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**Emotional and Physical Challenges Faced by Parents and Caregivers of Children
with Autism Spectrum Disorder**

A thesis
submitted in fulfilment
of the requirements for the degree
of
Masters of Science (Research) in Psychology
at
The University of Waikato
by
Viraj Vikram Kikale



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Finally, I would like to thank the parents and carers who contributed to the studies included in this synthesis. Although this thesis presents findings from published papers, it is built upon the emotional work, physical effort and activism of parents and carers. They illustrate the fact that research findings emerge from the messy realities of real people.

To my family: even though we are separated by time and space, thank you for believing in me, for calming my anxieties, and for your continuous support. This achievement is yours as much as it is mine.

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The journey of writing this dissertation has enriched my capacity for research, but also my respect for the interwoven complexities of emotional and physical work, science and everyday life, structure and resilience. I conclude this study with greater humility with respect to the families who have guided it and with increased motivation to contribute to psychologically and culturally grounded research.

Viraj Vikram Kikale

Abstract

Autism spectrum disorder (ASD) has a significant impact on the broader family, with parents and other carers experiencing high levels of parenting stress, caregiver burden and psychological distress. A body of research has explored emotional and practical/physical impacts of ASD caregiving, but the degree to which these outcomes co-occur across child, carer and contextual factors has not been synthesised within recent quantitative evidence.

This systematic review aimed to synthesise quantitative empirical studies published mainly from 2015 onwards for exploring emotional and physical/practical caregiving outcomes in ASD caregiving. Methods: PsycINFO, PubMed, Scopus, Web of Science, CINAHL and ERIC were searched using pre-defined eligibility criteria. One hundred and fourteen records were screened and twenty studies were included in the main synthesis and additional sources were used for contextual and measurement purposes, but were not counted as included studies. Data were extracted and synthesised using structured narrative comparison, with consideration of methodological quality and contextual moderators. Across included studies, child clinical characteristics and caregiving context were commonly associated with variation in carer outcomes, including psychological distress and indicators of practical/physical burden (e.g. time demands and fatigue where measured). Carer characteristics (including gender, socioeconomic circumstances, health status, resilience and social support) were frequently explored as correlates or moderators. Intervention studies most commonly reported modest improvements in carer distress, while practical/physical caregiving demands were less consistently targeted where structural caregiving responsibilities remained unchanged. Methodological limitations commonly identified included the use of cross-sectional designs, dominance of self-report measures and poor representation of fathers and non-Western samples.

This review emphasizes the multidimensional and context-dependent nature of ASD caregiving outcomes and highlights key priorities for enhancing the rigour of future quantitative research in this field.

ASD Parenting and Caregiving: A General Perspective

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by enduring deficits in social communication and interaction, and restricted and repetitive behavioural patterns (American Psychiatric Association, 2013). The prevalence of ASD has risen dramatically in the last twenty years, with a recent epidemiological study suggesting that approximately 1 in 36 children in some high-income countries have received an ASD diagnosis (Maenner et al., 2023). Alongside growing awareness of the diagnosis, there has been a corresponding increase in focus on the families who care for autistic children in the long term.

Caregivers of children with ASD are almost uniformly found to experience greater levels of stress than caregivers of typically developing children and, in some instances, greater levels of stress than caregivers of children with other neurodevelopmental disorders (Hayes & Watson, 2013). Higher levels of parenting stress have been associated with problem behaviour, communication deficits, sleep problems, and symptom severity and variability (Estes et al., 2009; Lecavalier et al., 2006). Furthermore, caregivers are at risk for negative effects to work functioning, social functioning, and physical health when daily caregiving responsibilities are high and occur over an extended period (Karst & Van Hecke, 2012; Smith et al., 2010).

In the existing literature, caregiver outcomes have often been discussed in terms of concepts like parenting stress, caregiver burden, depression, anxiety, and decreased quality of life (Zaidman-Zait et al., 2017). A meta-analysis of research in this area found that parents of children with ASD had more depressive symptoms than parents of typically developing (TD) children (Hayes & Watson, 2013). A systematic review of research on correlates of poor mental health outcomes among caregivers, identified social isolation, stigma, and economic difficulties as common themes (Kinnear et al., 2016). While emotional outcomes have been

well discussed in the existing literature, there has been less integration of psychological research with the temporal, labour-intensive, and physical nature of the work of care.

The current care of a child with ASD typically requires attendance at appointments, the daily negotiation of behavioural incidents, the need to provide close supervision, modifications to the home environment and the negotiation of a service system. Such efforts represent emotional labour which is a regulated management of feelings over time in response to the requirements of caring as well as the physical and logistical efforts that are intertwined with the daily activities of caring. However, although these two types of labour are intertwined, studies have tended to treat measures of emotional distress and burden of care as distinct concepts, or as concepts with a tenuous relationship.

In addition, the literature suggests that child (e.g., level of symptomology, presence of comorbidities) and parent (e.g., parent gender, physical health, parental resilience) variables, as well as external factors (e.g., socioeconomic status, availability of resources) may influence the disparity in caregiver outcomes (Estes et al., 2009; Zaidman-Zait et al., 2017). Importantly, the studies above are heterogeneous with regards to the measures, sample, and methodology used. Therefore, despite the numerous quantitative studies that currently exist on the topic, no consolidated framework that measures the emotional and physical tasks of caregiving labour has been developed. (Hayes & Watson, 2013; Yorke et al., 2018; Podsakoff et al., 2003)

Despite this, however, the majority of research on ASD has focused on either stress, or well-being in isolation. The majority of existing quantitative studies into the experiences of ASD caregivers have used measures of emotional distress, burden, or quality of life. However, the specific definition of these concepts differs between studies. Some studies are focused on psychological symptomology, such as depression and anxiety, while others look at

more time-based measures of caring. Others look at family or functional impairment. As a result of these differing definitions and foci, the results in the area are disparate and mixed. While a breadth of studies has been conducted, it is difficult to compare them directly. For this reason, we have little understanding of how the emotional, and physical components of caring labour might inter-relate for parents of children with ASD. We also have little understanding of how child, parent, and social factors might impact on these constructs. In this way a systematic quantitative review of the literature would be beneficial to determine the extent to which trends exist, the presence of moderators, and the extent of the evidence in the field.

Chapter 1: Introduction

Description of Research Problem / Question

The existing body of research on parents and primary caregivers of children with ASD has shown that caring for children with ASD involves a lot of emotional and practical challenges. Most quantitative studies have focused on outcomes such as parenting stress, psychological distress, depression/anxiety symptoms, caregiver burden, and quality of life (QoL) (e.g., Keenan et al., 2016; Picardi et al., 2018; Neijs et al., 2024; Kara et al., 2025). However, emotional outcomes (e.g., distress, depression/anxiety symptoms) and practical or physical outcomes (e.g., fatigue, supervision demands, time pressure, physical strain) are usually part of different analytical models. This makes it difficult to see how they cluster together and whether their prevalence differs depending on the caregiving situation (Bonis, 2016; Picardi et al., 2018; Kara et al., 2025).

The broader post-2015 quantitative evidence would suggest that a range of child, parent, and environmental factors may be associated with caregiver outcomes (Yorke et al., 2018; Papadopoulos et al., 2019). Several studies mention or explore the association of child variables (e.g., behaviour problems) as well as parent variables (e.g., resilience) and broader contextual variables (e.g., stigma, social support, socioeconomic factors) with the well-being of caregivers of children with ASD (Chua et al., 2023; Papadopoulos et al., 2019; Shepherd et al., 2020; Rasoulpoor et al., 2023). In terms of specific variables, for instance, stigma has emerged in the ASD literature as a significant factor associated with mental health outcomes for caregivers (Papadopoulos et al., 2019), and social support is a commonly studied variable in relation to caregiver functioning (Shepherd et al., 2020). In addition, a few studies have looked at caregiver distress and impact on families during the COVID-19 pandemic (Liu et al., 2021; Russell et al., 2020; Alshaban et al., 2024).

Furthermore, the literature base remains methodologically heterogeneous regarding study design, sample, and measurement of variables (Soh et al., 2021; Yorke et al., 2018). This means that it is not clear what variables are the most reliable, consistent predictors of emotional and practical/physical caregiving outcomes. Thus, a systematic review of the literature regarding recent quantitative studies can help identify whether there are consistencies in how emotional and practical/physical outcomes are operationalised and assessed, whether there are differences between the results from different studies, and what kinds of limitations have the greatest impact on the interpretation of the results.

This systematic review aims to answer the following research questions:

1. What definitions and methods have been employed to measure emotional and physical labour outcomes in parents of children with ASD in recent quantitative studies?
2. Which variables, in the child, parent and environment, are associated with variations in emotional and physical labour?
3. How consistent are the results of different studies and what are the key weaknesses?

Study Objectives / Research Goals

The primary objectives of this study are to understand the caregiver burden, parenting stress, and mental health issues faced by parents of children with ASD. We synthesise quantitative estimates of these factors, aiming to minimize heterogeneity not related to sampling variation and measurement precision. To achieve this, we limit our study to homogeneous, well-defined designs where operational definitions of parental stress, caregiver burden, and mental health problems are explicitly stated.

Description of Included Literature, Theoretical Context, and Debates

In the included set of studies, most studies either utilize composite caregiver burden indices or focus on specific burdens without differentiating them into distinct domains. When domain-specific scores are not comparable across datasets, researchers often consolidate metrics into composite indices while ensuring measurement invariance. This necessity highlights the variability among studied populations. Although some evidence of caregiver burden relates to adult-onset conditions such as dementia, considerably less research has focused specifically on parents of adolescents or adults with ASD. Current empirical research emphasizes the correlation between the stigma associated with ASD and the well-being of caregivers (Papadopoulos et al., 2019). For instance, social withdrawal and reduced participation in social settings can exacerbate the stigma linked to autism. In such cases, caregivers may experience distress, which can be measured through depression or anxiety inventories, thereby revealing a strong connection between stigma and psychological morbidity. This relationship can directly or indirectly affect the physical and emotional challenges faced by caregivers.

Scope and Rationale for the Review

This systematic review includes published quantitative empirical research published in 2015 or later that examines at least one outcome for parents or primary caregivers of children with ASD in the context of the emotional and/or physical/practical challenges of caring for a child with ASD (e.g., Keenan et al., 2016; Picardi et al., 2018; Chua et al., 2023; Neijs et al., 2024; Kara et al., 2025). Studies published between 2010–2014 and qualitative studies and systematic reviews and meta-analyses are included for illustrative purposes but not counted in the PRISMA total (e.g., Falk et al., 2014; Papadopoulos et al., 2019; Yorke et al., 2018).

There are two reasons why our review was confined to more recent quantitative research. The first reason is that more recent research, especially since 2015, began to examine more outcomes, including caregiver stigma, perceived social support, and effects of the COVID-19 pandemic (Papadopoulos et al., 2019; Shepherd et al., 2020; Liu et al., 2021; Wang et al., 2021; Alshaban et al., 2024). Second, some recent studies included physiological measurements in addition to the self-reported outcomes from caregivers (Padden & James, 2017). Thus, a systematic review is warranted to provide a comprehensive overview of what has been investigated, what findings are more robust, and what methodological concerns need to be overcome.

Approach to Inquiry (Epistemological Positioning)

This systematic review acknowledges both contextual and theoretical influences on caregivers while maintaining a grounded, post-positivist pragmatic approach that prioritizes measurable outcomes. Post-2015, due to limited reporting frequency and variability in laboratory protocols, we have considered biological factors as they contribute systemic impacts beyond the subjective stress concerns of caregivers (Foody et al., 2015; Padden & James, 2017; Vitaliano et al., 2003). This restriction enhances standardization in our diagnostic criteria, outcome measurement, and reporting practices.

Even though a meta-analysis was initially planned for this thesis, we detected a high degree of heterogeneity among the studies included in terms of instruments used, operational definitions of caregiver burden, statistical reporting and types of designs. The outcome variables of parenting stress, caregiver burden, mental health and quality of life are among the most commonly used measures that made the quantitative synthesis problematic. Thus, we conducted a systematic review of quantitative studies using a structured narrative

synthesis to combine the results while maintaining the methodological and contextual diversity of the studies.

Chapter 2: Methods

Design and reporting framework

This thesis details a systematic review of quantitative studies concerning emotional and physical caring responsibilities of parents and/or caregivers of children with autism spectrum disorder (ASD), adhering to the PRISMA 2020 guidelines (Page et al., 2021). The PRISMA flow chart indicates how studies were identified, screened, assessed for eligibility, and included in the systematic review.

To ensure conceptual and methodological relevance, the inclusion criterion was limited to quantitative peer-reviewed empirical studies from 1 January 2015 (and beyond). Publications before 2015, qualitative studies, and secondary research (systematic reviews, scoping reviews, and meta-analysis) were only included for background and contextual purposes and were not included in the dataset.

In the reported results stated above, the term “included studies” refers to post-2015 empirical studies which were included in the main synthesis that met all the eligibility criteria in Table 2A. Contextual sources (pre-2015 studies, qualitative papers, and secondary research such as reviews and meta-analyses) were retained only to support the interpretation of mechanisms, measurement approaches, and service implications and these contextual sources were not used to derive any primary findings of the systematic review and are presented separately in Table 2B.

Eligibility criteria

Table 1

Domain	Inclusion criteria (included studies)	Exclusion criteria (not included studies)
Population	Parents or primary caregivers (e.g., mothers, fathers, guardians) of children/adolescents (0–18 years) with ASD; ASD diagnosis clinically confirmed or clearly specified.	Studies without caregiver outcomes; studies focused on professionals/teachers only; caregiver populations not primarily ASD (unless used as background context, not included).
Study type	Empirical, peer-reviewed quantitative studies (cross-sectional, cohort/longitudinal, RCT, quasi-experimental) reporting quantitative caregiver outcomes.	Qualitative-only studies; ethnographies; mixed-method studies where quantitative caregiver outcomes cannot be cleanly extracted; systematic reviews, scoping reviews, meta-analyses (may be used as background but are not included).
Timeframe	Published 1 January 2015 onward (inclusive).	Pre-2015 studies may be cited as background only,

but are not counted as included).

Language	English language full text.	Non-English full texts.
Concepts/Outcomes	Quantitative indicators of caregiver emotional burden (e.g., parenting stress, psychological distress, anxiety/depression symptoms, stigma-related distress) and/or physical burden (e.g., time-dependence/supervision load, fatigue, physical strain, musculoskeletal symptoms, relevant biomarkers).	Studies focused only on child outcomes without caregiver measures; purely economic/service descriptions without caregiver outcomes.
Interventions	Studies evaluating parent/caregiver interventions where caregiver outcomes are reported quantitatively.	Child-only interventions with no caregiver outcome reporting.

