



Multidimensional Burden on Family Caregivers of Adults with Autism Spectrum Disorder: a Scoping Review

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Abstract

Family caregivers often play a critical role in supporting their relative(s) with autism spectrum disorder (ASD) across the lifespan. This can lead to great burdens on family caregivers themselves. However, to date, the potential burden on family caregivers has not been in the focus of research, particularly, with respect to caregiver burden as relatives with ASD advance to adulthood. Thus, this scoping review aimed to (a) systematically map research regarding multiple dimensions of caregiver burden on family caregivers of adults with ASD (i.e., time dependence, developmental, physical, social, emotional, and financial burden) and (b) identify interventions designed to reduce such burden. A total of $N = 33$ eligible studies highlighted the impact of caregiving demands for adults with ASD, mainly focusing on emotional burden of caregiving ($n = 27$), reporting decreased mental quality of life and mental health. Findings gave indications on all other dimensions of caregiver burden, but evidence is lacking. No study was identified that provided evidence for specific interventions to reduce or to prevent caregiver burden. Findings highlighted the urgent need for more research on this topic and the development of strategies to support family caregivers of adults with ASD.

Keywords Autism spectrum disorder (ASD) · Caregiver burden · Adults · Scoping review · Mental health · Family caregivers

Abbreviations

| | | | |
|---------|--|-------------|--|
| ASD | Autism spectrum disorder | PRISMA-ScR | Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews |
| CBI | Caregiver Burden Inventory (Novak & Guest, 1989) | QoL | Quality of life |
| CRA | Caregiver Reaction Assessment (Given et al., 1992) | WHOQOL-BREF | World Health Organization Quality of Life—abbreviated version (World Health Organization, 1996) |
| DASS-21 | Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995) | | |
| ID | Intellectual disability | | |

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Caregivers within families play an important role in supporting their relative(s) with autism spectrum disorder (ASD) across the lifespan. Although caring for a loved one might have positive influences on family functioning (Beighton & Wills, 2017; Phelps et al., 2009; Sarriá & Pozo, 2015), it can also be associated with numerous impacts and burdens on the lives of family caregivers of individuals with ASD (Hoffman et al., 2013; Marsack & Hopp, 2018; Sonido et al., 2022; Tint & Weiss, 2016). To date, research primarily focused on parental caregivers of children with ASD (Bonis & Sawin, 2016; Bromley et al., 2004; Davy et al., 2022; Safe et al., 2012), but the perspective of family caregivers of adults with ASD is gaining importance (Hare et al., 2004; Liao & Lin,

2013). This is essential, as ASD is a lifelong condition and impairments are pervasive across the lifespan. However, little is known about the specific challenges of caring for adult relatives with ASD and how this might affect family caregivers (Cridland et al., 2014). Thus, a better understanding of the burden of family caregivers would “promote the well-being of families, which in turn will contribute to fostering democratic, stable and cohesive societies” (United Nations, 2012, p. 2).

Caregiving Demands of Adults with ASD

The core symptoms of ASD include persistent impairments in social communication/interactions and restrictive, repetitive, and inflexible patterns of behavior, interests, or activities (American Psychiatric Association 2013; American Psychiatric Association 2022). Additionally, challenging behaviors (e.g., self-injury, suicide attempts, and aggression) and comorbid somatic and mental disorders are common (Croen et al., 2015; Vohra et al., 2017). One-third to one-half of individuals with ASD have an accompanying intellectual disability (ID; Maenner et al., 2020; Postorino et al., 2016). The nature of these symptoms usually leads to distinct challenges in caring for an individual with ASD, such as the need for mediation in social interactions, inflexible daily routines, lack of spontaneity, or inappropriate behaviors (Cadman et al., 2012; Cridland et al., 2014). Furthermore, a lot of individuals with ASD require informal care and assistance with personal care (e.g., dressing, toileting, meals), providing transport, general housework, and/or emotional support (Järbrink et al., 2003). As there are only very few services available that support individuals with ASD in adulthood (Lord et al., 2022; Nicolaidis et al., 2015), many adults with ASD rely on support by their families (Cadman et al., 2012). For example, the majority of adults with ASD remain co-residing with their parents well into their late 20s, irrespective of the presence of a comorbid ID (Levy & Perry, 2011; Roux et al., 2015).

Caregiver Burden

Previous research defined caregiver burden as a relative’s appraisal of stressors and challenges related to the provision of care (Novak & Guest, 1989). Novak and Guest (1989), who primarily focused their research on caregivers of individuals with Alzheimer’s disease, defined five dimensions of caregiver burden. First, *time dependence burden* includes restrictions on the caregiver’s time available for personal interests and activities (Altiere & von Kluge, 2009; Smith et al., 2010) or privacy (Marsack & Perry, 2018). Second, *developmental burden* refers to personal or social underdevelopment compared to peers who do not have a

relative who requires care (Novak & Guest, 1989), which can lead to feelings of isolation and a perception of being disconnected or detached from the social environment (Hare et al., 2004; Hines et al., 2014; Marsack & Hopp, 2018). Third, *physical burden* describes caregivers’ feelings of chronic fatigue and damage to physical health (Novak & Guest, 1989). Fourth, *social burden* comprise feelings of role conflicts, as well as limited time and energy that they can invest in relationships or in occupational participation (Novak & Guest, 1989). Fifth, *emotional burden* refers to negative feelings towards the relative with ASD (Novak & Guest, 1989), such as guilt and blame (Marsack & Hopp, 2018; Marsack-Topolewski & Graves, 2019). In extension to this initial definition by Novak and Guest (1989), prior research reported caregiving to also worsen family caregivers’ mental health, including higher levels of psychological distress (Abbeduto et al., 2004; Blacher & McIntyre, 2006), and higher prevalence’s of mental disorders (Magallon-Neri et al., 2018; Schnabel et al., 2020).

In addition to these dimensions of caregiver burden by Novak and Guest (1989), Marsack and Hopp (2018), who investigated parental caregivers of adults with ASD, added the *financial burden*. This burden includes effects of caring on financial resources, such as direct costs related to specialized therapies and indirect costs related to constraints on working life (Cidav et al., 2012; DePape & Lindsay, 2015; Marsack & Perry, 2018).

