes: (1) Non-Transferable Caregiving, (2) Reduction of the Supportive Social Network, (3) Neglect of Self-Care, (4) Fear for the Child's Future, and (5) Persistent Need for Advocacy.

Non-transferable caregiving

From the in-depth interviews with parents of adult children with ASD, it emerged that they consider caring for an adult child with autism to be their continuous and primary role. They define themselves as 24-hour caregivers. However, this is not new, as they had to define their roles, ideas, and expectations when their child was diagnosed with ASD. All mothers stated that there had been almost no change in their parental role compared to parents of children without disabilities. In this context, parental identity exceeds the usual life cycles of parenthood and persists even during a period in which, for the majority population, a reduction in childcare is expected (Piotrowski, 2021). Parents of adult children with ASD experience parenthood as a lifelong and non-transferable commitment. Due to its demands, the caregiving role forms the largest part of their parental identity (Singh, 2019). At the same time, they are aware that it is only a matter of time before they will have to face the topic of planning care for the future. In view of the risks and burdens that caregiving brings, they expressed a deliberate effort not to burden the healthy siblings with caregiving for the adult with ASD, thereby consciously taking over complete responsibility for the care. As P8 says: *"When you see what it really involves, you don't want to expect that from your neurotypical children. Even though they promised it."* Parents realize that such a caregiving burden could negatively affect the personal and professional lives of the healthy siblings.

Our findings are similar to research indicating that, despite the positive relationship of neurotypical siblings toward future care of their siblings with ASD, parents tend to protect their children in order to prevent the burden they themselves experience (Sosnowy et al., 2018). They expect that in contact with their sibling with ASD, they will take on rather specific duties (Elumar and Sani-bozkurt, 2023; Heller and Arnold, 2010; Sage and Jegatheesan, 2010). It is natural that parents have certain expectations of the siblings of young adults with ASD, as well as concerns about future caregiving in the event that they themselves will not be able to provide care (Heller and Arnold, 2010).

A particularly problematic factor is the strong emotional and behavioral attachment of adult children with ASD to their parents, which significantly complicates their adaptation to a change of environment or caregiver. As a result, parents withdraw into a *"Care bubble"*, which leads to their social isolation. Woodgate et al. (2008) describe a very similar situation and call it *"Living in a World of Our Own"*.

Reduction of the supportive social network

Long-term care for an adult child with ASD reduces caregivers' social networks, particularly peer relationships. Support from older family members declines, while maintaining friendships becomes difficult, leading to social withdrawal. Unlike parents

of neurotypical children, caregivers remain in long-term caregiving roles as their children do not become independent. As P1 says: *"When the kids were little, we used to meet up a lot. But now it's hard; for example, we can't go on a trip without the kids…"*

Different problems and interests cause parents of children with ASD to drift away from their friends and peers. P8: *"For us it's becoming increasingly difficult to 'find common ground' with parents of children without disabilities."* Several mothers spoke about increasing feelings of loneliness: *"We ended up alone. It's only on us."*

For parents, social interaction with people without similar experience is emotionally and logistically demanding, which leads to voluntary or even involuntary interruption of contacts. Within their social network, contacts with other parents of children with ASD dominate, as they share similar life situations and values, find understanding, exchange practical information, and experience a sense of belonging. The statement of parent P2: *"I naturally gravitate toward people like that, because they get what I'm going through. When I talk to a friend who doesn't have a child like that, I can kind of tell I'm boring her a little…"* confirms that they find relief and emotional stability in communities of parents with similar experiences.

The importance of supportive networks and their influence on mothers' well-being is confirmed by several studies (Bromley et al., 2004; Smith et al., 2012). Likewise, a study focusing exclusively on fathers (George-Levi et al., 2024) suggests that family cohesion and social support reduce fathers' levels of loneliness. Barker et al. (2011) report that a larger social network decreases the mother's anxiety. However, parents encounter misunderstanding, not only from people in public spaces but also from relatives and friends. Such everyday situations evoke feelings of frustration and marginalization (Currie and Szabo, 2020).

They find help in programs in which parents support other parents (parent-to-parent support groups) who share the same fate. In these communities, they mutually share their feelings and experiences, support growth, well-being, and psychosocial and emotional well-being of parents, and reduce anxiety and stress (Bray et al., 2017; Sharma et al., 2022).

Neglect of self-care

The thematic analysis confirmed that mothers in the role of long-term primary caregivers prioritize the needs of their child over their own, which leads to gradual deprivation in the areas of personal needs, health, social life, and self-care. In the interviews, they agreed that they *"had to forget about themselves and their own needs, and the child's needs come first"*. One participant described this dynamic reflectively: P1: *"But have you noticed we're always the ones who adjust? I never really thought about it until now… We're happy when everything's taken care of – and then, somewhere in all that, I'm in there… kind of an afterthought."*

Routine doctor visits are also problematic for the participants. Aligning their own needs with caregiving responsibilities requires a high level of organizational planning, which creates a constant sense of tension. One participant even reported feeling guilty when she had to prioritize her own health: *"I felt guilty that I had to be in that hospital, so I tried to make it up to her afterward."*

Caring for a child with ASD is exhausting for mothers, who often prioritize their child's needs over their own (Çelik and Ekşi, 2018; Hoogsteen and Woodgate, 2013). Limited support networks and a lack of respite services further restrict their ability to meet personal needs. Tailored respite care can reduce caregiver stress (Harper et al., 2013; Whitmore, 2016), yet families often face barriers such as limited availability, inaccessibility, or parental guilt and anxiety about entrusting care to others (Cooke et al., 2020).