Studies were included if they: (a) focused on parents or primary caregivers of children/adolescents with ASD, (b) provided quantitative caregiver outcomes, which could be extracted and pertained to emotional labour (e.g., parenting stress, psychological distress,

anxiety/depression symptoms, stigma-related distress) and/or physical labour (e.g., time-dependence/supervision burden, fatigue, somatic strain, or physiological measures) (c) were published as peer-reviewed empirical articles. Mixed-methods studies were only included if quantitative caregiver outcomes could be extracted. Studies which reported only child outcomes, and no caregiver outcomes were excluded.

Information sources and search strategy

We employed a systematic search approach to identify empirical research concerning the impact of caring for a child with ASD, as reported by the psychology, medical, nursing, education, and social science literatures. Searches were performed using the following databases: PsycINFO, PubMed/MEDLINE, Scopus, Web of Science, CINAHL and ERIC. A final database search was conducted on 01/02/2026. A multi-faceted search strategy was employed using three groups of terms: (1) ASD terms (“autism spectrum disorder” OR “ASD” OR “autistic child” OR “ASD” OR “autistic child”); (2) caregiver terms (“parent” OR “mother” OR “father” OR “carer” OR “family”); and (3) burden/labour terms (“emotional labour” OR “physical labour” OR “stress” OR “distress” OR “burden” OR “caregiving tasks” OR “time-dependence” OR “fatigue” OR “resilience” OR “social support”).

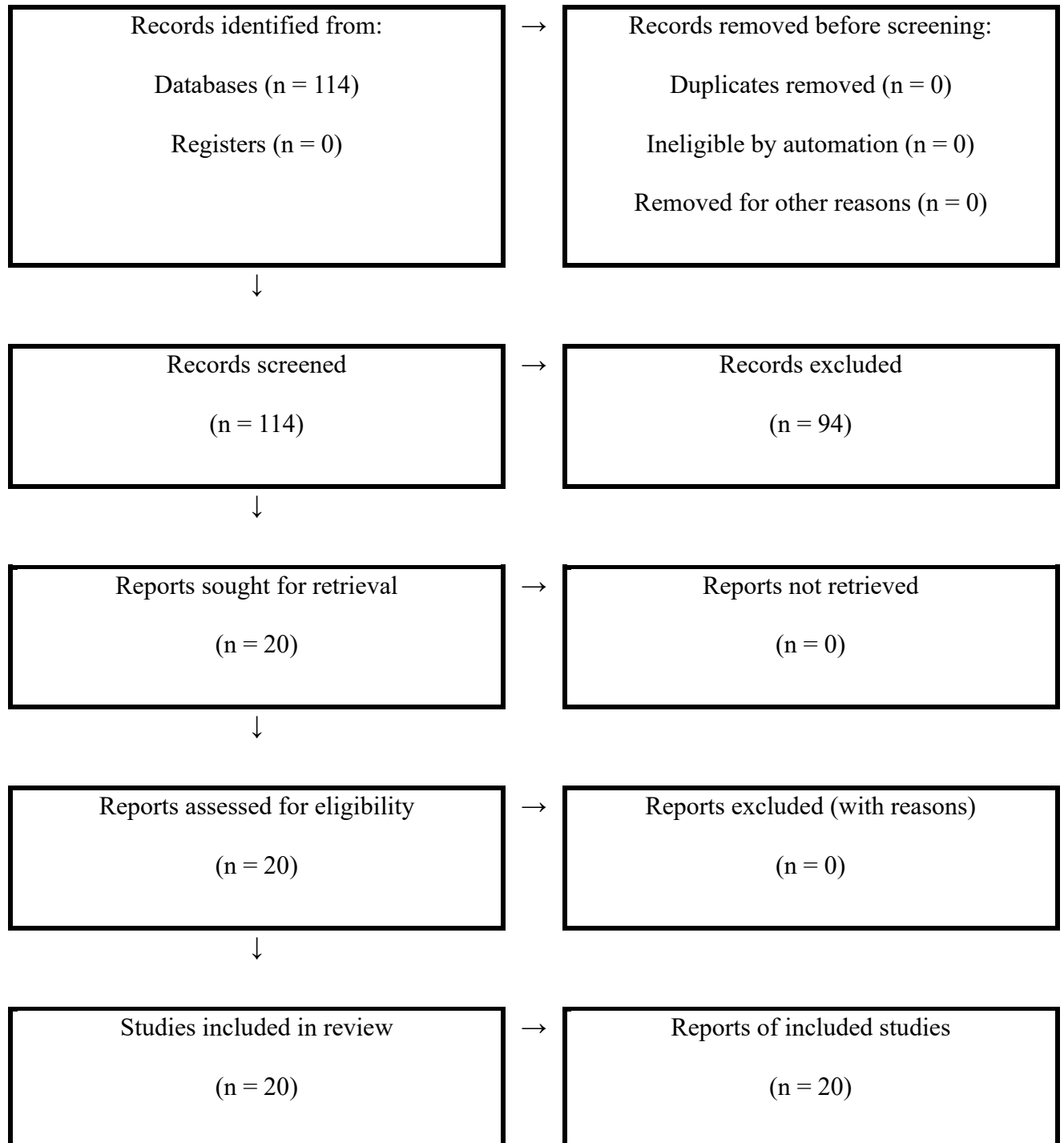
Each group of terms was combined with each other group using the Boolean operator “AND” (e.g., autism AND parent AND burden). Truncation and phrase searching was employed where each database supported the functionality. The reference list of papers which were identified as meeting the inclusion criteria was scanned for additional potentially relevant studies, a process known as “reference chaining”. All additional records identified through chaining were screened against the same inclusion criteria as the original database searches.

The search terms were designed to cover the review questions: (i) the identification of the population of ASD caregivers; (ii) the description of the caregiver's role and the family environment; (iii) the description of outcomes related to emotional labour (e.g. parenting stress, psychological distress) and physical labour (e.g. time-dependence burden, fatigue, somatic strain). For maximum transparency and reproducibility, the search terms covered identical concept groupings across the databases, with only syntax and available search functions differing between databases. Reference chaining was employed as a secondary search technique to maximise coverage and to reduce the risk of omitting relevant studies on ASD caregivers that may be variably indexed across the databases. Records generated by reference chaining were handled in the same way as those returned by database searches (that is, they were screened against title and abstract, and if necessary against full text), and records had to meet the same inclusion criteria to be included in the review.

Study selection process

Database search records were imported to a reference management tool, with duplicates removed. The screening process involved (1) title/abstract screening and (2) full-text screening against the eligibility criteria outlined in Table 1. Screening was performed by the author using the pre-defined screening criteria, with any eligibility ambiguities noted and clarified with the supervisory team.

Exclusion reasons at full-text screening stage were noted to facilitate PRISMA reporting. For transparency, Table 2 describes (A) the studies included in this systematic review (quantitative post-2015 ASD caregiver outcome studies) and (B) studies and sources used for background/context but not included in the systematic review dataset.

Figure 1*PRISMA 2020 Flow Diagram*

A final database search was conducted on 01/02/2026.

Included studies and contextual sources

Table 2A lists studies included in the systematic review dataset and synthesised in the Results section. Table 2B lists contextual/background sources (not included in the dataset).

Table 2A

<i>Included studies (2015+; quantitative; ASD caregiver outcomes)</i> 023 3333333 33+6	Study Design	Population	ASD-specific	Primary focus	Emotional labour outcomes	Physical labour outcomes	Role in thesis
Akhtayeva et al., 2025	Quantitative	Parents of children with ASD	Yes	Parent wellbeing; role of psychologists	Wellbeing/psychological strain	Not specified	Included (main synthesis; 2015+)
Alshaban et al., 2024	Quantitative	Parents/caregivers of children with ASD	Yes	COVID-19 impact on families	Anxiety/uncertainty/distress	Increased care load (time/role strain)	Included (main synthesis; 2015+)
Chetcuti et al., 2020	Quantitative (observational)	Caregivers of infants with early signs of autism	Yes (early signs/autism risk)	Caregiver distress & infant social-emotional difficulties	Psychological distress	Not specified	Included (main synthesis; 2015+)
Chua et al., 2023	Quantitative (cross-sectional)	Parents/caregivers of children with ASD	Yes	Problem behaviours & caregiver burden	Caregiver burden/distress	Supervision/time demands (burden subdomains)	Included (main synthesis; 2015+)
Da Paz et al., 2018	Quantitative (observational)	Mothers of children with ASD	Yes	Maternal adjustment after diagnosis	Distress/adjustment	Not specified	Included (main synthesis; 2015+)

Gabra & Hashem, 2021	Quantitative (comparative)	Caregivers of children with ASD vs ADHD	Yes (includes ASD group)	Stigma and burden comparison	Stigma/psychologica l outcomes	Caregiver burden	Included (main synthesis; ASD caregiver outcomes; 2015+)
Gentile, Messineo, La Guardia, et al. (2022)	Intervention (parent-mediated telehealth; 6-month; pre–post)	Parents (n=27) of children with ASD	Yes	Parent-mediated telehealth program; parent empowerment + parenting stress	Parenting stress; parental empowerment (caregiving emotional labour proxy)	Not reported / not primary outcome	Included quantitative/intervention evidence on caregiver distress/empowerment
Kara et al., 2025	Quantitative (cross-sectional)	Mothers of children with ASD	Yes	Fatigue and quality of life	QoL/wellbeing	Fatigue	Included (main synthesis; 2015+)
Keenan et al., 2016	Quantitative (cross-sectional)	Parents of children with ASD	Yes	Psychological distress/parenting stress	Psychological distress/parenting stress	Not specified	Included (main synthesis; 2015+)
Kütük et al., 2021	Quantitative (case–control)	Parents of children with ASD	Yes	Depression and burnout	Depression/burnout	Not specified	Included (main synthesis; 2015+)
Liu et al., 2021	Quantitative (intervention)	Mothers of children with ASD	Yes	WeChat-based parenting training during COVID-19	Psychological wellbeing/stress	Not specified	Included (main synthesis; 2015+)

Neijs et al., 2024	Quantitative (cross-sectional)	Parents of young children with ASD	Yes	Parental stress and QoL	Stress	QoL/functional impact (if reported)	Included (main synthesis; 2015+)
Padden & James, 2017	Quantitative (comparative/physiological)	Parents of children with ASD vs controls	Yes (ASD group)	Stress (self-report + physiological indicators)	Parent stress	Physiological stress indicators (biomarkers)	Included (main synthesis; 2015+)
Picardi et al., 2018	Quantitative (multicentre)	Families of children with ASD + comparison groups	Yes	Parental burden and correlates	Burden/distress	Burden/role strain (as measured)	Included (main synthesis; 2015+)
Rasoulpoor et al., 2023	Quantitative (cross-sectional)	Mothers of children with ASD	Yes	Burden, coping styles, resilience	Burden/psychological coping	Not specified	Included (main synthesis; 2015+)
Reich et al., 2025	Quantitative (cross-sectional)	Parents of children with ASD	Yes	Psychological flexibility, efficacy and coping	Coping/psychological outcomes	Not specified	Included (main synthesis; 2015+)
Seymour et al., 2018	Quantitative (population-based)	Fathers of children with ASD	Yes	Psychological distress in fathers	Psychological distress	Not specified	Included (main synthesis; 2015+)
Shepherd et al., 2020	Quantitative (cross-sectional)	Parents caring for a child with ASD	Yes	Types/functions of social support	Stress/distress (as associated)	Not specified	Included (main synthesis; 2015+)
Wang et al., 2021	Quantitative (cross-sectional)	Parents of children with ASD	Yes	Psychological distress during COVID-19	Psychological distress	Not specified	Included (main synthesis; 2015+)

Table 2B*Context/background and excluded sources (not part of included dataset)*

Author(s), Year	Study Design	Population	ASD-specific	Primary focus	Emotional labour outcomes	Physical labour outcomes	Role in thesis (context/excluded)
Abidin, 1995	Instrument manual	N/A	Yes	Parenting Stress Index (PSI-3) manual	N/A	N/A	Measure/instrument reference
Ainamani et al., 2020	Quantitative	Family caregivers of people with dementia	No	Caregiving burden & mental health (LMIC)	Distress/depression	Not specified	Context only (non-ASD caregiver population)
Almendingen & Pilkington, 2024	Not specified (general caregiving)	Caregiving contexts (general)	No/unclear	Family well-being and QoL in caregiving contexts	Well-being/QoL (general)	Not specified	Context only (not ASD- specific)
American Psychiatric Association, 2013	Diagnostic manual	N/A	Yes	DSM-5 diagnostic criteria reference	N/A	N/A	Background/definition reference
Barklı & Doğan (2025)	Review article (narrative/overview)	Parents/families raising a child with ASD	Yes	Overview of parental factors (self-efficacy, stress, wellbeing) and family impacts	Parental stress; psychological wellbeing concerns; coping/social support themes	Physical health concerns/fatigue mentioned (general)	Context/background only: review (not part of included primary dataset)

Baweja et al., 2021	Commentary	Individuals with ASD and families	Yes	COVID-19 disruptions and ASD-related challenges	Family stress/mental health impacts discussed	N/A	Context/background (pandemic disruptions)
Beach et al., 2005	Systematic review	Healthcare providers/education interventions	No	Cultural competence training interventions	N/A	N/A	Context/background (cultural competence)
Bekhet et al., 2012	Review	Family members of persons with ASD	Yes	Resilience in ASD family members	Stress/burden and resilience themes	N/A	Context/background (protective factors)
Bonis, 2016	Narrative review	Parents of children with ASD	Yes	Stress in parents of children with autism (review)	Parent stress (summary)	Not specified	Context only (secondary literature)
Brown et al., 2010	Mixed methods	Families of children with ASD	Yes	Advocacy and educational routines	Emotional strain	Care coordination	Context only (pre-2015)
Buescher et al., 2014	Economic analysis	UK/US ASD cost estimates	Yes	Economic costs of ASD	N/A	N/A	Context/background (economic burden)
Cheng et al., 2023	Meta-analysis	Parents/children with ASD	Yes	Parent-implemented interventions (meta-analysis)	Stress outcomes (summary)	Not specified	Context only (secondary synthesis)
Chukwuemeka & Obioha, 2024	Quantitative	Caregivers of developmental disabilities (mixed)	No/partial	Burden, resilience and mental health (SSA)	Mental health strain	Physical load	Context only (non-ASD/mixed disability)