To date, no comprehensive overview of burdens on family caregivers of adults with ASD was published. Existing reviews either focused on ASD in childhood (Tint & Weiss, 2016) or only assessed mental well-being of family caregivers (Sonido et al., 2019). Therefore, this scoping review aims to provide an overview of research on the abovementioned dimensions of burden on family caregivers of adults with ASD (i.e., time dependence, developmental, physical, social, emotional, and financial burden), to identify previously published interventions or supporting services designed to reduce such burden, and to detect existing knowledge gaps for further research. Thus, the following research questions were formulated: (a) What is known about the time dependence, developmental, social, physical, emotional, and financial burden on family caregivers of adults with ASD? (b) Which interventions exist to reduce caregiver burden on family caregivers of adults with ASD?

Method

This scoping review is based on the framework for scoping reviews by Arksey and O’Malley (2005), and conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). A scoping

review protocol was developed a priori, which was not preregistered.

Eligibility Criteria

This scoping review includes different types of peer-reviewed publications (quantitative, qualitative, mixed-method studies, and reviews). The following inclusion criteria were used: (1) publications written in English or German; (2) target population was either first- or second-degree family members (including partners/spouses); (3) of adult relatives (18+ years); (4) with secured ASD diagnosis; and (5) results included indications of caregiver burden and/or interventions to reduce caregiver burden.

Search Strategy

A comprehensive search strategy was performed in the databases PubMed and EBSCOhost between June 2022 and January 2023. Publication year was not restricted. The reference and citation lists of included studies were used to locate additional eligible studies. See Table S1 for full search terms.

Study Selection and Data Extraction

After removing duplicates, titles and abstracts were screened. Studies including participants with unspecific diagnostic groups (e.g., individuals with unspecific developmental and/or intellectual disabilities) or undefined range of age were excluded to provide a homogenous evidence base. Remaining studies were screened for eligibility in full by first author (S.D.) and a trained student research assistant. Screening resulted in 93% agreement rate for a randomly selected data sample (20% of all publications). Disagreements were clarified through consented discussion.

A data extraction sheet was developed, which contained the following data items: (1) title; (2) author(s); (3) year of publication; (4) country of origin; (5) study design, method; and data analysis; (6) eligibility criteria; (7) sample characteristics of caregivers and care recipients; and (8) results and original authors' interpretation. S.D. and a trained student research assistant extracted the data from all included papers. Results were categorized into the six dimensions of caregiver burden (time dependence, developmental, physical, social, emotional, and financial burden) based on the definitions by Novak and Guest (1989) and Marsack and Hopp (2018). An overview of the burden definitions used in previous research and in the current scoping review is shown in Table S2. Some studies

reported data without differentiating between the dimensions of caregiver burden, which is presented as caregiver burden composite in the "Results" section. For results with overlapping contents, burden-specific categorization was discussed with the last author (J.P.) until consensus was reached. Results over studies were synthesized by the first author and were reported according to each dimension of caregiver burden.

Results

A total of 33 articles were included in the scoping review. For details, see the flowchart of the study selection process (Fig. 1). The 33 studies consisted of 17 quantitative, eight qualitative, and three mixed methods studies, as well as five literature reviews (see Table 2 in Appendix I). Most studies were conducted in the USA (55.9%), followed by the UK (23.5%; see Table 1). The majority of family caregivers of adults with ASD were parents (in 58.1% of studies), and the most investigated burden was the emotional burden (34.6% of studies; see Fig. 2). The caregivers' age ranged from 18 to 87 years, and investigated caregivers were predominantly female (58.4–100%). The care recipients' age ranged from 18 to 96 years, and, except for one study, the majority of adults with ASD were male. Six studies investigated caregivers of adults with ASD and comorbid ID.

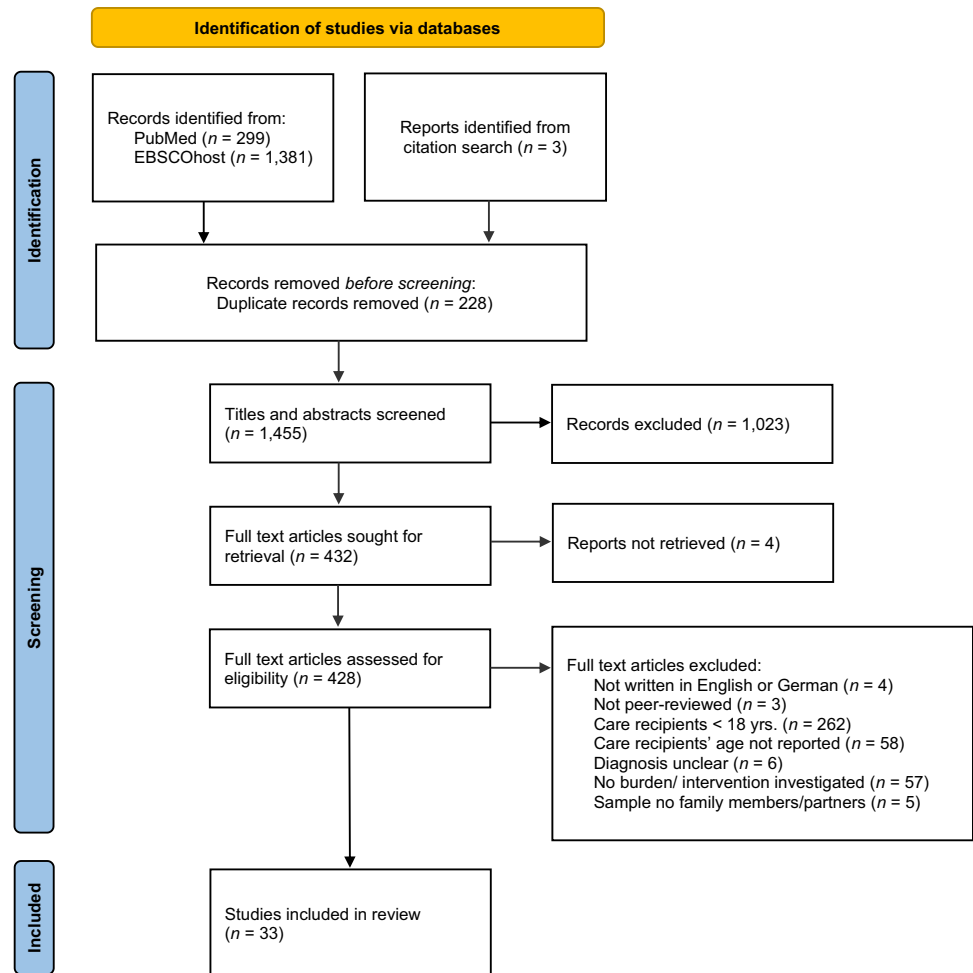
Dimensions of Burden on Family Caregivers of Adults with ASD

All dimensions of burden were detected within the included studies on family caregivers of adults with ASD. However, the amount of available research data differed. For an overview, see Fig. 2. In the following sections, detailed results are presented according to individual dimensions of burden. No evidence on interventions to reduce or prevent caregiver burden was identified.