Neglecting their own self-care as well as the inability to recover due to a lack of respite services evokes feelings of helplessness, emotional exhaustion, and reduces caregivers' resilience to stress (Okoro and Inyang, 2024). As a result of long-term care for a child with ASD without relief, several mothers reported significant physical and psychological exhaustion: *"Sometimes I ask myself whether I can keep going like this."*

They also described organizing everyday activities, cultural events, or leisure activities as challenging. The mothers emphasized that they deeply long for these activities, yet often cannot carry them out due to their child's behavior. Because of the child's challenging behaviour, parents frequently give up social activities to avoid unpleasant situations in public (Divan et al., 2012; Myers et al., 2009).

Fear for the child's future

In the accounts of all participants, the theme of fear about the future of their adult child with ASD resonated very strongly. Parents described the gradual decline of their own strength and at the same time the need for help in order to preserve their own health. They fear what will happen when they fall ill, when they will need medical treatment or possibly hospitalization, and finally, they worry about what will happen to their child after their death. One mother stated that she intentionally avoids this topic: P2: *"But this is mentally exhausting. I tell myself I won't think about it yet – it's far away."*

Another expressed her deep existential fear about what will happen to her child, not only in the future, but also after her death: *"One is also afraid of dying."*

Fear of the future is strongly influenced by a lack of trust in existing forms of residential care, which, according to their experience, fail to provide dignified, individualized, and respectful support for adults with ASD. Their worries are tied to the idea that their child would be *"put away"* in an institution, where they would be *"pharmacologically subdued"*, deprived of autonomy, and not provided with appropriate support. P9: *"Where can we even place them? We know that in those institutions the only solution they'll offer is to dope them up on medication."*

One mother also reported fears of abuse: *"She* [daughter with ASD] *is very affectionate, she hugs everyone. And that can be dangerous for her…"*

The mothers also discussed how the institutional environment should be prepared for this type of client. Several expressed their ideas regarding the quality of personnel and the methods of work in available facilities. For example, they stated: *"Everyone should be prepared and trained. From the cleaning staff to the director. Because everyone comes into contact with the clients and should know how to react in various situations."*

Parents consider making decisions about their child's future to be very stressful. The lack of specialized services, inadequate care, insufficient supervision, and the risk of abuse evoke legitimate concerns among parents (Dillenburger and McKerr, 2009). Nevertheless, they are aware that it is necessary to plan future care for their child (Dillenburger and McKerr, 2011; Oti-Boadi et al., 2020).

Persistent need for advocacy

The aforementioned fears about the future have a strong motivational significance for the participants. Awareness of insufficient support and the absence of systemic solutions stimulates

them to ensure that *"their voice"* continues to be heard. The mothers perceive their advocacy activities as a necessary way to improve conditions for their adult children. One of them expressed it succinctly: P3: *"We are still at square one, always starting over. But our needs remain the same. Our children did not grow out of autism, that's why I explain, I go, I ask."*

From their perspective, the societal situation has improved only slightly. Public awareness of autism is still insufficient. Attention continues to focus mainly on children, and as a result, adult persons with autism fall out of available support. This reinforces the need for parents to continuously educate both the general public and professionals. P5: *"In the hospital, they don't understand that an autistic person cannot sit for an hour in the waiting room. That's why I welcomed the opportunity to comment on the Ten Principles for Approaching Patients with ASD – a document for healthcare workers on how to improve care for people with ASD."*

Many mothers actively participate in lectures for schools, discussions in the media, organizing conferences, or supporting the mutual exchange of information. In one case, a difficult situation prompted a mother to establish a day care center. P4: *"You know, when something like a day care center gets started, it's usually because parents push for it."*

Our findings indicate that advocacy gives parents a sense of control and helps them cope with fear, frustration, and anxiety in long-term caregiving. Parents' advocacy aligns with Balcazar's taxonomy, engaging in all stages – beginner, involved, and activist – by defending their children's rights, joining peer programs, and promoting systemic changes (Balcazar et al., 1996). Advocacy also aims to improve services, raise public awareness, reduce stigma, and enhance family quality of life (Boshoff et al., 2016), while allowing parents to actively manage challenges (Luong et al., 2009).

Conclusion

Our findings demonstrate that caregiving extends far beyond traditional parental roles, evolving into a continuous, intensive commitment that often isolates families socially and limits opportunities for self-care. The absence of adequate formal services, respite care, and tailored long-term support intensifies parents' concerns about aging, loss of capacity, and the future safety and well-being of their children. In this context, advocacy emerges as both a coping strategy and a practical necessity, enabling parents to address systemic gaps, shape service development, and raise public awareness.

Overall, the study underscores the urgent need for comprehensive, accessible, and autism-responsive adult services, as well as interventions designed to support caregivers' well-being. Our findings highlight the need to build accessible and flexible community-based programs that provide regular support for adults with ASD, thereby alleviating the burden on primary caregivers. To ensure continuity of care, it is important to establish services such as day centers, supported employment, and leisure activities. Psycho-social support programs for caregivers, including counseling, peer-support groups, and educational workshops, should also be introduced. Another key challenge is improving access to respite care services to reduce burnout and enhance caregivers' quality of life. Caregivers should be actively involved in planning to strengthen cooperation and take their capacities and needs into account, which requires effective coordination between health, social, and community services. Participants' statements also indicate a pressing need to support training and education for professionals working with individuals with ASD.

Future research should explore strategies to enhance caregiver wellbeing and evaluate interventions aimed at reducing structural barriers. Addressing these gaps is essential, not only for improving family quality of life but also for ensuring dignified and sustainable support for adults with ASD across the lifespan.

Ethical aspects and conflict of interest

The research received approval No. EK-5/5K/2025 from the ethics committee of the Faculty of Health Care and Social Work, Trnava University. The authors have no conflict of interest to declare.

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