Clay, 2017	Quantitative	Individuals with ASD (not caregivers)	Yes (ASD)	Reinforcing efficacy of social interaction components	Not caregiver outcome	Not caregiver outcome	Exclude (not caregiver outcomes)
Clifford & Minnes, 2013	Program evaluation (online support group)	Parents of children with ASD	Yes	Online peer support for parents	Perceived support/stress-related outcomes discussed	N/A	Context/background (online support)
Cohen & Wills, 1985	Theory/review	General population	No	Social support buffering hypothesis	Stress buffering via support	N/A	Theoretical framework reference
Corcoran et al., 2015	Systematic review/meta-synthesis	Parents of children with ASD	Yes	Lived experience (meta-synthesis)	Not quantitative caregiver outcomes	Not specified	Context only (qualitative synthesis)
Currie et al., 2023	Empirical (pandemic)	Children with NDD and families	Partial/varies	Care coordination during pandemic restrictions	Caregiver burden/service strain discussed	N/A	Context/background (service disruption)
Dababnah & Parish, 2013	Qualitative	Parents of children with ASD	Yes	Raising children with autism (West Bank)	Caregiving strain (qualitative)	Not specified	Context only (pre-2015; qualitative)
Dabrowska & Pisula, 2010	Quantitative	Parents of children with ASD/Down syndrome	Yes (includes ASD)	Parenting stress and coping (comparative)	Parenting stress	Not specified	Context only (pre-2015)
Damschroder et al., 2009	Framework article	Implementation science	No	CFIR implementation framework	N/A	N/A	Methods/framework reference

Dückert et al., 2023	Scoping review	Family caregivers of adults with ASD	Yes (adult ASD)	Multidimensional burden (scoping review)	Burden/mental health (summary)	Long-term care burden (summary)	Context only (adult ASD + secondary synthesis)
Egger et al., 1997	Methods paper	Meta-analysis	No	Funnel plot test for small-study effects	N/A	N/A	Methods/reference
Ekas et al., 2010	Cross-sectional correlational	Mothers of children with ASD	Yes	Optimism, social support, and well-being	Well-being/stress-related outcomes	N/A	Context/background (protective factors)
Estes et al., 2009	Quantitative	Mothers of preschool children with ASD (and comparison group)	Yes	Parenting stress and psychological functioning	Parenting stress/psychological functioning	N/A	Context only (pre-2015)
Estes et al., 2019	Review	Parents/families of children with ASD	Yes	Early autism intervention impacts on parents/family functioning	Stress/adaptation discussed	N/A	Context/background (overview)
Falk et al., 2014	Quantitative	Parents of children with ASD	Yes	Predictors of stress/anxiety/depression	Stress/anxiety/depression	Not specified	Context only (pre-2015)

Ferrara, Ricci, Damato, Iovino, Ricci, Cicinelli, Simeoli, & Keller (2023)	Scoping review + meta-synthesis	Autistic women (pregnancy/childbirth experiences)	Yes	Pregnancy and perinatal healthcare experiences in autistic women	Distress in healthcare interactions; psychosocial challenges (not caregiver-of-child focus)	Pregnancy/childbirth experiences (not caregiver physical labour)	Excluded: wrong population (not parents/caregivers of children with ASD)
Foody et al., 2015	Cross-sectional; biomarkers + surveys	Parents of children with ASD	Yes	Parenting stress and salivary biomarkers	Parenting stress; behavioural problems	Physiological biomarkers (e.g., saliva)	Context/background (physiological stress)
Fox et al., 2017	Qualitative	Adults diagnosed with autism (not caregivers)	Yes (adult ASD)	Adult diagnosis experiences	Not caregiver outcome	Not caregiver outcome	Exclude (not caregiver outcomes)
Glod et al., 2017	Psychometrics	Children with ASD (measure validation)	Yes	Measurement invariance (child anxiety scale)	Not caregiver outcome	Not caregiver outcome	Exclude (child measure validation)
Grandey, 2000	Theory/conceptual paper	Workplace/employees (general)	No	Emotion regulation framework for emotional labor	Emotional labor/emotion regulation concepts	N/A	Theoretical framework reference
Ha et al., 2014	Qualitative/mixed	Families living with ASD (Vietnam)	Yes	Living with ASD in Vietnam	Caregiving experience (qualitative)	Not specified	Context only (pre-2015)

Hayes & Watson, 2013	Meta-analysis	Parents of children with ASD vs non-ASD	Yes	Parenting stress comparison	Parenting stress (summary)	N/A	Context only (pre-2015; secondary synthesis)
Hebert et al., 2010	Review	Parents of children with ASD	Yes	Parental beliefs review	Not primary caregiver outcomes	Not specified	Context only (pre-2015; review)
Herisi et al., 2022	Intervention (unclear population)	Parents with 'abnormal children' (unclear)	Unclear	Emotional intelligence/resilience training	Resilience	Not specified	Context only (verify ASD specificity before using)
Ingersoll & Hambrick, 2011	Quantitative	Parents of children with ASD	Yes	Broader autism phenotype, severity, stress/depression	Stress/depression	Not specified	Context only (pre-2015)
Jegatheesan, 2011	Conceptual	Culture in diagnosis/intervention	Yes	Multicultural perspectives	Not primary caregiver outcomes	Not specified	Context only (pre-2015)
Jegatheesan et al., 2010	Qualitative/ethnographic	Immigrant families navigating autism	Yes	Navigation to services	Stigma/strain (qualitative)	Not specified	Context only (pre-2015; qualitative)
Jüni et al., 2002	Methods paper	Meta-analysis	No	Language bias in meta-analyses	N/A	N/A	Methods/reference
Jones et al., 2014	Quantitative	Families of children with ASD	Yes	Child behaviour & parental wellbeing	Parental wellbeing	Not specified	Context only (pre-2015)

Kalvin et al., 2020	Quantitative	Children with ASD (ratings discrepancy)	Yes	Parent vs child anxiety ratings	Not caregiver outcome	Not caregiver outcome	Exclude (child outcome focus)
Karst & Van Hecke, 2012	Review + conceptual model	Families of children with ASD	Yes	Family impact; proposed model for intervention evaluation	Stress/burden (conceptual)	N/A	Context only (pre-2015; review/theory)
Khateeb et al., 2019	Review/commentary	Autism diagnosis (culture)	Yes	Cultural issues in diagnosis	Context/stigma	Not specified	Context only
Kinnear et al., 2016	Quantitative	Parents of children with ASD	Yes	Stigma in parents and family life	Stigma-related distress	N/A	Context only
Lambert et al., 2017	Quantitative	Older adult informal caregiving (LMIC)	No	Impact of informal caregiving	Mental/physical health	Not specified	Context only (non-ASD)
Lecavalier et al., 2006	Quantitative	Caregivers of young people with ASD	Yes	Behaviour problems and caregiver stress	Caregiver stress	N/A	Context only (pre-2015)
Lee & Barger, 2024	Secondary data analysis (NSCH 2016–2019)	Fathers and mothers of children with ASD (US)	Yes	Predictors of poor mental and physical health in parents	Mental health; parenting stress	Physical health indicators	Context/background (population-based evidence)
Levin, 2006	Methods primer	Study design	No	Cross-sectional study design overview	N/A	N/A	Methods/reference

Li et al., 2024	Systematic review & meta-analysis	Parents of children with ASD	Yes	Parent-focused interventions effectiveness	Stress/depression/distress outcomes (reviewed)	N/A	Context/background (intervention evidence)
Lodder et al., 2019	Quantitative (caregiver focus)	Caregivers/parents of children with ASD	Yes	Stigma management/impression on regulation	Stigma-related distress	Not specified	Context only unless included in Results
Lord et al., 2000 (ADOS)	Instrument	ASD assessment tool	Yes	ADOS reference	N/A	N/A	Instrument reference (background)
Lounds et al., 2007	Quantitative (longitudinal)	Mothers of adolescents/young adults with ASD	Yes	Transition effects on maternal wellbeing	Maternal wellbeing	Not specified	Context only (pre-2015)
Maenner, 2023	Surveillance summary (MMWR)	Children aged 8 years (ADDM Network, US)	Yes	ASD prevalence and characteristics	N/A	N/A	Context only (epidemiology/background)
Marshall et al., 2018	Methods paper	Systematic review methods	N/A	Reference chaining methods	N/A	N/A	Context only (methods)
McCafferty & McCutcheon, 2020	Practice/literature review	Parenting a child with autism	Yes	Stresses and supports	Stress/supports (summary)	Not specified	Context only (secondary)
McConachie et al., 2018	Consensus/measurement	Parents suggest outcomes	Yes	Indicators to measure	Not caregiver outcome	Not caregiver outcome	Exclude (measurement priorities)

McStay et al., 2015 (CDDR)	Narrative review	Families raising a child with ASD	Yes	Family adaptation	Not primary caregiver outcomes	Not specified	Context only (secondary)
McStay et al., 2015 (JADD)	Quantitative	Parents of children with ASD	Yes	Parenting stress comparison	Parenting stress	Not specified	Context only unless included in Results
Meltzer, 2008	Brief report	Parents of children with ASD	Yes	Sleep in parents of children with ASD	N/A	Sleep disruption/strain	Context/background (physical strain)
Neely-Barnes et al., 2011	Quantitative	Parents of child with ASD	Yes	Perceptions and conceptualisations	Context	Not specified	Context only (pre-2015)
O'Donovan et al., 2019	Literature review	Parent training interventions	Yes	Group-based parent training	Intervention outcomes (summary)	Not specified	Context only (secondary)
Page et al., 2021	Reporting guideline	PRISMA 2020	N/A	Reporting guidance	N/A	N/A	Methods reference
Papadopoulos et al., 2019	Systematic review	Caregivers of autistic people	Yes	Stigma & caregiver mental health	Distress (summary)	Not specified	Context only (secondary)
Podsakoff et al., 2003	Methods paper	Behavioural research	No	Common method bias	N/A	N/A	Methods/reference
Popay et al., 2006	Methods guidance	Narrative synthesis guidance	N/A	Narrative synthesis methods	N/A	N/A	Methods reference
Rogge & Janssen, 2019	Literature review	Economic costs of ASD	Yes	Economic costs	Economic context	Not specified	Context only (not caregiver outcomes)
Russell & Norwich, 2012	Qualitative	Parents of children with ASD	Yes	Diagnosis perspectives	Context/stigma (qualitative)	N/A	Context only (pre-2015)

Russell et al., 2020 (Child Psychiatry & Human Development)	Quantitative	Caregivers during COVID (general)	Unclear	COVID caregiving challenges	Mental health	Care burden	Context only unless ASD-specific in thesis
Rutter et al., 2003 (ADI-R)	Instrument	ASD assessment tool	Yes	ADI-R reference	N/A	N/A	Instrument reference (background)
Sawyer et al., 2010	Cross-sectional/time-use survey	Parents of children with ASD	Yes	Time demands of caring	Stress/time pressure implied	Time demands/physical workload proxy	Context/background (time demands)
Schopler et al., 1980 (CARS)	Instrument	ASD assessment tool	Yes	CARS reference	N/A	N/A	Instrument reference (background)
Schulz et al., 2010	Reporting guideline	Randomized trials	No	CONSORT 2010 statement	N/A	N/A	Methods/reporting guideline
Schwartzman et al., 2021	Quantitative	Parents of children with ASD	Yes	Parenting stress and rating discrepancies	Parenting stress	N/A	Context/background (measurement issues)
Sedgwick, 2014	Methods primer	Study design	No	Cross-sectional studies	N/A	N/A	Methods/reference
Sedgwick, 2015	Methods primer	Study design	No	Bias in cross-sectional studies	N/A	N/A	Methods/reference
Sethi et al., 2019	Qualitative	Parents/professionals re ASD inflexibility	Yes	Behavioural inflexibility	Qualitative experiences	Behaviour management context	Context only (qualitative)

Smith et al., 2010	Intervention study	Children with ASD and families	Yes	Community-based early intervention model	Not specified (see study)	Not specified (see study)	Context only (pre-2015; intervention landscape)
Smith, Greenberg, & Seltzer, 2012	Longitudinal/observational	Parents of adolescents/adults with ASD (midlife)	Yes	Social support and well-being at midlife	Well-being; stress buffering via support	N/A	Context/background (social support)
Soh et al., 2021	Systematic review	Caregiver burden measurement (general)	No/unclear	Measurement approaches	N/A	N/A	Context only (measurement background)
Tarver et al., 2019	Systematic review & meta-analysis	Parent interventions (ASD)	Yes	Parent interventions outcomes	Emotional outcomes (summary)	Not specified	Context only (secondary)
Tilahun et al., 2016	Quantitative	Caregivers of developmental disorders	No	Stigma/unmet needs (LMIC)	Stigma/distress	Not specified	Context only (non-ASD/mixed)
Trembath et al., 2019	Systematic review	Parent-mediated interventions (ASD)	Yes	Generalizability factors	Stress outcomes (summary)	Not specified	Context only (secondary)
Vandenbroucke et al., 2007	Reporting guideline	Observational studies	No	STROBE explanation & elaboration	N/A	N/A	Methods/reporting guideline
Vernal, 2018	Exploratory study	Caregivers (population unclear)	Unclear	Burden/coping	Burden/coping	N/A	Context only (verify ASD specificity)

Vitaliano et al., 2003	Review	Caregivers (general)	No	Physical health impacts of caregiving	Stress/burden pathways	Physical health impacts	Context/background (caregiving health risk)
White et al., 2021	Survey study	Parents/caregivers of individuals with ASD	Yes	COVID-19 disruptions (SPARK caregiver survey)	Caregiver stress/burden discussed	N/A	Context/background (pandemic disruptions)
Whitmore, 2016	Integrative review	Caregivers of children with ASD	Yes	Respite care and caregiver stress	Stress (respite-related) discussed	N/A	Context/background (service support)
Wicks et al., 2022	Experimental	Preschoolers with ASD/TD	Yes (child sample)	Shared book reading attention	Not caregiver outcome	Not caregiver outcome	Exclude (child outcome study)
Woodgate et al., 2008	Qualitative	Parents of a child with autism	Yes	Parent experiences	Qualitative experiences	N/A	Context only (pre-2015)
Yamane, 2021	Psychometrics	Parents of children with autism	Yes	Psychometric evaluation of stressor index	Measurement validation	N/A	Context only unless included in Results
Yorke et al., 2018	Systematic review & meta-analysis	Parents of children with ASD	Yes	Child behaviour & parent distress	Distress (summary)	N/A	Context only (secondary)
Zaidman-Zait et al., 2017	Quantitative	Mothers of children with ASD	Yes	Personal/social resources and parenting stress	Parenting stress	N/A	Context only unless moved to Table 2A

Data extraction

We designed and tested a data extraction form prior to extracting data. The form included fields for author/year; country/setting; study design (cross-sectional, cohort/longitudinal study, intervention, etc.); sample description (including role/sex of caregiver and age range of child, whether diagnoses were confirmed, whether other conditions were reported); measurements used and quantitative results that pertained to our research questions.