Time Dependence Burden

In total, 11 studies provided evidence on time dependence burden (for details, see Table 2 in Appendix I). Except for one study, all participants were parents. All quantitative studies ($n = 4$; Marsack & Hopp, 2018; Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Wang, 2022) measured time dependence burden with the Caregiver Burden Inventory (CBI; Novak & Guest, 1989). Studies found an increased CBI mean score for the subscale "time dependence burden," indicating that parental caregivers experienced strain

Fig. 1 PRISMA flowchart



due to caring for the adult family members with ASD on a descriptive level (Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Wang, 2022; Marsack & Hopp, 2018). Moreover, parents who provided care to at least one adult child with ASD and another care recipient (compound caregivers) had significantly higher levels of time dependence burden than parents who only provided care for an adult child with ASD (noncompound caregivers; Marsack-Topolewski, 2021). A higher functional level or increased independence with respect to daily living skills in adult relatives with ASD was associated with less time dependence burden in parental caregivers (Marsack-Topolewski et al., 2021). However, the time dependence burden was found to be no significant predictor of parental quality of life (QoL) (Marsack-Topolewski & Church, 2019).

Qualitative studies ($n = 5$) provided deeper insights on causes and effects as well as subjective relevance of time dependence burden (Hare et al., 2004; Hines et al., 2014; Marsack & Perry, 2018; Oti-Boadi et al., 2020; Tozer & Atkin, 2015). Parents stated that they “navigate the

24/7 needs” of their adult children with ASD (Marsack & Perry, 2018, p. 545), and reported a substantial impact on their daily routines (Hines et al., 2014; Marsack & Perry, 2018) in several respects including lack of spontaneity and flexibility (Hines et al., 2014), and reduced privacy and time for themselves (Marsack & Perry, 2018; Oti-Boadi et al., 2020). Supported living for the adult child with ASD had positive effects such as more free time and freedom for the parents (Krauss et al., 2005). One study by Tozer and Atkin (2015) investigated siblings of adults with ASD and reported difficulties to spend time with their own commitments (e.g., spouses/partners, children, friends, parents, or work) and their sibling with ASD, to balance demands, and presence of a constant tension and feelings of guilt.

Developmental Burden

In total, 11 studies reported on developmental burden and all investigated parental caregivers of adult children with ASD. All quantitative studies ($n = 4$; Marsack-Topolewski, 2021;

Table 1 Identified articles

| | N of included articles (%) |
|--|----------------------------|
| Country of data collection ^a | |
| USA | 19 (55.9) |
| UK | 8 (23.5) |
| Australia | 2 (5.9) |
| Other (Belgium, France, Ghana, Netherlands, New Zealand) | 5 (14.7) |
| Relation to adult with ASD ^b | |
| Parents (mothers and fathers) | 18 (58.1) |
| Mixed family members | 6 (19.4) |
| Siblings | 4 (12.9) |
| Mothers | 2 (6.5) |
| Spouses | 1 (3.2) |

N sample size, ASD autism spectrum disorder

^aOne study collected data from the USA and the UK

^bTwo studies did not report information on the relationship

Marsack-Topolewski et al., 2021; Marsack-Topolewski & Wang, 2022; Marsack & Hopp, 2018) detected developmental burden in parental caregivers, assessed with the CBI (Novak & Guest, 1989). Developmental burden was significantly higher when adults with ASD were more dependent in completing activities of daily living, as well as in compound caregivers (Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Wang,

2022). It was assumed that parents who were less involved in assisting were more likely to find the time to engage in other social roles that would decrease their developmental burden (Marsack-Topolewski et al., 2021).

Qualitative studies ($n = 5$) discussed potential reasons for developmental burden with focus on the balancing fulfillment of own needs and providing care for the adult relative with ASD (Griffith et al., 2012; Hare et al., 2004; Hines et al., 2014; Marsack & Perry, 2018; Oti-Boadi et al., 2020). Parental caregivers reported restrictions on their lives and social exclusion, leading to feelings of isolation (Hare et al., 2004) and negative comparisons with peers (Marsack & Perry, 2018). Two main reasons for social exclusion were identified: First, caregiving demands caused the social network to shrink (Hare et al., 2004; Hines et al., 2014; Marsack & Perry, 2018; Oti-Boadi et al., 2020). Second, misunderstandings and stigma about ASD led to social exclusion (Griffith et al., 2012; Marsack & Perry, 2018; Oti-Boadi et al., 2020). The hidden nature of ASD and a lack of visible physical markers of disability may lead to the perception to be non-autistic (Griffith et al., 2012; Marsack & Perry, 2018). Parents felt that their caregiving demands were neither understood nor appreciated by the general public, leading to this sense of isolation (Griffith et al., 2012).

One mixed methods study by Krauss et al. (2005) found that one-fifth of the investigated parents reported social isolation to be a negative aspect of cohabiting with an adult child with ASD. Another mixed-method study by Marsack-Topolewski and Church (2019) found that the developmental burden (besides investigated time dependence, emotional, and financial burden) was the strongest predictor of the parental mental QoL, demonstrating an inverse relationship.

Physical Burden

Three studies (investigating siblings, parents, or especially mothers) provided indications for physical burden on family caregivers of adults with ASD. One quantitative study reported decreased general health in siblings of adults with ASD compared to siblings of adults with Down Syndrome (Hodapp & Urbano, 2007).

Qualitative data revealed that parents developed protracted physical illnesses and suggested it was caused by long-term stress and worry related to the care of their child with ASD (Oti-Boadi et al., 2020).

A mixed-method study found that living together with the adult child with ASD is related with stress and fatigue (Krauss et al., 2005).

Social Burden

The social burden was studied in one quantitative, five qualitative, and one mixed-method study, investigating

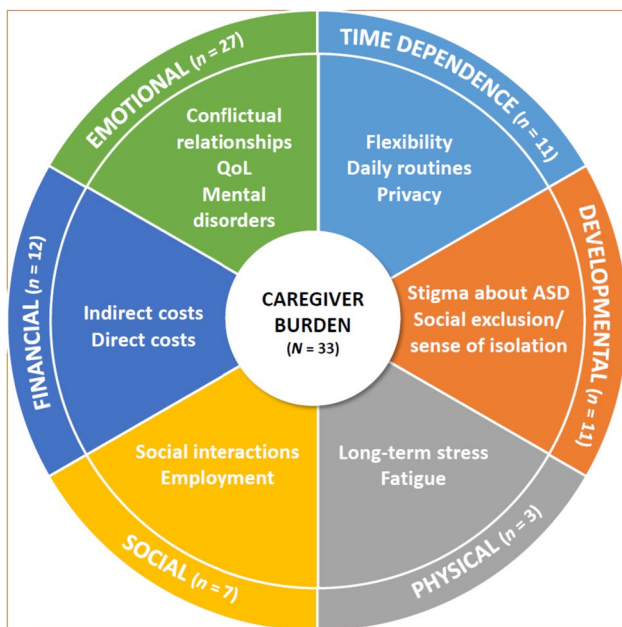


Fig. 2 Findings of burden on family caregivers of adults with ASD. ASD, autism spectrum disorder; QoL, quality of life. Some studies investigated multiple dimensions of caregiver burden

siblings and parents. Quantitative data revealed that siblings of adults with ASD reported a stronger impact on their relationship with the parents compared to siblings of adults with Down Syndrome (Orsmond & Seltzer, 2007).

All qualitative studies ($n = 5$) interviewed parental caregivers and found a negative impact of continuous care on other relationships and social activities (Hare et al., 2004; Hines et al., 2014; Marsack & Perry, 2018; Oti-Boadi et al., 2020; Tozer & Atkin, 2015). Parents discussed the potential threat of a crisis in their child's life and a lack of adequate respite care impacting their own social and recreational opportunities (Hines et al., 2014). This applied to friendships as well as to relationships within the families (Marsack & Perry, 2018; Oti-Boadi et al., 2020). For example, the feeling of not knowing the own partner/spouse anymore (Hare et al., 2004) or lack of time for other children without ASD (Hare et al., 2004; Marsack & Perry, 2018) were described because the majority of the time was spent caring for the adult family member with ASD. This was assumed as possible reasons why some families took the adult child with ASD into care (Hare et al., 2004). Furthermore, one study identified disruptions in the professional careers of maternal caregivers, as they could not combine work and care for the adult child with ASD (Oti-Boadi et al., 2020).

A mixed-method study explored positive and negative aspects of adult children with ASD living at home or in care, revealing that the living situation influences the social and work life (Krauss et al., 2005).

Emotional Burden

In total, 27 studies provided evidence on the emotional burden of caregiving in family caregivers of adults with ASD. Of these studies, 11 studies provided evidence on negative feelings or relationships towards the adult with ASD according to the definition of Novak and Guest (1989) (see Table S2). In addition, 22 studies gave evidence on influences on the mental QoL or the development of mental disorders in family caregivers.

Negative Feelings/Relationships

Quantitative studies ($n = 6$; Hodapp & Urbano, 2007; Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Wang, 2022; Marsack & Hopp, 2018; Orsmond & Seltzer, 2007) utilized either the CBI (Novak & Guest, 1989) to investigate parents ($n = 3$) or the positive affect index of relationship quality (Bengston & Black, 1973) to investigate siblings ($n = 2$). Studies in parents revealed no emotional burden (Marsack

& Hopp, 2018) or only slightly increased scores on a descriptive level (Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021). Research comparing the relationship quality of siblings of adults with ASD to siblings of adults with Down Syndrome showed that the latter felt like more respectful and fair towards their sibling (Hodapp & Urbano, 2007) and reported significantly higher levels of positive affect in their relationship than siblings of adults with ASD (Orsmond & Seltzer, 2007).

Qualitative studies ($n = 4$) investigated parents ($n = 2$), spouses ($n = 1$), and siblings ($n = 1$), and indicated an often conflictual relationship towards the adult with ASD, irrespective of the relationship (Hines et al., 2014; Lewis, 2017; Marsack & Perry, 2018; Tozer & Atkin, 2015).

A mixed-method study found that emotional burden did not predict parental QoL (Marsack-Topolewski & Church, 2019).

Influences on Mental QoL/Mental Disorders

Quantitative studies ($n = 12$) investigated parents ($n = 5$; Barker et al., 2011; Lee & Shivers, 2019; Marsack-Topolewski, 2020; Marsack & Samuel, 2017; Rattaz et al., 2017), siblings ($n = 3$; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007; Tomeny et al., 2017), or mixed family caregivers of adults with ASD ($n = 4$; Grootsholten et al., 2018; Herrema et al., 2017a, 2017b; Sonido et al., 2022). Several studies found higher levels of depressive symptoms and anxiety, and lower QoL in caregivers of adult family members with ASD (e.g. Barker et al., 2011; Grootsholten et al., 2018; Lee & Shivers, 2019). Across a 10-year period, depressive symptoms in caregivers remained constant, whereas anxiety decreased, and behavior problems of the care recipient correlated positively with depressive and anxiety symptoms (Barker et al., 2011).

Studies on caregivers' mental QoL revealed a number of predictors based on caregiver variables (e.g., age, intolerance of uncertainty, unpreparedness for the future) and care-recipient variables (e.g., ID, mental comorbidities, adaptive skills, symptom severity) (Herrema et al., 2017b; Rattaz et al., 2017; Sonido et al., 2022). The care recipients' age and the utilization of formal social support revealed no significant relation to caregivers' QoL (Lee & Shivers, 2019; Marsack & Samuel, 2017). One study reported that depressive behaviors of care recipients mediated the relationship between caregiver burden and mental QoL (Sonido et al., 2022). Lower levels of QoL were reported for compound caregivers compared to noncompound caregivers (Marsack-Topolewski, 2020). Grootsholten et al. (2018) found higher emotional distress in caregivers of adults with ASD compared to caregivers of adults with schizophrenia. Furthermore, caregivers of adults with ASD frequently expressed concerns, worries, and anxiety about the future and potential

support (Herrema et al., 2017a). Findings by Sonido et al. (2022) identified caregiver coping and cognitive dispositions as a predictor for caregiver mental well-being. Studies assessing siblings of adults with ASD found that parent-focused parentification was positively correlated with anxiety and stress in these siblings (Tomeny et al., 2017), and that they experienced higher levels of depressive symptoms compared to siblings of individuals with Down Syndrome (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007).