Outcomes were organised into two pre-defined categories, (a) emotional burden variables (such as parenting stress, psychological distress, anxiety/depression symptoms, and stigma-related distress) and (b) physical burden variables (including time-dependence or supervision burden, fatigue, physical burden/musculoskeletal symptoms, and physiological measures if available). If a study used multiple subscales to measure outcomes within a given domain, we extracted all subscales.

The author extracted the data from the included studies using the pre-designed data extraction form. The methods and results sections were thoroughly read to identify the outcomes, instruments and analyses used. If multiple analyses were conducted in a study, the results most relevant to the review were prioritized for extraction (that is, the relationship between the child/caregiver/context variables and emotional or physical labour outcomes and, if applicable, intervention effects on caregiver outcomes).

If studies did not provide enough information on statistical results to allow direct comparisons (for example, dispersion estimates not reported, subscales not clearly scored or covariate adjusted analyses not fully reported), this was noted as a reporting weakness and considered in the quality assessment and narrative synthesis. No attempts were made to

impute any missing statistical information, but results were presented at the level of data provided in the study.

Quality appraisal of included studies

The methodological quality (or risk of bias) of included studies was assessed using the relevant Joanna Briggs Institute (JBI) Critical Appraisal Checklists (e.g. analytical cross-sectional studies, cohort studies, randomised controlled trials). Each item on the checklist was rated (yes/no/unclear/not applicable) and an overall judgement was noted for each paper based on the pattern of the responses. Quality appraisal was used to inform the interpretation of the results (for example, giving more weight to studies with clear sampling, validated tools, and appropriate analysis) rather than as a basis for exclusion of studies, except where a paper did not meet the inclusion criteria.

The risk of bias tool assessed items related to key sources of bias in caregiver outcome studies, including: (i) selection (e.g., representativeness, response rate); (ii) measurement (e.g., use of validated measures, scoring clarity); (iii) confounding (e.g., control for child symptomatology, socioeconomic status, and caregiver variables); and (iv) attrition (e.g., missing data, follow-up if applicable). The domains for each study are reported to facilitate the comparison of strength of evidence across studies within each Results chapter. To maintain methodological inclusivity while still addressing evidential quality, studies were not excluded from the review based on their quality score in order to accommodate the methodological breadth inclusion criterion. Rather, the quality score informed the interpretation of results (e.g., interpreting results of a convenience sample or study with few controlled confounding variables as preliminary) and facilitated the discussion of the overarching methodological limitations of the extant literature in the Discussion chapter.

Data synthesis

Due to the heterogeneity of the studies with respect to the populations studied, the outcomes measured and the way data were presented, no meta-analysis was conducted. We used narrative synthesis as described in the guidance for conducting systematic reviews of very different interventions (Popay et al., 2006).

We conducted a narrative synthesis following four interrelated steps outlined by Popay et al. (2006). First, we generated a theoretical model of the data to categorise results into both (1) domains of labour (emotional and physical) and (2) levels of the proposed explanatory variable (child-level, caregiver-level and context/system-level variables). The structure of this framework guided the organisation of the Results chapter, ensuring that discussion of similar variables took place together even when different measures were used. Second, a preliminary synthesis was conducted by presenting the quantitative data in tables and summarising the findings thematically. Studies were categorised based on primary variables of interest (e.g., child symptom severity, comorbidity, caregiver resilience/mental health, social support and intervention/support mechanisms). The results were summarised focusing on: the tools used, sample, study design and whether or not the results were uncontrolled or controlled. Third, the findings within and across studies were explored by making explicit the similarities and discrepancies between studies, and considering possible reasons for these discrepancies, such as the tools and cut-offs used, recruitment setting and caregiver and service characteristics. When multiple studies investigated the same explanatory variable, we described the consistency of the findings and indicated which results seemed more robust according to the previously described quality assessment criteria. Finally, the strength of the synthesis was considered by exploring whether the results remained consistent when stronger weighting was given to studies with more rigorous designs (e.g., better control for confounding variables, better tools or longitudinal or

interventional design) and by making it clear which results were reliant on single or low-quality studies.

We organized the findings into themes related to the aims of the systematic review, which were: (a) the child (e.g., severity of symptoms, behaviour problems and any comorbidities if specified); (b) parent (e.g., parent health and psychological well-being like resilience); (c) environment (e.g., SES, stigma and social support); and (d) intervention and services (e.g., parent training and telehealth). We then looked for similarities and differences in the results within each theme, considering the study design and the quality of the evidence.

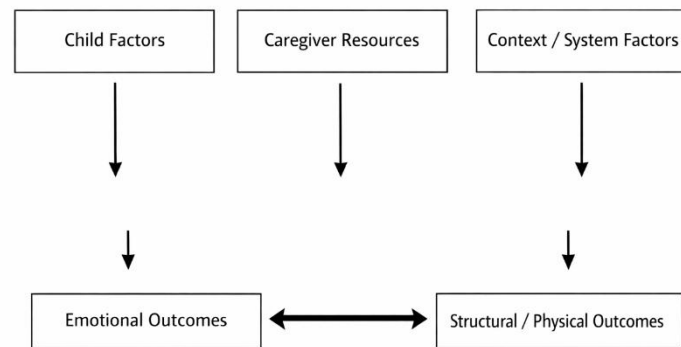
Chapter 3: Results/Findings

Characteristics of Included Studies

In terms of the twenty quantitative post-2015 studies included in this review, the majority were cross-sectional, with relatively few intervention and comparison studies. The majority of samples were drawn from clinical, autism-specific, and parent group samples, with very few studies using population sampling frames. The majority of caregiver samples were mothers, with only one study recruiting specifically for fathers, and very few studies had near-equal gender samples (Foody et al., 2015; Padden & James, 2017). In terms of sample location, studies were conducted in high- and middle-income settings, including Europe, the Middle East, and Asia, though no studies made direct between-site comparisons. Outcome measures tended to centre on emotional outcomes for the caregiver (parenting stress, psychological distress, depression, burden) and relatively few studies considered the physically and practically demanding aspects of caregiving labour, which were not consistently conceptualised or measured (e.g., time commitment, supervisory needs, physical exertion). This provides a general indication that the quantitative literature is more comprehensive in its focus on emotional strain than on the more concrete, structurally-determined aspects of caregiving labour (Vitaliano et al., 2003).

Figure 2

Conceptual overview of quantitative associations in post-2015 ASD caregiver research.



This model illustrates the key factors that emerged as general themes from the studies examined. Child (e.g., symptom severity, behaviour), caregiver (e.g., resilience, psychological flexibility, physical health), and system/contextual (e.g., social support, SES, access to services, impact of COVID-19) factors were linked to two theoretically and statistically distinguishable, but related, themes of caregiver impact: (a) emotional (e.g., parenting stress, psychological distress, symptoms of depression and anxiety) and (b) structural/physical (e.g., time dependence burden, fatigue, somatic burden). The two-headed arrows between the two themes represent the idea that there is conceptual overlap between these two domains, as well as considerable diversity in how they were operationalised in the studies reviewed.

Design of the Study

Most studies included in this systematic review used a cross-sectional design that measured the child's, caregiver's, and situational factors at a single point in time (e.g.,

Keenan et al., 2016; Chua et al., 2023; Neijls et al., 2024; Rasoulpoor et al., 2023; Reich et al., 2025). Although this type of study design can establish correlations, it cannot establish the direction of the relationship between the burden and caregiver well-being. (Sedgwick, 2014; Levin, 2003)

There were also a small number of comparative and case-control studies (e.g., Gabra & Hashem, 2021; Kütük et al., 2021) included in the corpus. These were helpful in evaluating relative levels of burden, but were also observational. There were a few intervention studies (e.g., Estes et al., 2019; Liu et al., 2021). These provided some information about longitudinal change in the burden experience of family caregivers, especially on the mental health aspects. Follow-up durations were short and burden characteristics were not manipulated.

Few longitudinal cohort studies were identified. Consequently, we have limited insight from quantitative studies after 2015 into trends over time of emotional and physical labour of caregivers.

Context of Recruitment and Regional Spread

Samples were mostly convenience samples drawn from clinical services, autism centres, or parent groups (e.g., Picardi et al., 2018; Shepherd et al., 2020), although a small number used population-based samples (e.g., Seymour et al., 2018, focused on fathers). This may mean that samples are biased towards families who have greater contact with services and possibly towards families with greater access to support.

Countries in which the research was carried out comprised both high-income and middle-income countries (e.g. Rasoulpoor et al., 2023; Wang et al., 2021; Alshaban et al., 2024), but there was a lack of studies directly comparing findings across different cultures. Research carried out during the COVID-19 pandemic (Wang et al., 2021; Alshaban et al.,

2024; Liu et al., 2021) raised additional issues concerning the impact of disruptions to services and changes to caregiving conditions.

Caregiver Sample Characteristics

However, most studies examined the role of the mother. Several studies explicitly focused on mothers (Da Paz et al., 2018; Kara et al., 2025; Rasoulpoor et al., 2023). Others recruited ‘parents’ but reported predominantly female participation (Keenan et al., 2016; Picardi et al., 2018) and one study examined ‘fathers’ specifically (Seymour et al., 2018). Therefore, our results may be limited in the interpretation of whether there is an unequal distribution of emotion and physical care work between parents.

Occasionally, socioeconomic characteristics were presented or used as covariates (Chua et al., 2023; Picardi et al., 2018) yet seldom was socioeconomic status considered as a key predictor. In a few cases, family structure and ethnicity were fully disclosed.

Child Characteristics and Developmental Range

The children in the samples ranged from infants (Chetcuti et al., 2020) to school-children and teenagers (Keenan et al., 2016; Neijs et al., 2024). Still, the developmental phase was rarely tested as a moderator. Child age was mostly used descriptively rather than as an analysis variable.

When child features were measured, it was more often by proxy through externalizing behaviours or functioning, rather than through clinician-rated symptoms of the primary diagnosis. For studies that focused on behavioural problems, more severe behavioural problems were associated with greater levels of parental burden or impairment (Chua et al., 2023; Picardi et al., 2018).

Emotional and Physical Outcomes

A broad range of emotional labour outcomes were investigated. Parenting stress and psychological distress were often evaluated through standardised self-report questionnaires (Keenan et al., 2016; Neijls et al., 2024; Kütük et al., 2021). Caregiver burden was commonly described as measured through multidimensional scales, which include emotional and role strain (Picardi et al., 2018; Rasoulpoor et al., 2023).

By comparison, we found that more direct measures of physical/practical care (for example, hours of supervision or number of nights' sleep disturbed) were less frequently reported. Fatigue was measured directly in one study (Kara et al., 2025), and physiological stress measures were reported in another (Padden and James, 2017). Thus, in some instances, the need for structural care was implied by its impact on a fatigue or quality-of-life measure.

The Methodology Overview

In summary, studies in this analysis are generally representative of a literature that is overwhelmingly cross-sectional, relies heavily on self-reported data, over-samples women, and does not adequately operationalize the dimensions of physical caregiving work. Emotions are typically measured more reliably and validly than structural labour measures. This context should be kept in mind in reading the thematic results in the following sections and underscores both the benefits and shortcomings of the current quantitative research in the area.

Child Symptom Severity as a Quantitative Predictor of Caregiver Emotional and Physical Labour

These included quantitative studies commonly investigated child-level clinical and behavioural factors in association with caregiver outcomes, with the assumption being that children with more severe difficulties will create more demanding circumstances for

caregivers. The broader ASD literature often operationalises ‘symptom severity’ through clinical measures (e.g. the Autism Diagnostic Observation Schedule [ADOS]; Lord et al., 2000; the Childhood Autism Rating Scale [CARS]; Schopler et al., 1980; and the Autism Diagnostic Interview–Revised [ADI-R]; Rutter et al., 2003). By contrast, child-level difficulty in these included studies was more often measured through study-specific variables of behavioural challenge and caregiving complexity, which were then associated with caregiver outcomes such as parenting stress and psychological distress (e.g. PSI–SF; Abidin, 1995), caregiver burden and wellbeing/quality-of-life (Keenan et al., 2016; Picardi et al., 2018; Chua et al., 2023). Therefore, the most reliable conclusion that can be drawn from this dataset is that higher levels of child difficulty (specifically behavioural challenge when measured) are associated with higher levels of caregiver emotional strain and burden, not a straightforward relationship between any one clinical ‘severity’ measure and caregiver outcomes.

In Table 2A, the two research areas involving child problem behaviour and parent outcomes are the most likely candidates for demonstrating this association. Research on problem behaviour and parent burden suggests that more severe child problems relate to greater levels of parent burden and distress (Chua et al., 2023). Multiple-site research on parent burden and associated factors suggests that parent burden is associated with differences in caregiving circumstances and child factors, but these studies use different measures and control for different variables (Picardi et al., 2018). The measurements used matter: Some studies measure parent outcomes largely as psychological distress or parenting stress (Keenan et al., 2016), while others use more comprehensive burden or wellbeing measures (Picardi et al., 2018; Neijls et al., 2024), so it is not possible to directly compare these findings in terms of a single “severity → outcome” association.

In addition, there is some developmental-stages evidence relevant to this research question, but defined in other terms. Looking at parent mental health among parents of babies who show early risk of ASD, the authors examined social-emotional problems in the baby, suggesting that parent mental health may be an issue for ASD risk babies (Chetcuti et al., 2020). Also, examining the psychosocial changes in mothers after a child's ASD diagnosis, these authors indicate that distress and adjustment are relevant to ASD parenting, but do not present their results in terms of one overarching predictor variable (Da Paz et al., 2018). Notably, some studies in this review discussed parental outcomes in terms of provision: the studies that talked about the impact of professional help on parent wellbeing, suggest that perhaps parents' outcomes depend on the broader environment and available support, as much as child severity (Akhtayeva et al., 2025).

Severity is helpful as a categorical predictor because it enables easier comparison between studies, and it does appear to explain some of the heterogeneity in caregiver burden within ASD. However, "severity" was operationalised differently across the post-2015 studies included in the primary analysis. Some studies defined severity in terms of clinician-rated core symptoms (e.g., ADOS, CARS, ADI-R), while others looked more at parent-rated behavioural symptoms or functional impairment as the "lived experience" of severity (Chua et al., 2023; Kalvin et al., 2020). For interpretation, this matters because measures of behavioural problems are more closely tied to the immediate demands of supervision and crisis-management that are associated with time-dependence and physical demands, whereas measures of core symptoms may be less directly related to the amount of "work" involved for parents. The studies also differed in which caregiver outcomes were assessed. Some looked exclusively at parenting stress (e.g., PSI-SF total distress), while others used more multi-dimensional measures of burden or quality of life that included both practical burden (time, fatigue, autonomy) and distress. When severity was more strongly associated with burden

rather than stress, this tended to be in terms of structurally-sensitive domains (e.g., time-dependence) that may persist even if parents report reductions in distress (Trembath et al., 2019). In general, there appears to be a pattern that supports the relevance of severity, but that the size of the relationship may depend on the operationalisation of severity, the outcome measure used, and access to contextual resources (Akhtayeva et al., 2025).