Qualitative studies ($n = 8$) investigated burden on mental health in parents ($n = 6$; e.g., Griffith et al., 2012; Hare et al., 2004; Hines et al., 2014), siblings ($n = 1$; Tozer & Atkin, 2015), and spouses of adults with ASD ($n = 1$; Lewis, 2017). In line with the quantitative results, parents reported high levels of psychological distress, anxiety, and worries about the future (e.g., Griffith et al., 2012; Marsack-Topolewski & Graves, 2019; Oti-Boadi et al., 2020). Furthermore, the strain on marriage (possibly leading to divorce), other children, and the family unit as a whole, directly attributed to having a child with ASD, were discussed as emotionally burdening (Hines et al., 2014). Parental mental health was reported to decrease due to lack of service provision, lack of knowledge in healthcare providers, maintaining emotional balance for the family, and care recipients' inappropriate behaviors (e.g., Griffith et al., 2012; Hines et al., 2014; Marsack & Perry, 2018).

One qualitative study on siblings of adults with ASD reflected on difficulties growing up with someone who has ASD, unresolved emotional issues, and resentments about the past. Most siblings expressed sadness and frustration about the limited reciprocity in their relationship, including a sense of loss because they did not have a typical reciprocal sibling relationship and rather felt the need to protect the sibling with ASD (Tozer & Atkin, 2015). In line with other caregivers, partners/spouses reported worries about the future and unmet emotional needs (Lewis, 2017). However, they reported the lack of intimacy/sex and shifted relationship roles due to the ASD of their partner/spouse as emotionally distressing (Lewis, 2017).

A mixed-method study by Krauss et al. (2005) investigated the impact of housing situations on maternal emotional burden. They reported positive aspects of living together with the child (e.g., peace of mind, shared love) and several negative aspects (stress, negative impact on siblings, worries about the future) affecting mental health. Positive aspects of children living outside the home (e.g., better marriage, benefits to other children) and negative aspects (e.g., feelings of guilt/worries/concerns, missing of child) were reported, too.

A systematic review by Sonido et al. (2019) on mental well-being of caregivers of adults with ASD differentiated contributors to carer stress and carer resources. Carer stress based on the previously mentioned care-recipient-related factors and carer-related contributors to stress. Potential carer resources included higher socioeconomic status, age, education, number of children, informal support received, marital status and support, caring relationship, perceptions of ASD, and optimism.

Financial Burden

In total, 12 studies reported evidence on financial burden in parental caregivers of adults with ASD. Quantitative studies ($n = 5$) reported financial burden (Marsack & Hopp, 2018; Marsack-Topolewski, 2021; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Church, 2019; Marsack-Topolewski & Wang, 2022), always assessed with the Caregiver Reaction Assessment (CRA; Given et al., 1992). Two studies reported that financial burden was significantly higher in noncompound caregivers than in compound caregivers (Marsack-Topolewski, 2021; Marsack-Topolewski & Wang, 2022). One study found a weak significant association between the adult child's dependence level and parental financial burden (Marsack-Topolewski et al., 2021). The authors suggested that other factors (e.g., availability of medical insurance, discretionary income to pay for out-of-pocket services) are likely to have a stronger influence on the financial burden than the adult child's dependence in the activities of daily living (Marsack-Topolewski et al., 2021). Financial burden was not a predictor of parental QoL (Marsack-Topolewski & Church, 2019).

All qualitative studies ($n = 3$) reported loss of employment and high costs for care as potential sources of financial burden in parents (Hare et al., 2004; Marsack & Perry, 2018; Oti-Boadi et al., 2020). Two studies reported associations between difficulties to combine work with care, which led to unemployment and negative effects on the financial situation (Marsack & Perry, 2018; Oti-Boadi et al., 2020). In addition, increased need for money to finance care for their adult child was reported (Hare et al., 2004; Oti-Boadi et al., 2020).

Reviews ($n = 4$) found evidence that costs of informal care and productivity loss were substantial in caregivers and substantiated a large part of overall costs related to ASD in the USA and the UK (Buescher et al., 2014; Ganz, 2007; Knapp et al., 2009; Rogge & Janssen, 2019). Absence of comorbid ID increased costs for parents of adults with ASD (Buescher et al., 2014; Knapp et al., 2009; Rogge & Janssen, 2019).

Caregiver Burden (Composite)

Six studies (five quantitative and one mixed methods study) assessed four of the caregiver burden dimensions (time dependence, developmental, emotional, and financial burden) as a composite score (without differentiation between the four dimensions) in parental caregivers. Burden were measured with the CBI (Novak & Guest, 1989), the CRA (Given et al., 1992), or caregiver burden (Heller et al., 1994). Studies showed increased composite scores for caregiver burden in family caregivers of adults with ASD (Marsack-Topolewski, 2021). In addition, they provided evidence on factors influencing the intensity of burden of caregivers. Studies reported that care recipients' health, level of maladaptive behavior, degree of independence in activities of daily living, presence of comorbid ID, and availability of informal support were related to total caregiver burden, and partially mediated the relationship between caregiver burden and parental QoL (Burke & Heller, 2016; Marsack & Hopp, 2018; Marsack & Samuel, 2017; Marsack-Topolewski et al., 2021; Marsack-Topolewski & Maragakis, 2020). Marsack-Topolewski and Wang (2022) showed significant correlations between the four dimensions of caregiver burden, with the strongest correlations between the emotional and the developmental burden, and the time dependence and developmental burden.

Discussion

This scoping review aimed to investigate and summarize the existing literature on dimensions of burden in family caregivers of adults with ASD, thereby scrutinizing the exact nature, relevance, and potentially influencing factors of specific burdens. In total, 33 studies provided evidence on all six dimensions of burden (time dependence, developmental, social, physical, emotional, and financial) or a composite score. No study was identified that provided evidence on interventions or suggestions for services tailored for family caregivers of adults with ASD.

Emotional burden was the most prominent dimension, with a focus on the impact of caregiving on family caregivers' mental health. Several care-recipient-related and carer-related variables influencing caregivers' mental health were identified. Thus, findings suggest that the expansion of the original emotional burden definition (Novak & Guest, 1989) by including these aspects like low-threshold symptoms of mental disorders and/or QoL is justified. These aspects also play a significant role in family caregivers of individuals with other chronic diseases, such as Alzheimer's disease (Pinyopornpanish et al., 2021), schizophrenia, and bipolar

disorders (Karambelas et al., 2022), and should be considered in future research.

To date, all other dimensions of caregiver burden have been less thoroughly investigated both in caregivers of adults with ASD and in caregivers of other disorders, e.g., schizophrenia (Awad & Voruganti, 2008), presumably resulting from mental health being the most extensively studied and operationalized area in research compared to the other dimensions of caregiver burden. Findings indicate the presence of all dimensions but evidence remains insufficient. Especially the presence of the social and physical burden could not be conclusively clarified as qualitative findings suggest family caregivers suffer from these burdens but quantitative evidence is lacking. However, findings of all dimensions supported the assumption that, for example, the residential situation, the level of independence of the adult with ASD, and the presence of informal and formal support might have potential to reduce the intensity of caregiver burden cross-dimensional.

Some relations between the dimensions of caregiver burden have been analyzed. One study examined influences of the time dependence, developmental, emotional, and financial burden on the parental mental QoL (Marsack-Topolewski & Church, 2019). Findings of these study found that the developmental burden strongly predicts the parental mental QoL, but the reasons for this remains unclear. While the developmental burden has been studied in other research fields (e.g., dementia), there has been less in-depth research in the area of ASD (Marsack-Topolewski et al., 2021). Therefore, developmental burden needs to become a scientific focus. However, to date, the relationship between the other dimensions of caregiver burden has not been investigated, but it can be assumed that, for example, social burden is influencing emotional burden, as it is closely related to mental QoL (Beierlein et al., 2012).

With respect to the second research aim, no intervention study was included in the scoping review. However, it can be assumed that corresponding services for family caregivers of adults with ASD exist (e.g., self-help groups) that have not yet been empirically investigated. Clinically, most health care systems are organized to meet the needs of the individuals with ASD; the needs of family caregivers are rarely addressed (Karst & Van Hecke, 2012). Services could be potentially effective, particularly with regard to the emotional burden, as results from intervention studies on caregivers of children with ASD or Alzheimer's disease showed, for example, decreased depressive and anxiety symptoms and improvements in QoL (Beinart et al., 2012; Bekhet, 2017; Smith et al., 2010). Furthermore, some of the included studies indicated that caregivers demanded interventions to reduce

caregiver burden (e.g. Grootsholten et al., 2018; Hare et al., 2004; Lewis, 2017).

In sum, the results reveal missing evidence on several aspects: (a) influencing factors of the specific burdens; (b) relationships between different dimensions of burden and potential dependencies; (c) associations between presence of burden and well-being of caregivers and other family members; (d) potential interactions between caregivers well-being and care recipients well-being; and (e) interventions/services to prevent and/or to reduce specific burden.

Limitations and Future Research

First, this review is limited in mapping all possible perspectives on caregiver burden in adults with ASD. There is a low ratio of participating fathers, reflecting the difficulty of recruiting fathers for autism research studies (Johnson & Simpson, 2013). Maternal perspectives are important but may not necessarily reflect those of other family members (Cridland et al., 2014). It is assumed that fathers either might not have time to participate or might not be involved into caregiving due to the traditional role of maternal parenting (Smith et al., 2010). Siblings and partners/spouses were barely examined so far, although the findings indicated that they also experience multiple caregiver burden. Furthermore, the identified studies were assessed in mostly high-income countries and, hence, do not account for additional challenges faced by families in low- and middle-income countries who may experience limited access to supports. It remains unclear whether the inclusion of other perspectives may have been associated with different emphasis of specific burdens on caregivers in adult ASD. Additional research is needed to illustrate multiple perspectives and address cultural impact on caregiver burden in ASD.

Second, quantitative data was often collected with the CBI (Novak & Guest, 1989), a questionnaire developed for caregivers of individuals with Alzheimer's disease. It remains unclear whether the CBI adequately applies to the burdens of caregivers in ASD. In addition, some dimensions appeared to be overlapping and should therefore be examined for discriminatory power.

Third, similarities in sample size and sociodemographic variables have been registered, giving reason to believe that data from the same sample may have been included in several publications, which must be taken into account in order to ensure the representativeness of the results of this scoping review (Marsack & Hopp, 2018; Marsack & Samuel, 2017; Marsack-Topolewski, 2020; Marsack-Topolewski, 2021;

Marsack-Topolewski et al., 2021; Marsack-Topolewski & Church, 2019; Marsack-Topolewski & Maragakis, 2020; Marsack-Topolewski & Wang, 2022).

Lastly, reported findings were often secondary results, i.e., not the focus of the original research, and therefore might not provide a comprehensive picture. Future research should aim to combine longitudinal quantitative and qualitative data from heterogeneous samples to enable an increased focus on the dimensions of caregiver burden. A better understanding of the origin and relationship between dimensions of burden should be the priority of future research in this field. Based on this, the development and evaluation of services for family caregivers of adults with ASD should represent a long-term goal. The focus should not only include the treatment of manifest mental disorders, but also the prevention of perceived caregiver burden and the maintenance of mental health. Furthermore, there is a need to provide adequate healthcare for adults with ASD, which could also relieve the burdens on family caregivers. Future research should try to shed more light on these topics since they might be a key to improve the life of family caregivers of adults with ASD.