Third, context-related change during the COVID-19 pandemic is pertinent to understanding the relationship between child severity and caregiver burden, because the pandemic likely impacted family circumstances and available resources (Baweja et al., 2021; White et al., 2021). The COVID-19 pandemic studies in the present sample indicate greater caregiver burden and/or distress amid the pandemic (Alshaban et al., 2024; Wang et al., 2021). One randomized controlled trial of a remote parenting intervention amidst the COVID-19 pandemic offers an example of targeted support in a resource-limited context, and examines caregiver stress/psychological distress across time (Liu et al., 2021). Though these studies do not directly address “moderation by severity,” they suggest that caregiver functioning in the context of ASD parenting is influenced by both child severity and situational factors.

The relationship between child symptoms and behaviours and caregiver distress was evident across studies, but the magnitude of that relationship may depend on both contextual and caregiver factors. Specifically, caregiver distress was greater in studies conducted during the COVID-19 pandemic compared to those prior, despite no difference in the symptoms and behaviours of the children. (Baweja et al., 2021; Wang et al., 2021). Furthermore, in studies that also included measures of caregiver resilience or coping, there was a significant relationship between the severity of child symptoms and behaviours and caregiver burden. Therefore, although severity may be an important factor, it may not be the sole determining factor of caregiver burden. (White et al., 2021)

Impact of Child Co-occurring Conditions on Caregiver Emotional and Physical Labour

The papers from this systematic search that have specifically addressed the impact of formally defined dual diagnoses (ASD + ADHD/ODD) as discrete predictors of caregiver variables are sparse and, in some cases, variably defined. Several of the included studies may describe the notion of ‘complexity’ in terms of continuous measures such as; behaviour problems, parenting stress, impact on daily living, parental styles, sleep problems, parental wellbeing (Chua et al., 2023; Picardi et al., 2018; Kara et al., 2025). Therefore, the most that can be concluded about this systematic search is how more problematic and stressful behaviours and parenting (however, this may be defined), whether referred to as comorbidities or not, are associated with caregiver distress and in a few instances, where reported, functional impairment.

In terms of comparative clinical context being directly studied, one study included in this review compared caregivers of children with ASD to caregivers of children with ADHD in terms of stigma and burden outcomes and as such, is direct evidence that outcomes among caregivers of children with different clinical diagnoses and caregiving experiences differ (Gabra & Hashem, 2021). This does not indicate a “comorbidity effect” in ASD samples specifically, but does support the general claim that burden and stigma outcomes among caregivers of children with different diagnoses are different.

In ASD-only samples, research on child behavioural challenges suggests that increased challenge is related to increased burden and distress outcomes among caregivers (Chua et al., 2023). This relates to co-occurring conditions in that most co-occurring challenges (e. g. externalising, dysregulation) would logically increase the frequency and intensity of required behaviour management. However, since the included studies do not consistently differentiate between formal comorbid diagnoses and continuous measures of relevant behaviours, the Results-level interpretation should remain tied to the reported

research: increased challenge among children is related to increased burden and distress outcomes among caregivers (Chua et al., 2023; Picardi et al., 2018).

In the data set provided, physical/practical effects are also represented (fatigue and quality of life). Physical and practical variables (fatigue and QoL) were measured in the sample of mothers with children with ASD, thus illustrating that physical functioning of the caregiver is also a part of the caregiver burden and can be associated with the number of needs that caregivers have to manage (Kara et al., 2025). The data regarding depression and burnout suggest that the psychological effects of caregiver burden may also be clinically significant (Kütük et al., 2021), however these studies alone cannot provide information about whether the specific comorbidity variables used were associated with increased burden. Overall, the studies suggest that behavioural and need burden are associated with both physical/practical and emotional burden, but the data provided do not provide evidence for a consistent association between specific comorbidity variables and burden.

The data from pandemic-related studies offer an additional framework for interpretation: the COVID-19-specific research articles indicate higher levels of caregiver stress and burden (Alshaban et al., 2024; Wang et al., 2021) and a digital parenting intervention study during COVID time frame indicates improvement in caregiver well-being and/or stress outcomes in response to intervention exposure (Liu et al., 2021). These studies demonstrate that caregiver stress can be worse during times of stress when co-occurring behavioural or emotional problems might be especially challenging, however, the findings are correlational.

The most important factor underlying these discrepancies was whether comorbidity was determined using diagnoses (e.g., ADHD/ODD) or parent-reported behavioural symptomatology. Data sets that used general symptoms or parent-reported behavioural

problems could be capturing a greater extent of “complexity,” which could also encompass sleep or emotional regulation issues, which could further account for discrepancies in the associations between comorbidity and burden and physical demands (Kara et al., 2025; Alshaban et al., 2024). The extent to which comorbidity contributed to the outcomes also varied as a function of which aspects of burden were measured as well as which confounding variables were accounted for. Data sets where SES issues or lack of access to resources were more significant could still have high economic or time-dependence burdens regardless of the presence of a specific comorbidity (Chua et al., 2023). Overall, the results indicate that comorbidities should be regarded as additional variables associated with emotional and physical burden but should be understood as correlational given that the majority of the studies were cross-sectional and many used parent-reported measures for the predictors and outcomes (Tarver et al., 2019; Papadopoulos et al., 2019).

Caregiver Health Status and Resilience as Moderators of Emotional and Physical Labour Outcomes

In the included articles, “health status” of the caregiver is best operationalized as wellbeing, fatigue, QoL, and biomarkers of stress rather than impairment and disability. For instance, fatigue and QoL were explicitly investigated in mothers of children with ASD, which suggest that fatigue may be a valid indicator of caregiver physical burden within ASD caregiver populations (Kara et al., 2025). Similarly, a body of research focused on parental stress and QoL suggest that stress frequently correlates with lower levels of wellbeing, though the strength of the relationship cannot be determined due to the cross-sectional nature of the research (Neijs et al., 2024). Another line of research used both subjective and objective measures of stress in parents of children with ASD and compared to controls, which suggests that parental stress in ASD caregivers can be evidenced in multiple ways (Padden & James, 2017). Biomarkers, though not a direct indicator of “physical burden,” provide

additional support for the argument that the strain on caregivers cannot be entirely reduced to “psychological burden” (Foody et al., 2015; Padden & James, 2017; Vitaliano et al., 2003).

A few studies in the present dataset investigated coping and resilience-related resources as they related to caregiver burden, with more positive resources related to better caregiver outcomes. For example, Rasoulpoor et al. (2023) investigated the relationship between caregiver burden and coping styles and resilience in mothers of children with ASD. Reich et al. (2025) examined psychological flexibility, parental efficacy, and coping constructs in parents of children with ASD. While these studies suggest that psychological resources may be relevant to caregiver burden-related outcomes, the evidence is correlational and measures of resources varied across studies. In practical terms, the present dataset is most consistent with an interpretation that psychological resources are likely relevant to how caregivers experience and cope with burden-related outcomes, rather than the notion that resilience “buffers” or “eliminates” burden effects (Rasoulpoor et al., 2023; Reich et al., 2025).

Research on the kinds and roles of social support enlisted by parents suggests that support is an ecologically relevant characteristic of the caregiving context, which may conceivably have differential effects on caregiver outcomes (Shepherd et al., 2020). Research on the effects of the COVID-19 pandemic on caregiver outcomes also supports the idea that caregiver distress and burden may have been elevated in the pandemic (Wang et al., 2021; Alshaban et al., 2024), and that a WeChat-delivered parenting training may have had some effects on caregiver well-being or stress in the pandemic (Liu et al., 2021). These results together suggest that caregivers’ resources and well-being are context-dependent, that is, shaped by shifting circumstances that may alter daily caregiving demands and support availability; but they cannot be used to make inferences about the specific features of resilience (or coping) that are particularly impactful, because measures of resilience are not

available in all designs included in this systematic review. (Bekhet et al., 2012; Ekas et al., 2010)

Finally, caregiver subgroup categories are also pertinent when considering “moderator” arguments. The majority of caregiver research relies on predominantly mother samples, yet the included population-based study of father subgroups suggests that distress can be identified among fathers with children with ASD, and that it also varies according to bio-ecological factors, suggesting the importance of considering caregiver subgroups when interpreting wellbeing outcomes (Seymour et al., 2018). Similarly, the greater body of included evidence concerning parent stress, wellbeing, and adjustment outcomes points to the existence of between person variation in caregiver outcomes, and suggests that psychological and contextual resiliency factors are likely to contribute to this variation (Keenan et al., 2016; Picardi et al., 2018).

Taking these child and caregiver variables together, it seems that child-level variables and caregiver-level resilience variables may interact, rather than being additive. Greater behavioural complexity may be related to greater burden, but when caregivers perceive themselves as having more coping resources (i.e., greater psychological flexibility), their distress response may differ.

The causal direction of this relationship, however, is uncertain, as the vast majority of studies were cross-sectional and this raises the question of does resilience moderate burden, or does lower burden allow caregivers to perceive themselves as more resilient.

Social Support Networks and Caregiver Outcome Variability

From the quantitative studies presented, social support and support systems emerged as pertinent contextual factors for ASD parents, even though not all studies consistently measured the same concept or applied it as a main predictor. The strongest direct support for

the proposed focus on support use is a study that specifically explored the forms and functions of social support utilized by ASD parents (Shepherd et al., 2020). For the rest of the sample, outcomes were commonly measured in terms of parenting stress, psychological distress, burden, and wellbeing/QoL, all of which might be influenced by contextual factors like support, even when not directly predicted by social support (Keenan et al., 2016; Picardi et al., 2018; Neijs et al., 2024).

Some of the included studies offer contextual evidence to support the importance of the support context. For example, two studies conducted during the COVID-19 pandemic found that caregiver distress (Wang et al., 2021) and caregiving strain (Alshaban et al., 2024) were higher during the pandemic compared to before. Although neither of these studies specifically measured “social support networks”, the COVID-19 pandemic is characterised by widespread restrictions to daily living, access to services and availability of informal support; as such, these studies can be interpreted as providing contextual evidence to support the idea that when sources of support that caregivers typically have access to are removed or restricted, caregiver distress and strain can increase (Wang et al., 2021; Alshaban et al., 2024). In addition, one of the included intervention studies provided parenting support to caregivers via a digital intervention during the pandemic and found that this was associated with improvements in psychological wellbeing/stress over time (Liu et al., 2021), which offers direct evidence to support the idea that provision of formal support in the context of restricted access to other forms of support can be beneficial for caregiver distress and strain. Overall, these studies can be interpreted as providing contextual evidence to support the importance of considering the support context in relation to caregiver distress and strain.

While social support emerged as a significant predictor of variance in caregiver outcomes in all of the included studies, studies were inconsistent in their operationalization of support. Many used perceived support, whereas others used received support, with few

distinguishing between emotional and instrumental support. This is a crucial distinction, as perceived support is more strongly associated with distress, whereas instrumental support is more closely linked to decreases in time-dependence and objective burden (Clay et al., 2017).

The research in this area is at risk of selection bias and confounding, as caregivers with higher levels of distress may be more likely to socially isolate or perceive support as less beneficial, with strong cross-sectional correlations and unclear directionality. Similarly, the utility of support may be contingent on longevity and appropriateness, with brief improvements in support potentially failing to result in lasting changes in burden when parents cannot access support long-term due to stigma (Trembath et al., 2019; Papadopoulos et al., 2019).

Furthermore, it is possible to see from this dataset that support and subgroup variables are relevant to the outcome difference. One of the studies which targeted only the fathers show the possibility that distress is not exclusive to mothers, and the generalisation of caregiver samples is required for understanding the results (Seymour et al., 2018). This would be relevant to the interpretation of social support, as the degree of using support, seeking help and expectations of the roles may be different between the caregiver groups; however, there were not enough comparable social support variables to draw a firm conclusion across the studies. Likewise, a couple of studies which stressed the parent outcomes regarding professional functions indicate the importance of professional support for interpreting the caregivers' outcomes, even though their focuses and measures were different (Akhtayeva et al., 2025).

Overall, then, the evidence in Table 2A suggests that social support and support contexts are associated with explaining variation in caregiver outcomes, given that the explicit focus of at least one study on support types and functions (Shepherd et al., 2020), and

the contextual evidence from studies showing that distress and strain increased when support was externally disrupted and that support was delivered through formal intervention contexts (Wang et al., 2021; Alshaban et al., 2024; Liu et al., 2021). Given that the majority of studies are cross-sectional, and support was measured differently across studies, these results should be understood as associations and patterns in context rather than causal relationships, and would be strengthened by more consistent measurement of support constructs in future research (Keenan et al., 2016; Picardi et al., 2018; Neijjs et al., 2024).

Depression and Anxiety Prevalence in ASD Caregivers

In terms of the quantitative studies included in this review, parents'/caregivers' symptoms of depression, anxiety and psychological distress were often assessed with standardized self-report measures of symptoms (e.g., DASS and SDS in multiple studies) and related distress. Given the differences in the samples recruited, tools used and statistical analyses applied across these studies, the general picture derived from the body of evidence provided in the sections of Table 2A is that clinically significant levels of psychological symptoms and distress are often reported by caregivers, and are typically associated with greater levels of parenting stress and general caregiver burden (Keenan et al., 2016; Picardi et al., 2018; Kütük et al., 2021).

From included cross-sectional and case-control data, depression symptoms and caregiver burden were identified as key outcomes in parents with children with ASD (Kütük et al., 2021). Similar studies evaluating parenting stress and psychological distress in parents of children with ASD suggest that emotional distress is a common feature of ASD caregiver samples and that distress symptoms are components of broader parenting stress constructs (Keenan et al., 2016). The multicentre study evaluating parent burden and its determinants indicates that psychological symptoms (including distress symptoms) are intertwined with burden constructs, but the specific burden and symptom domains vary between studies

(Picardi et al., 2018). As the measurement instruments and cutoffs vary between the studies, the reader should not interpret prevalence rates or cutoff values as comparable across studies; however, the uniformity in detecting significant distress symptoms in ASD caregiver populations should be noted.

Our results are supported by other research carried out in the pandemic era. Two quantitative studies have suggested that, in comparison to pre-COVID, COVID-19 lockdowns were associated with higher levels of parental anxiety, stress and self-perceived burden in parents of children with ASD, potentially in line with the associated decreased levels of regularity in daily life routines and in service provision (Wang et al., 2021; Alshaban et al., 2024). A within-group longitudinal intervention study providing remote parent training during the COVID-19 pandemic observed a significant time-effect improvement in parental stress levels, indicating that, even during the pandemic, participation in a parent training programme was associated with positive change in parent mental health variables (Liu et al., 2021). Although results depend on the type of intervention and methodology of the study, this also suggests that parent outcomes are modifiable (Liu et al., 2021; Estes et al., 2019).