Conclusion

Based on our analysis, this is the first scoping review that gives a comprehensive overview on existing literature about different dimensions of burden (time dependence, developmental, social, physical, emotional, financial) on family caregivers of adults with ASD. Indications for all dimensions of caregiver burden were detected, highlighting the emotional burden on family caregivers with focus on family caregivers' mental well-being. Accordingly, potential factors of influence were reported (e.g., carer and care recipient related variables). However, evidence on all other dimensions of caregiver burden was partially lacking or conflicting. Despite the cross-dimensional burden and impact of caregiving, no interventions to address specific or overall burden in family caregivers of adults with ASD were identified in the literature. Although concerns of family caregivers are increasingly addressed in autism research, there is still a lack of comprehensive, in-depth evidence regarding the underlying mechanisms, interactions, and time course of the different dimensions of caregiver burden. Further research on all dimensions of caregiver burden is required to develop tailored services to reduce burden on family caregivers of adults with ASD.

Appendix 1

Table 2 Study characteristics

| Author(s) | N (caregivers, ASD subgroup) | Caregiver sub-groups | Mean caregivers' age in years (SD/Range) | Mean care recipients' age in years (SD/Range) | Key finding(s) | Outcome measure(s) | Dimension(s) of caregiver burden |
|-----------------------------|------------------------------|---|--|---|--|--|----------------------------------|
| Quantitative studies | | | | | | | |
| Barker et al. (2011) | 379 | Mothers | 51.22 (10.52) | 21.91 (9.40) | Anxiety and depressive symptoms | Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977); Anxiety subscale of the Profile of Mood States (POMS; McNair et al., 1981) | Emotional |
| Burke and Heller (2016) | 130 | Parents (mothers = 83.9%, fathers = 16.2%) | 54.64 (9.77) | 25.02 (6.59) | Maladaptive behaviors and poor health of the adult with ASD related to greater caregiving burden | Caregiving satisfaction (Lawton et al., 1982); Caregiver self-efficacy (Heller et al., 1999); Caregiving burden (Heller et al., 1994) | Composite |
| Grootscholten et al. (2018) | NR | Spouses = 56.7%, parents = 29.8%, other (sibling, child, other family member) = 13.5% | 48.2 (11.3) | 39.9 (14.0) | Caregivers of adults with ASD experience overall consequences comparable to caregivers of patients with depression or schizophrenia | Involvement Evaluation Questionnaire (IEQ; van Wijngaarden et al., 2000); General Health Questionnaire (GHQ-12; Goldberg et al., 1997); Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001) | Emotional |
| Herrema et al. (2017b) | 109 | Parents = 82%, siblings = 8%, carer = 1%, spouses = 4.5%, others = 4.5% | 54 (9) | 27 (9) | Co-occurring mental health difficulties of care recipient associated with higher levels of worry, depression, anxiety and stress, and poorer quality of life | Intolerance of Uncertainty Scale (IUS-12; Carleton et al., 2007); Penn State Worry Questionnaire (PSWQ; Meyer et al., 1990); Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995); self-developed QoL measure | Emotional |

Table 2 (continued)

| Author(s) | N (caregivers, ASD subgroup) | Caregiver sub-groups | Mean caregivers' age in years (SD/ Range) | Mean care recipients' age in years (SD/ Range) | Key finding(s) | Outcome measure(s) | Dimension(s) of caregiver burden |
|---------------------------|------------------------------|--|---|--|--|---|---|
| Herrema et al. (2017a) | 120 | Mothers = 72%, fathers = 9%, siblings = 9%, carer = 2%, spouses = 5% | 54 (9) | 28 (11) | Worries about the future care of relative with ASD | concerns about the future (derived from themes from literature review) | Emotional |
| Hodapp and Urbano (2007) | 176 | Siblings | 30.6 (12.6) | 26.7 (13) | Compared with siblings of adults with ASD, siblings of adults with Down syndrome showed closer, warmer sibling relationships, better health, lower levels of depressive symptoms | Adult Sibling Questionnaire (ASQ; designed for this study) | Physical, emotional |
| Lee and Shivers (2019) | 61 | Parents = 96.4% | NR | 24.57 (8.93) | Lower levels of parental QoL | Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997); ASQ (Hodapp & Urbano, 2007); SF-12 (Ware et al., 1995); Family Needs Questionnaire (FNQ; Kreutzer et al., 1998); Brief COPE (Carver, 1997) | Emotional |
| Marsack and Hopp (2018) | 320 | Parents (unspecified) | NR (50–74) | NR | Parental caregivers were experiencing burden in all areas except emotional burden | Caregiver Burden Inventory (CBI; Novak & Guest, 1989), Caregiver Reaction Assessment (CRA; Given et al., 1992) | Time dependence, developmental, emotional, financial, composite |
| Marsack and Samuel (2017) | 320 | Parents (unspecified) | NR (50–70 s) | NR | Caregiver burden had a negative impact on mental QoL | World Health Organization Quality of Life—BREF (WHOQOL-BREF; World Health Organization, 1996), CBI (Novak & Guest, 1989), ENRICH Social Support Inventory (Mitchell et al., 2003) | Emotional, composite |

Table 2 (continued)

| Author(s) | N (caregivers, ASD subgroup) | Caregiver sub-groups | Mean caregivers' age in years (SD/ Range) | Mean care recipients' age in years (SD/ Range) | Key finding(s) | Outcome measure(s) | Dimension(s) of caregiver burden |
|------------------------------------|------------------------------|-----------------------|---|--|--|---|---|
| Marsack-Topolewski (2020) | 320 | Parents (unspecified) | NR (50–70 s) | NR (18–62) | Compound caregivers had lower QoL than noncompound caregivers | ENRICHD Social Support Inventory (Mitchell et al., 2003), CBI (Novak & Guest, 1989), CRA (Given et al., 1992), WHO-QOL-BREF (World Health Organization, 1996) | Emotional |
| Marsack-Topolewski et al. (2021) | 320 | Parents (unspecified) | NR (50–70 s) | NR | Caregiver burden was negatively impacted by the lack of independence in functional ability | CBI (Novak & Guest, 1989), CRA (Given et al., 1992) | Time dependence, developmental, emotional, financial, composite |
| Marsack-Topolewski et al. (2021) | 320 | Parents (unspecified) | NR (50–70 s) | 25.1 (7.09) | Caregiver burden decreased, particularly time dependence and developmental burden, when relative were less dependent in daily life | CBI (Novak & Guest, 1989), CRA (Given et al., 1992) | Time dependence, developmental, emotional, financial, composite |
| Marsack-Topolewski and Wang (2022) | 320 | Parents (unspecified) | NR (50–70 s) | 24.82 | Significant correlations between time dependence, developmental, and financial burden | CBI (Novak & Guest, 1989), CRA (Given et al., 1992) | Time dependence, developmental, financial, emotional |
| Orsmond and Seltzer (2007) | 77 | Siblings | 38.17 (7.73) | 34.88 (9.62) | Higher levels of positive affect in their relationship than siblings of adults with ASD than siblings of adults with Down Syndrome | Positive Affect Index (PAI; Bengtson & Black, 1973), Revised Activities of Daily Living Index (Seltzer & Krauss, 1989); Multidimensional Coping Inventory (Carver et al., 1989); Questionnaire on Resources and Stress (Friedrich et al., 1983) | Social, emotional |