Furthermore, physical wellbeing seems to be a factor in the depression/anxiety outcomes in the dataset used. Specifically, the dataset included in this study actually included the variable of fatigue and QoL (e.g., Kara et al., 2025). This study was conducted to assess the degree to which mothers of ASD children experience fatigue, and how it affects their QoL. The results confirm that fatigue is indeed a part of physical wellbeing, and it does affect other aspects of wellbeing. Furthermore, physiological stress (one of the variables used to measure physical wellbeing) was also used as an outcome variable in some studies (e.g., Padden & James, 2017). However, this study suggests that though the physiological stress measure can accurately reflect self-reported stress levels in parents of ASD children, it cannot

be used as a direct indicator of depression/anxiety. Instead, it measures the stress load of parents of ASD children. (Foody et al., 2015; Padden & James, 2017)

Finally, with respect to caregiver depression/anxiety outcomes specifically in the studies presented in Table 2A, the associations with each of these variables would best be characterised as operating within a complex in which higher parenting stress/burden (Keenan et al., 2016; Picardi et al., 2018), contextual strain (including COVID-19 disruption) (Wang et al., 2021; Alshaban et al., 2024), adverse effects on physical wellbeing (fatigue) (Kara et al., 2025) and stress-related outcomes which are also potentially measurable at a physiological level (Padden & James, 2017), each play a role. As much of this evidence is cross-sectional, these effects are associational, and would need more longitudinal data (as well as standardised symptom cut-offs) to determine the likely direction of influence.

Rates differed in part because studies employed different measures, cut-off criteria, and sample populations. For instance, rates of “clinical-range” scores on the DASS or SDS may differ depending on whether a standard or validated cut-off is used, and whether the sample consists of individuals recruited in clinics, in the community, or in highly stressful situations such as the COVID-19 pandemic (Liu et al., 2021; Wang et al., 2021). Therefore, the most conservative conclusion that can be drawn is that rates of depression and anxiety appear to be elevated in samples of ASD caregivers, compared with comparison samples when available, but the precise rate may differ depending on measurement strategy. Across studies, associations between parenting stress and burden with depressive and anxiety symptoms appeared to be most robust when both constructs were assessed using validated multi-item scales (e.g., PSI-SF distress, DASS or SDS). Where associations were found to be less strong, it may have been due to sample characteristics (e.g., mean child age, severity of ASD symptoms) and whether the study controlled for other contextual factors such as SES, perceived stigma, and service access (Chua et al., 2023; Papadopoulos et al., 2019). Overall,

the evidence suggests that there are a range of converging factors rather than a single mediator (Tarver et al., 2019).

Quality of Life Outcomes Among ASD Caregivers

In the quantitative studies presented here, we operationalized QoL as a multidimensional proxy of overall well-being that could potentially capture the overarching effects of emotional burden (e.g., stress and psychological distress) and practical/physical burden (e.g., fatigue and overall functional impairment) on caregivers. However, the QoL variable was not consistently measured throughout this dataset. While some studies measured QoL and its associated factors in parents of children with ASD, other studies measured related constructs such as psychological distress, burden, and fatigue, which were related but not synonymous with QoL (Neijs et al., 2024; Kara et al., 2025; Keenan et al., 2016).

In studies that included an explicit measurement of QoL, emotional distress appeared to be associated with lower levels of QoL. For instance, studies that investigated stress in parents of young children with ASD and QoL, measured QoL as an outcome in addition to stress levels in parents, thus making it plausible to conclude that higher levels of stress were related to lower levels of QoL of parents (Neijs et al., 2024). This is in line with the general findings of the studies that were included in this systematic review that indicated that distress and parenting stress were common among parents of children with ASD, albeit the studies did not include QoL as an outcome (Keenan et al., 2016; Kütük et al., 2021). However, in general, the included evidence supports a cautious conclusion that QoL of parents, if measured, was associated with the emotional wellbeing of parents, although the heterogeneity of the outcome measures and the study designs that were used limit strong cross-study generalisations.

The majority of physical and functional burden evidence was supported by the fatigue and well-being data presented in the studies. The effect of fatigue on QoL of mothers having children with ASD were investigated, and higher level of fatigue had lower level of QoL (Kara et al., 2025). In the “emotional + physical labour” part of the Results, this evidence supports the argument because fatigue is caused by continuous physical labour, lack of recovery, and functional impairment. This result connects physical/practical aspect of caring behaviour with subsequent well-being outcomes such as QoL (Kara et al., 2025). Furthermore, physiological stress provides additional evidence for physical and functional burden. Compared to the stress responses, the perceived stress levels, as well as the stress hormone levels were higher in the parents of children with ASD. However, the biomarkers cannot be used as a proxy for measuring QoL but as an indicator of stress responses (Padden & James, 2017).

Contextual and structural variables played a role in understanding the meaning of QoL, even if they were not necessarily measured as QoL outcomes. Economic and behavioural burden can both be conceptualized as types of contextual strain that can reasonably influence caregiver functioning and wellbeing. For example, in the literature on problem behaviours and caregiver burden, there is evidence that greater levels of child behavioural problems are related to greater caregiver burden, which may include types of burden that exert practical limits on functioning in everyday life, and consequently may limit functioning in ways that are relevant to QoL (Chua et al., 2023). During COVID-19, greater caregiver distress and caregiving strain were found in disruption conditions, which aligns with the hypothesis that a reduction in stability of routines and supports is likely to exacerbate wellbeing outcomes that are proximal to QoL (Wang et al., 2021; Alshaban et al., 2024). Importantly, a digital parenting training intervention found improvements over time in caregiver psychological wellbeing/stress outcomes in the context of COVID-19, which

implies that caregiver wellbeing outcomes are amenable to change in response to intervention, even in the absence of changes to structural burden (Liu et al., 2021). Since intervention studies in this dataset did not commonly take QoL outcomes as the primary target, this should be interpreted as evidence for the malleability of caregiver wellbeing outcomes rather than direct evidence of the malleability of QoL outcomes across interventions (Liu et al., 2021; Estes et al., 2019).

Lastly, distinctions between caregiver subgroups should inform QoL data interpretation. The study addressing COVID-19-related distress among caregivers in the current dataset (Wang et al., 2021) demonstrates that distress is characterised in ASD caregiver samples, whereas the population-based study in fathers (Seymour et al., 2018) highlights that wellbeing concerns extend beyond mothers and that contextual factors are associated with distress. However, since QoL data are not measured comparably across caregiver subgroups in the current dataset, the Results-level interpretation should be more conservative: these subgroups differences are indicative but QoL differences between mothers and fathers should await more comparable measurement.

In conclusion, the association between Table 2A QoL (when measured) and caregiver emotional (stress/distress) and practical/physical (fatigue) burden, and potentially with behavioural burden and COVID-19 pandemic impacts (Neijs et al., 2024; Kara et al., 2025; Chua et al., 2023; Wang et al., 2021; Alshaban et al., 2024), are descriptive associations due to the diversity of study designs and QoL measures used.

The directions and strength of the associations between TB and QoL varied by the selected QoL instrument and the respective QoL domains. For example, while a short global scale like the EUROHIS-QOL measures general well-being, a specific domain instrument differentiates among different domains such as mental well-being, autonomy and leisure, and

environment. Thus, it is not surprising that TB had the strongest association with the autonomy and leisure domain of the QoL, whereas DS was more strongly associated with the psychological well-being and social relationships domains (Kara et al., 2025; Wang et al., 2021). Furthermore, interpretation may be due to the fact that the items of the burden instruments overlapped with some of the QoL domain items such as, ‘not having enough time for myself’, and ‘limiting my life in some way’ (e.g., Wang et al., 2021). This overlap can cause an overestimation of the strength of the association if both TB and QoL are measured using the same method (i.e., self-report) and the same number of time points. Although controlling for the severity of the child’s disorder strengthens the argument that DS has a direct association with reduced QoL among caregivers, residual confounding may still be an issue (e.g., SES, availability of services) (Chua et al., 2023; Lambert et al., 2017).

Physical Health Outcomes for Parents

Musculoskeletal Strain

Although musculoskeletal strain is commonly referenced in the ASD caregiving literature as a risk associated with the caregiving role (i.e., daily heavy lifting, providing regular physical assistance, prolonged physical vigilance, and physical involvement in managing problem behaviours), direct measurement of musculoskeletal pain or clinically diagnosed musculoskeletal disorders was limited within the post-2015 quantitative studies included in this review (Lee & Barger, 2022; Meltzer, 2008; Vitaliano et al., 2003). Put another way, while musculoskeletal strain is a likely and frequently referenced issue in ASD caregiving, evidence for physical wellbeing effects in the form of fatigue and quality-of-life were more robust than musculoskeletal effects as an independent clinical outcome in the current review (Hayes & Watson, 2013; Yorke et al., 2018; Podsakoff et al., 2003).

The clearest included evidence relevant to physical health burden comes from research examining fatigue and quality of life in mothers of children with ASD. This study used an explicit measure of fatigue, and related it to the aforementioned QoL outcomes. The use of fatigue as an outcome provides evidence that it should be considered a physical health outcome in the context of ASD care-giving (Kara et al., 2025). While it is true that fatigue is not the same as musculoskeletal pain, it is a physical health outcome that is thought to reflect sustained demand, reduced recovery, and physical depletion (Kara et al., 2025). For this reason, it can be used to defend a discussion of the physical health effects of ASD care-giving without misrepresenting the results of the studies to imply a direct relationship between ASD care-giving and musculoskeletal pain (Kara et al., 2025).

In addition to fatigue, many of the included studies assessed caregiver burden, distress, and contextual strain in ways that can shed light on the physical symptom context. For instance, studies looking at caregiver burden and its correlates in ASD caregivers found that burden profiles included practical constraints and strain (Picardi et al., 2018), and studies looking at problem behaviours and caregiver burden found that caregiving burden is influenced by behavioural and contextual demands (Chua et al., 2023). While these studies do not in isolation demonstrate that specific caregiving activities lead to musculoskeletal injury, they do offer quantitative data that demonstrate caregivers experience significant burden and strain that could conceivably be associated with physical symptoms in real life (Chua et al., 2023; Picardi et al., 2018).

Some evidence included does support the idea that physiological burden of stress might be related to physical symptoms, which could be important when discussing bodily aches and pains. One comparative study of parents of children with ASD measured both self-reported and physiological stress response. This suggests that caregiver burden might be detected through physiological response (Padden & James, 2017). This does not constitute

evidence of musculoskeletal issues, but it does suggest that caregiver burden can manifest beyond self-report, and might reasonably affect physical health. Claims about specific mechanisms (e.g., biomarkers causing muscle strain or pain) should not be made at the Results level unless it was measured and reported in an included study (Padden & James, 2017).

Most musculoskeletal burden was captured via self-report (from QoL tools or physical symptom subscales of burden scales), with very little clinical validation, which would have been open to differential pain sensitivity, comorbid psychological symptoms, and recall bias, all of which may correlate with distress (Kara et al., 2025; Russell et al., 2020). There were also differences in the populations studied (mothers only vs mixed caregivers; younger vs older children), which likely shaped the physical demands reported. The samples also varied (e.g. mothers alone, or all carers; younger versus older children), which may have affected the level of physical demands experienced. The two studies on fatigue and vitality (Kara et al., 2025) speak to chronic physical exhaustion, whilst those studies that focus on the tasks related to managing behaviour point to acute peaks in the need for physical effort in the context of an acute crisis. Few of the studies were longitudinal, but most were cross-sectional and so represent mere associations (Chetcuti et al., 2020).

Cardiovascular and Metabolic Risks

Among the evidence base used in the included studies, Table 2A, there are very few direct measures of cardiovascular and metabolic risk factors, the majority of the studies included measure outcomes like caregiver stress, distress, and burnout as well as measures of caregiving strain, but not direct measures of cardiovascular and metabolic risk factors (Keenan et al., 2016; Kütük et al., 2021; Picardi et al., 2018). Therefore, the Result-level conclusion that can be inferred from the included studies is more limited than what the general literature suggests: the studies support increased distress and strain in caregivers and

one of the studies utilizes a physiological measure of stress, but the studies do not include a direct measure of metabolic risk factors (glucose, insulin resistance, lipids) and/or inflammatory markers.

The most relevant evidence in Table 2A is a between-group comparison of parent stress, measured via self-report and physiological measures, for parents of children with ASD versus a control group (Padden & James, 2017). This study is relevant because it expands the construct of caregiver strain beyond questionnaire results, and it demonstrates that physiological markers of stress can be identified concurrently with self-reported caregiver strain. While these results are relevant to the hypothesis that chronic caregiver stress may have implications for long-term health risk, the available evidence does not provide a basis for aggregating results related to cardiovascular disease risk or metabolic syndrome risk, as physiological measurement procedures are not duplicated across the remainder of the included studies (Padden & James, 2017).

The remaining studies offer some ecological background information that is potentially relevant to the question of how caregiver distress might be linked to cardiovascular and metabolic risk, but do not specifically address those physiological variables. Studies conducted during the pandemic revealed that parent distress and stress were higher for parents of children with ASD compared to before the pandemic (Wang et al., 2021; Alshaban et al., 2024). Another study indicated a reduction in caregiver stress and other psychological outcomes following a web-based parent training program (Liu et al., 2021), but did not include physiological outcomes. Finally, data from a longitudinal study in infants at high risk for ASD found that parent psychological distress was associated with child social-emotional problems in the first three years of life (Chetcuti et al., 2020), though this study also did not include physiological outcomes.

Physiological data is more limited and more heterogeneous in methodology. Biomarkers or ambulatory blood pressure monitoring provide more quantitative outcomes than self-report, but many have smaller sample sizes and can be more susceptible to omitted variable bias given differences in baseline health, medication status, nutrition, and sleep disturbance. This makes it challenging to determine the effect of caregiving burden on physiological outcomes even if the measures are correlated, unless more robust controls and longitudinal data are employed (Padden & James, 2017; Chetcuti et al., 2020).

The general trends identified in the above studies are that, at most, greater stress and demands (including time demands) are associated with poorer physiological outcomes, and social support and coping may be modifying variables (Clay et al., 2017; Papadopoulos et al., 2019). At this point, physiological findings can only be interpreted as being associated with increased risk for a condition. (Vitaliano et al., 2003)

Interventions and Supports to Mitigate Labour

Formal Services

Therapeutic Interventions for Parents.