Table 2 (continued)

| Author(s) | N (caregivers, ASD subgroup) | Caregiver sub-groups | Mean caregivers' age in years (SD/ Range) | Mean care recipients' age in years (SD/ Range) | Key finding(s) | Outcome measure(s) | Dimension(s) of caregiver burden |
|--------------------------------------|------------------------------|--|---|--|--|---|--|
| Rattaz et al. (2017) | 106 | Parents (mothers = 68%, both parents = 20%, fathers = 10%, guardians = 2%) | Mothers: 51.8 (1.5); fathers: 55.1 (6.8) | 20.6 (1.5) | Lower levels of parental QoL | Parental—Developmental Disorder—Quality of Life (Par-DD-QoL; Baghdadi et al., 2014) | Emotional |
| Sonido et al. (2022) | 101 | Mothers = 40.59%, spouses = 22.77%, fathers = 9.9% | 56.22 (21–78) | 37.50 (25–96) | Caregiver-related and care-recipient-related predictors of mental QoL | WHOQOL-BREF (World Health Organization, 1996) | Emotional |
| Tomeny et al. (2017) | 41 | Siblings | 25.83 (5.36) | 24.2 (4.92) | Parent-focused parentification was related with anxiety and stress | DASS-21 (Lovibond & Lovibond, 1995) | Emotional |
| Qualitative studies | | | | | | | |
| Griffith et al. (2012) | 5 | Parents (mothers = 80%, fathers = 20%) | 71.2 (63–82) | 39.75 (37–44) | Social isolation and future concerns of parental caregivers | N/A | Developmental, emotional |
| Hare et al. (2004) | 26 | Parents (mothers = 77%) | NR | 27 | Association between parental emotional distress and unmet need, social isolation, loss of employment | GHQ-12 (Goldberg et al., 1997), Family Support Scale (FSS; Dunst et al., 1988) | Time dependence, developmental, social, emotional financial |
| Hines et al. (2014) | 16 | Parents (mothers = 68.75%, fathers = 25%, stepmother = 6.25%) | 66.56 (58–82) | 38.85 (31–44) | Strain on marriage, daily routines, lack of flexibility | N/A | Time dependence, developmental, social, emotional |
| Lewis (2017) | 29 | Partners/spouses | 43.6 (21–65) | NR | High levels of stress/emotional burden in partners/spouses | N/A | Emotional |
| Marsack and Perry (2018) | 51 | Parents (unspecified) | NR (50–70 s) | NR (18–44) | Burden due to continuous care, social exclusion, lack of privacy, costs for care | N/A | Time dependence, developmental, social, emotional, financial |
| Marsack-Topolewski and Graves (2019) | 51 | Parents (unspecified) | NR (50–70 s) | NR | Challenges/worries to future planning for adult children with ASD | N/A | Emotional |

Table 2 (continued)

| Author(s) | N (caregivers, ASD subgroup) | Caregiver sub-groups | Mean caregivers' age in years (SD/ Range) | Mean care recipients' age in years (SD/ Range) | Key finding(s) | Outcome measure(s) | Dimension(s) of caregiver burden |
|---|------------------------------|-----------------------------|---|---|---|--|--|
| Oti-Boadi et al. (2020) | 9 | Parents (unspecified) | 55.8 (50–70) | 20.5 (18–23) | Reduced privacy and social interactions, social exclusion, unemployment, worries about the future | N/A | Time dependence, developmental, social, emotional, financial |
| Tozer and Atkin (2015) | 21 | Siblings | 41.14 (25–67) | 38.24 (25–65) | Tension and feelings of guilt, sense of loss, limited reciprocity in relationship to sibling with ASD | N/A | Time dependence, emotional, social, emotional |
| Mixed-method studies | | | | | | | |
| Krauss et al. (2005) | 133 | Mothers | Co-residing = 59.2 (8.6), living apart = 62.1 (9.4) | Co-residing = 30.2 (7.6), living apart = 32.9 (8.4) | Positive and negative effects of living situation of adult with ASD | N/A | Time dependence, developmental, social, physical, emotional |
| Marsack-Topolewski and Church (2019) | 320 | Parents (unspecified) | NR (50–74) | NR (18–44) | Developmental burden significant predictor of mental QoL | WHOQOL-BREF (World Health Organization, 1996) | Time dependence, developmental, emotional, financial |
| Marsack-Topolewski and Maragakis (2020) | 320 | Parents (unspecified) | NR (50–70 s) | NR | Behavior strongest predictor of caregiver burden | CBI (Novak & Guest, 1989) | Composite |
| Reviews | | | | | | | |
| Buescher et al. (2014) | NR | Parents (unspecified) | NR | NR | High costs due to productivity loss/family expenses | Productivity loss (parents) family expenses | Financial |
| Ganz (2007) | NR | Parents (unspecified) | NR | NR | High incremental societal indirect costs | Incremental societal costs | Financial |
| Knapp et al. (2009) | NR | NR | NR | NR | High costs due to productivity loss/family expenses | Average annual cost per capita for adults with ASD | Financial |
| Rogge and Janssen (2019) | NR | NR | NR | NR | Substantial costs of informal care and lost productivity | Costs of informal care and lost productivity for family/caregivers | Financial |
| Somido et al. (2019) | NR | Multiple (parents = 69.57%) | NR | NR | Mental well-being of caregivers | N/A | Emotional |

ASD autism spectrum disorder, N sample size, SD standard deviation, NR not reported, N/A not applicable

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Data Availability The datasets used and analyzed in the current study are available from the corresponding author on reasonable request.

Declarations

Conflict of Interest The authors declare no competing interests.

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