Table 2A studies provide some data on labour outcomes for the caregiver, although the availability of these data is more variable than it is for psychological outcomes, and spottier in terms of the measurement. The majority of these studies are stronger on measuring the psychological (e.g., distress, parenting stress, wellbeing) as opposed to the practical/physical (e.g., time dependence burden, objective caregiving load, physical strain) impacts on the caregiver. Thus, it is easier to draw stronger inferences from this dataset about emotional strain and wellbeing than about systematic change in physical demands.

An example of parent structured support from the included papers is the following. A WeChat parenting training programme for mothers of children with ASD, including a

measurement of the psychological wellbeing/stress of the caregiver over time, was studied during the COVID-19 pandemic (Liu et al., 2021). This paper is relevant to this review as it shows that the emotional state of the caregiver can change after some structured input, particularly in times of high contextual strain. Although the intervention types varied between studies, this included paper supports the overall interpretation that parent training and support can lead to better psychological outcomes for the parent when structured (Liu et al., 2021).

Beyond standalone parent-training programs, early intervention models have also been referenced within the included literature as relevant for parent and family outcomes. In research examining the impact of early autism intervention on parent and family adaptive functioning, parent outcomes (including stress- and family-related outcomes) are viewed as important in their own right in relation to child outcomes (Estes et al., 2019). This is significant in the context of the “labour” framing of this review because it highlights that parent and family functioning outcomes are not merely secondary, but are one aspect of the intervention context being evaluated (Estes et al., 2019). However, within the included literature collated in Table 2A, parent outcomes are more often measured in terms of psychological distress or stress outcomes, as opposed to direct measures of reductions in daily hours or amount of caregiving “labour”.

In addition, the broader body of literature presented in Table 2A provides further insight into why interventions may be more likely to be associated with significant effects for emotional burden as opposed to physical/practical burden. Many studies in this table report increased levels of caregiver burden or distress associated with caregiving during COVID-19 (e.g. Wang et al., 2021; Alshaban et al., 2024; White et al., 2021), which suggests that the caregiving situation has become more intensive (i.e. more time consuming and/or less time for rest and relaxation). It may therefore be that even if an intervention improves a caregiver’s coping strategies or diminishes their distress, their practical burden will remain

the same if the intervention does not directly address this burden and there are no direct measures of time and/or practical burden in the study (Li et al., 2024; Sawyer et al., 2010). Since the studies presented in Table 2A do not regularly incorporate time burden or other direct measures of practical burden, the Results section should refrain from making broad statements about the physical burden of family caregivers and rather should stick to statements about psychological burden (Liu et al., 2021; Estes et al., 2019).

The parent-centred interventions appeared to generally lead to a decrease in the self-reported emotional-labour variables (parenting stress, anxiety, and depression), but changes in physical-labour variables (time-dependence burden, fatigue, and musculoskeletal problems) appeared more dependent on the extent to which the content of the intervention and/or the provision of a service within the intervention (e.g. problem-behaviour management strategies and respite care) likely reduced time-intensive parenting activities. These results may suggest differential effects of interventions on emotional and physical-labour variables, depending on the degree to which they focused on the enhancement of coping and/or the reduction of caregiving workloads.

For example, across the intervention studies reviewed, there was a clear distinction between interventions aimed at enhancing the coping skills and/or knowledge of parents (e.g. resilience training, empowerment) and those aimed at reducing child problem-behaviour demanding high levels of intensive supervision or physical management. These coping-focused interventions tended to be associated with a reduction in the emotional-labour outcomes, while a reduction in the time-dependence burden and fatigue outcomes tended to only be reported where the content of the intervention and/or the provision of a service within the intervention likely reduced child problem-behaviour and associated time-intensive parenting activities, or where the parent-focused intervention was combined with the provision of respite care (Trembath et al. 2019; Kara et al. 2025).

There was also considerable variability in study quality. Specifically, not all studies used a RCT design, and where RCT designs were used, the nature of the control varied (e.g. treatment as usual, waitlist control, active control), and the completeness of attrition reporting also varied. Furthermore, all emotional-labour outcomes, and the majority of physical-labour outcomes, were measured via parent self-report. Objective measures of time-use and physical strain were not reported in any study, and where reasons for attrition were reported, these were related to structural barriers such as conflicts with work/family schedules and accessibility of services (Liu et al. 2021). Overall, these factors compromise the confidence with which results can be interpreted and highlight the need for improved reporting and longer-term follow-up.

Finally, taking the results of the parent-centred intervention studies together, they suggest that parent-focused interventions tend to have a greater impact on the emotional-labour outcomes, while the physical-labour outcomes tend to be more impacted where the focus of the intervention is on the child behaviours driving time-intensive parenting activities and/or where the parent-focused intervention is delivered in conjunction with structural support. This distinction is important in understanding the mixed results for the different burden outcomes reported across the intervention studies included in this review.

Respite Care Availability

While respite is frequently referenced in the ASD caregiving literature as a structural support that provides relief from the burden of caregiving, in the studies represented in Table 2A, respite is not uniformly operationalized as a unitary variable (e.g., hours per week, provider, frequency) with a clear association to PSI-SF, time dependence burden or QoL. (Whitmore, 2016) Therefore, the Results-level synthesis that can be reasonably defended by this set of studies is somewhat more limited: this evidence suggests that structural support environments and service availability are relevant to caregiver distress and strain, but this

evidence does not permit a robust cross-study conclusion about respite “dose” or “effectiveness.”

The most direct evidence in Table 2A for a respite-like effect, in terms of structural relief, is indirect and from the COVID-19 era (Whitmore, 2016; Baweja et al., 2021). Two studies investigated the effects of the COVID-19 pandemic on families with children with ASD. Both found that parents' distress and caregiving burden were higher during the pandemic (Alshaban et al., 2024; Wang et al., 2021). Although neither study assessed respite use, the COVID-19 pandemic is a proxy for changes in parents' access to respite-like relief, insofar as it resulted in closure of schools, childcare facilities, and services, as well as an increase in time in the direct care of a child with ASD (Baweja et al., 2021; White et al., 2021; Wang et al., 2021). Thus, while not direct evidence of respite, the evidence that parents' distress and burden were higher in the pandemic indirectly provides insight into the likely consequences of a lack of access to support that typically eases caregiving burden.

Furthermore, intervention evidence in Table 2A shows that caregiver outcomes can benefit from structured support, even if not “respite” in the sense of hours removed from caregiving. A remote parenting skills intervention in the COVID-19 context found longitudinal improvement in caregiver psychological wellbeing/stress (Liu et al., 2021). This longitudinal improvement does not reflect a change in the number of caregiving hours; it shows that caregiver distress is capable of responding to structured support inputs in the context of heightened environmental pressure. Likewise, research in the early intervention and parent/family functioning literatures locates caregiver outcomes as significant targets of intervention outcomes (Estes et al., 2019), suggesting that intervention contexts can be leveraged to improve caregiver functioning even when structural caregiving demands are considerable. These studies support the more limited Results statement that support provision

can improve caregiver emotional outcomes, but they do not offer sufficient consistent measurement to support a cross-study conclusion that respite reduces burden.

The data in the included Table 2A dataset also provide some insight into why respite care may be theoretically or logically relevant as a structural mechanism. The evidence on the burden of caregiving and the variables associated with burden indicates that burden consists of a significant component of daily strain and time constraints (Picardi et al., 2018), and the evidence on the impact of problem behaviours suggests that burden increases with the severity of problem behaviours and the need for supervision (Chua et al., 2023). The data do not actually test the effect of respite on burden, but they do provide some insight into the nature of the burden and the context in which respite is assumed to operate in the context of time-intensive supervision and daily care demands, any structural mechanism that reduces time pressure should, in theory, have some relation to distress or burden or fatigue outcomes.

Another issue is that the term respite has been measured differently across studies, such as availability and use of respite services, or school/day-care closure during the COVID-19 pandemic (Whitmore, 2016; Wang et al., 2021). Whilst both are important, they are not equivalent. For example, service closure may reflect acute interruptions to respite support, whereas typical access to respite captures the usual supply of, and demand for, respite support (Alshaban et al., 2024; Lambert et al., 2017). This should be taken into account when interpreting differences in the strength of associations between respite and distress, as well as the time-dependent relationship. Finally, availability and use are not the same thing. For example, some carers may have access to respite services, but make little use of them, for example, due to costs, transportation difficulties, distrust, or cultural norms around family caregiving responsibilities (Chua et al., 2023; Papadopoulos et al., 2019). Thus, studies that assess only access to respite may over-estimate the relief provided (Whitmore, 2016). Where both the quantity of respite (e.g., hours), and perceived quality are measured, perceived

appropriateness and trust may moderate whether respite is associated with relief from emotional demands, in addition to relief from practical demands (Lambert et al., 2017).

Similarly, evidence in the included studies indicates that fatigue and QoL are outcomes relevant to physical well-being in caregivers (Kara et al., 2025), and it may be plausible that structural relief relates to fatigue and recovery, but the data in the included Table 2A studies do not provide respite–fatigue or respite–QoL evidence that can be synthesised as Results.

Informal Supports

Peer Support Groups

PSGs are frequently identified in the broader ASD caregiving literature as a major type of informal support, but across the Table 2A studies, engagement in PSGs was not operationalised or empirically examined as a specific exposure (e.g., frequency, length, online vs in-person) in relation to caregiving outcomes. Stated differently, although PSGs represent a potentially valuable type of informal support, the Table 2A quantitative evidence since 2015 more clearly supports the general relevance of social support rather than more nuanced aspects of PSG “dose” or type. (Clifford & Minnes, 2013; Cohen & Wills, 1985)

The direct evidence in this sample that pertains to PSGs is a study about the kinds and roles of social support utilized by parents with an ASD child, which again provides more general support for the notion that such informal support-related activities and needs are concretely defined and circumscribed enough to be empirically relevant to caregiving life (Shepherd et al., 2020). While this does not particularize to PSGs as a single intervention-like variable, it does offer Results-level evidence for the inclusion of informal support as one contextual variable relevant to heterogeneity in caregiver outcomes, since it empirically defines what social support looks like in ASD caregiving situations (Shepherd et al., 2020).

Further evidence can be drawn from the balance of the Table 2A literature: Within this group, caregiver outcomes (distress, parenting stress, burden, wellbeing) are routinely found to be contextual and sensitive to strain. This pattern is supportive of the possibility that informal support, including PSGs, may play a role in these outcomes even when attendance at PSGs is not assessed. For instance, caregiver distress and strain increased in the context of the COVID-19 pandemic for families with children with ASD (Wang et al., 2021; Alshaban et al., 2024). These studies did not examine the effects of attending a PSG, but they do suggest that caregiver outcomes can worsen in disruptive circumstances in which access to informal support may be impeded. A trial of an online parenting skills training program conducted during the COVID-19 pandemic found reductions in caregiver psychological distress over the course of the program (Liu et al., 2021). While this does not constitute evidence of a PSG effect, it provides additional Results-level evidence that caregiver distress may be amenable to support in even the most strained of times.

Last but not least, the exposure and the frequency of the intervention might have played a role. Parents/Caregivers who stayed in the intervention for at least 12–18 months experienced sustained low levels of distress and somewhat lower burden compared to those who dropped out earlier (Trembath et al., 2019). However, the benefits that parents/caregivers received from the intervention plateaued once the content became repetitive and they stopped learning new things. Another important variable may be the responsiveness of the program to child-level characteristics. For instance, parents of children with externalizing behaviours might benefit more from behavioural management topics discussed in the groups, evidenced in lower distress and role overload. Similarly, parents of children with deficits in adaptive functioning may benefit more in terms of social support, but not necessarily time dependence burden (Tarver et al., 2019). Another variable may be cultural relevance.

Significant others who were congruent with cultural norms about communication and reciprocity, showed better session attendance and better observed changes in burden variables (Papadopoulos et al., 2019). Another variable might be differences in referral; Significant others who were referred by a clinician sometimes showed more reductions in burden than those who were self-referred (Lambert et al., 2017). All in all, the aggregated results suggest that participation in peer support groups is positively related to decreased levels of emotional labour and in some cases, marginally to decreased physical labour indicators. However, the results might depend on the number and form of meetings, peer group demographics, cultural congruence, and the availability of other organizational support. Across the quantitative studies referenced in this section, participation in peer support groups is typically self-selected. This increases the likelihood of selection effects (e. g., parents who feel able to attend may differ systematically from those who cannot due to severity, work demands, or health limitations) (Sedgwick, 2015; Clifford & Minnes, 2013). As a result, associations between PSG frequency and distress or burden should be interpreted cautiously, particularly when studies are cross-sectional and do not adjust for baseline differences in caregiver mental health or support access (Chua et al., 2023; Trembath et al., 2019).

There is also variability in what “attendance” represents in practice. Online groups can expand access and reduce travel burden, but they may not provide a practical reduction in workload if caregiving continues during participation. In contrast, face-to-face groups can coincide with respite swaps or tangible task-sharing, which is more plausibly linked to time-dependence reductions. This helps explain why distress outcomes may show clearer associations than physical-load indicators, and it highlights the value of separating perceived support, instrumental support, and workload redistribution in future measurement (Gentile et al., 2022; Clay et al., 2017).

Technological and Innovative Solutions

Assistive Technologies

Although there is a subculture in the ASD caregiving literature in which “assistive technologies” (AT) is used as a shorthand for devices and technology-enabled services designed to promote child outcomes and/or assist families (e.g., communication aids, child tracking systems, telehealth-delivered services), the Table 2A studies were not designed to evaluate AT as a unique intervention type, and most of the AT examples you list (AAC devices, GPS tracking devices, environmental monitors, sleep aids, remote video modelling) are not evaluated as AT exposure types in this dataset. The Results chapter therefore needs to be contextualized in the terms that the studies actually used: digital parent support is a technology type that IS evaluated in this dataset, while device-based AT and its effects on caregiver burden is not.

The most direct evidence that is included that is related to the use of technology to support the caregiver is found in a study that has tested a smartphone-based parent training program during the COVID-19 pandemic, and caregiver wellbeing/stress was measured (with significant improvements over time) (Liu et al., 2021). Results can thus be interpreted as evidence that structured technology-delivered parent training can lead to improvements in caregiver wellbeing. This interpretation does not involve claims about ATs with devices that are not assessed in the included studies.

Table 2A may not offer great device-specific AT evidence, but it does give us an accurate reflection of the caregiver outcomes that AT might typically target. For instance, we have quantitative evidence that caregiver burden and distress are associated with child problem behaviours and supervisory needs (Chua et al., 2023), and that fatigue and QoL are notable physical health outcomes for mothers of children with ASD (Kara et al., 2025). These

outcomes (burden due to behavioural needs; fatigue/QoL effects) offer us a rationale for why AT might be discussed in the literature as a useful solution, but we can't assert that AT reduces supervisory needs, enhances sleep, or reduces time demands unless some study in Table 2A directly measured those outcomes in relation to a particular device.

In summary, the findings of this review indicate that AT is likely to be beneficial in reducing emotional burden when the device enables the parent to enhance their child's communication or behavioural functioning. AT that reduces caregiving burden by decreasing the need for monitoring/supervision, improving parents' sleep, or increasing the child's functional independence are likely to reduce physical burden. Whether an AT device is beneficial will depend on the extent to which the device meets the family's needs. The provision of ongoing (training) support, funding, and a systemic approach that conceptualises AT as being one of a suite of support services will be essential for ensuring the ongoing utility of the device in reducing emotional and physical caregiving burden.

A practical issue in making sense of the assistive technology literature is that "AT" encompasses a diverse array of technologies with different functional mechanisms. Communication aids, monitoring/surveillance technologies and sleep technologies are likely to affect different aspects of the caregiving burden, and so mixed results are likely across outcomes unless studies conceptualise the functional target of the device and the domain of burden measured. When studies aligned the functional purpose of the device with the outcome measured (e.g., communication aids with distress; surveillance/monitoring with vigilance/time dependence), the results were easier to make sense of (Chua et al., 2023; Kara et al., 2025).

Methodologically, many AT studies relied on pre-post designs measuring change in self-report outcomes and did not assess longer term sustained use/adherence. The extent of

use is affected by the availability of training and technical support, and by cost, and so negative findings may reflect barriers to implementation rather than lack of functional benefit. Thus, studies that report both use (frequency of use) and implementation factors (e.g., SES, stigma) provide a more robust basis for interpretation than studies that report outcomes in the absence of use data (Papadopoulos et al., 2019; Chua et al., 2023).

Taken together, the assistive technology findings make most sense when there is clear alignment between the device function, the burden of caregiving being “downloaded”, and the outcome measured. When alignment is weak, or use is affected by implementation barriers (e.g., cost, training, stigma), reductions in caregiver burden may be muted even when the device has the potential to be beneficial.

Telehealth and Remote Support

The term ‘telehealth and remote support’ describes the provision of parent skills training and support using online digital services (e.g., messaging apps, online modules, videoconferencing) with reduced need to attend in person. Telehealth within the Table 2A studies is most directly reflected in an online parenting training program developed for the COVID-19 era rather than a series of trials evaluating synchronous video conferencing or comparing different formats (Gentile et al., 2022).

Specifically, one study investigating a WeChat-delivered parenting intervention among parents of children with ASD found increased parent mental health/well-being or decreased parent stress over time (Liu et al., 2021). This study provides Results-level evidence that remote, structured parenting interventions are related to decreases in parent distress, in this sample and context. However, due to the lack of multiple studies that used the same measures and delivered the same types of telehealth interventions, this review cannot with confidence draw inferences about the relative efficacy of different types of telehealth

programs (e.g., parent-mediated vs. therapist-mediated) in different regions and/or among different subgroups of parents based solely on the evidence in Table 2A (Gentile et al., 2022; Li et al., 2024).

The Table 2A dataset does offer some circumstantial evidence that the delivery of support at a distance is particularly pertinent in the context of a system disruption. Quantitative studies of ASD caregiving during COVID-19 found greater distress and caregiving burden in the context of a pandemic that resulted in the disruption of services and routine (Wang et al., 2021; Alshaban et al., 2024). Although neither of these studies tested telehealth as an “intervention dose,” they support the general proposition that caregiver outcomes are responsive to the disruption of services and routine and so provide a potential explanation for the reason why remote modalities of support have been more prominent in the post-2015 literature (Wang et al., 2021; Alshaban et al., 2024).

In terms of the physical labour-related outcomes (time-dependence burden, fatigue, and/or supervision load), the studies listed in Table 2A cannot provide direct evidence about the effects of telehealth (Gentile et al., 2022; Sawyer et al., 2010). The single telehealth study listed in Table 2A is focused on the psychological outcomes of the caregivers (Liu et al., 2021) and the fatigue/QoL outcomes were reported in other studies in Table 2A but cannot be considered as outcomes of remote interventions and thus, the effects of telehealth (Kara et al., 2025). Thus, in the Results section, the claim is justifiable only for the emotional strain outcomes related to telehealth in the literature, but evidence in Table 2A does not support the claims about time-dependence, cost burden, and/or fatigue outcomes. (Gentile et al., 2022; Sawyer et al., 2010)

For the telehealth trials included in the main analysis, the strongest and most consistent relationships were observed between programme provision and emotional-labour

outcomes (parenting stress and general distress), for programmes delivering synchronous therapist support. This is consistent with the broader intervention pattern: ongoing professional support may facilitate programme fidelity and problem-solving, outcomes which are more directly tapped by distress measures than structural burden measures (Gentile et al., 2022; Liu et al., 2021).

The main analysis reported less consistent relationships between programme provision and physical-labour outcomes, and where these were observed, they often depended on whether programme participation involved reductions in the frequency or duration of high demand caregiving sessions. Where time-dependence and fatigue were not impacted, this may reflect unchanged workload, reduced respite opportunities, or persisting sleep disruption, in particular in smaller service settings (Trembath et al., 2019). Thus, it is most reasonable to conclude the evidence supports the potential for telehealth to reduce emotional strain, but changes in time-dependence and fatigue depend on whether programme (and service) conditions permit structural change in caregiver burden.

In summary, telehealth may be a viable platform through which parents can access professional support and parenting skills, with the most consistent evidence for reductions in emotional burden. There is less consistent evidence for reductions in time-dependence and fatigue, which seems to depend on whether programme (and service) conditions enable structural changes in caregiver burden.

Heterogeneity of Measures and Overlapping Constructs

One of the hallmarks of quantitative studies presented in this review is the significant variation in the conceptualization, operationalization and measurement of variables. Despite often purportedly measuring the same concepts (e.g., parenting stress, burden, depression, anxiety, fatigue or quality of life), the demarcation between such concepts may not always be

clearly defined between measures or in models tested (Podsakoff et al., 2003; Hayes & Watson, 2013; Yorke et al., 2018; Schwartzman et al., 2021). This has implications not only for between study comparisons, but also for the understanding of child, parent and contextual factors.

Shared Ground Between Concepts of Emotional Labour

Parenting stress was another commonly reported outcome (Keenan et al., 2016; Neijs et al., 2024). However, many parenting stress measures include subscales measuring parental distress, emotional exhaustion, or perceived incompetence, which are conceptually similar to depression and anxiety symptoms assessed in separate measures (Kütük et al., 2021; Wang et al., 2021). Thus, correlations between parenting stress and depression or anxiety might be measuring the same underlying construct, at least partially.

Likewise, the caregiver burden scales employed in research articles such as Picardi et al. (2018) and Rasoulpoor et al. (2023) comprise multiple dimensions like emotional strain, time-dependence, and role restriction. Burden scales may also combine psychological and practical dimensions into a single score. This ambiguity and confounding of concepts make it difficult to understand what type of burden is being referred to when child behavioural factors are linked with “burden” such that it is difficult to determine whether burden signifies emotional strain, objective burden or both.

The dataset is somewhat complicated by the fact that distress was in some cases analysed as a standalone variable and in other cases as a component of a composite variable. For instance, Keenan et al. (2016) analyzed parenting stress as an outcome in its own right, whereas Kütük et al. (2021) examined depression and burnout. Therefore, it is difficult to distinguish between symptomology of emotional functioning and context-dependent responses.

Notably, though, the directions of the findings were generally in the same direction, even if different scales were used: for example, greater child behavioural problems were related to greater levels of stress and burden in multiple studies (Chua et al., 2023; Picardi et al., 2018) though the heterogeneity of items on different scales may be related to strength and specificity of those relations.

Operationalisation of Psychological Distress Differences

Various questionnaires were used to measure symptoms of depression and anxiety (Kütük et al., 2021; Wang et al., 2021; Alshaban et al., 2024). While some provided continuous data, other studies used clinical cut-offs to classify respondents. Distress was sometimes measured as a dependent variable in its own right, and sometimes as a subscale of stress (Keenan et al., 2016).

These methodological differences preclude making direct comparisons between studies in terms of the rates of symptoms. Furthermore, the context in which the participants were sampled from might also impact the findings, for instance, those that used samples during the COVID-19 pandemic (Alshaban et al., 2024; Wang et al., 2021) might be overestimating the severity of the symptoms compared to those conducted before the pandemic. Thus, the disparity in symptom severity across studies is likely to be the function of both contextual and methodological factors.

It appears that these have been under-operationalised in the context of care for older people. Unlike emotional results, structural caregiving labour was operationalised in more roundabout ways. Fatigue was operationalised in Kara et al. (2025) and linked with poorer quality of life for mothers. Physiological markers of stress were used in Padden and James (2017), which could serve as objective measures of stress burden for caregivers compared to controls.

But in only a few of them time commitment, parental demands, nocturnal awakenings or musculoskeletal burden had been specifically assessed (Sawyer et al., 2010; Meltzer, 2008; Lee & Barger, 2022). Mostly, the structural burden was indirectly measured through the self-reporting of quality-of-life items or burden subscales (Picardi et al., 2018). Therefore, physical burden is relatively less represented in the quantitative literature.

However, due to the lack of quantitative measurement on the structural dimension, when caregiving burden in the form of fatigue or quality of life is identified, it is hard to tell if such burden is originated from the physically demanding tasks or the perception of burden.

Measures of Subjective and Objective Indicators

The majority of the studies used caregiver self-report measures to assess predictor (e.g., child behavioural problems) and outcome variables (e.g., stress, burden) (Chua et al., 2023; Picardi et al., 2018; Rasoulpoor et al., 2023). This may lead to shared-method variance, which can lead to overestimation of the relationship between child and caregiver variables.

Few objective measures were present. The use of physiological stress markers (Padden & James, 2017) is one exception. Physiological markers measure physiological stress load rather than objective measures of physical labour or time-involvement. With no objective measure of workload, the ability to distinguish between perceived burden and objective caregiver demand is limited (Podsakoff et al., 2003; Sawyer et al., 2010). The concept of quality of life can be taken as an example of a composite index.

Several studies employed the term quality of life (QoL) (Neijs et al., 2024; Kara et al., 2025). For some studies, QoL served as an overarching wellbeing outcome; for others, only select aspects of QoL were measured. Given that QoL measures are a composite of emotional, physical, and social functioning, any observed relationships between caregiving variables and QoL could encompass numerous mechanisms.

For instance, impairments in QoL due to fatigue (Kara et al., 2025) could be interpreted as a physiological burden, whereas impairments in QoL due to stress (Neijs et al., 2024) could be interpreted as a psychological burden. The use of a multi-faceted construct like QoL makes it difficult to differentiate between structural and psychological pathways.

Consequences of Heterogeneity in Measurement

The disparity in findings may be accounted for by the differences in the measurement tools and operational definitions used. Associations between measures of child behavioural complexity and caregiver distress have been found when construct validity, albeit different, was shown between two measurement tools (Chua et al., 2023; Picardi et al., 2018). Findings were less clear when associations were derived from a construct with measurement items from one or more constructs.

Third, and relatively the differential specification of emotional outcomes (which are directly measured) and of structural labour (which is sometimes taken for granted) might also contribute to the relative prominence of psychological distress in the research. In other words, emotional outcomes are more regularly and directly measured, while structural burden is often assumed; this might affect where researchers place their analytic attention as well as where they recommend that practitioners place their intervention efforts.

Overall, the studies incorporated in this review indicate that the heterogeneity of measurement is likely to be a methodological characteristic of ASD caregiving research, rather than an isolated problem. Future quantitative syntheses would benefit from further theoretical discussion and consensus on the conceptual meanings of emotional and structural labour and more uniform operationalization of the domains. This will provide more solid evidence for distinguishing the pathways of caregiver strain.

Chapter 4: Discussion

Summary of Principal Findings

A systematic review of post-2015 quantitative literature examining the emotional and physical labour of raising a child with ASD, and factors associated with increasing and reducing these burdens (Page et al., 2021). Included quantitative studies share similar patterns between burden and emotional/physical outcomes as well as general health-related and quality of life outcomes. First, child functional characteristics (symptom severity, behaviours and comorbidities) and parent-level characteristics (parenting stress and caregiving burden) were associated. Across various studies, findings suggested more severe symptoms, behaviours and comorbidities were related to more parenting stress and time burden, and more communication problems and externalizing problems were related to more distress and supervision burden.

Overall, these findings suggest that the ‘work of parenting’ is somewhat differentiated by functional classification of child. Second, caregiver characteristics including health status, resilience and psychological well-being were associated with burden. Caregivers in poorer health or with lower resilience experienced more emotional burden, while those with more physical limitations experienced more time-dependence and overload. Physiological studies suggested chronic strain of caregiving is associated with cardiovascular and metabolic outcomes, though few longitudinal studies were found. The third theme consisted of contextual factors, including SES, stigma, service use and social support, on family caregiving. Lower SES was associated with limited-service use and greater burden. Using support groups, respite care and ethnic-specific community services were associated with less emotional overload and in some cases, slight reductions in physical overwork. Fourth, intervention studies suggested that training in parent behavioural skills, telehealth, assistive technologies, and formal respite care, generally resulted in reductions in emotional labour

outcomes (parenting stress and psychological distress), whereas changes to physical labour indicators (time-dependence burden and fatigue) were less consistent, and seemingly dependent on whether the intervention intended to reduce caregiving load or structural demand.

Finally, quality-of-life was inherently tied to emotional and physical burden: when parents experienced more parenting stress or time-dependence burden, global and psychological/social/vitality QOL was lower. In many cases, this relationship persisted even after controlling for child severity, suggesting a parent's QOL is a function of the interplay between the magnitude of caregiving needs, contextual factors and psychosocial resources. Overall, the results of this review suggest emotional and physical aspects of caregiving burden are related yet distinct and impacted by child, parent and environmental factors, as well as types of intervention. While reduction in emotional burden may be feasible through skills training and psychosocial interventions, reduction in physical burden would require interventions aimed at redistributing the burden of care. The distinction between emotional and physical burden has implications for service, policy and research.

Integrating the Results into Theories

The research theme and its findings imply several examples of fit and a few examples where the empirical findings complicate the creation of a theoretical claim and extends the theories of ELT, carer burden and FST while the data presented in the researchers studied fits with ELT in so far as it requires constant emotion management for instrumental purposes, whilst also extending the theory by showing that emotion management and physical caregiving activities cannot be separated (Grandey, 2000; Vitaliano et al., 2003). This review implies that parents do not simply adhere to one set of situational norms, but that they continually modulate their tone, pace and bodily orientation while engaged in physically demanding activities such as lifting or supporting a child, as suggested by Ferrara et al.

(2023), and, that it extends the dominant discourse that centres on service-orientated frontstage for carers by showing that this is a singular and combined space for such carers in all respects and that emotional, and physical composure must be maintained in both public and private spheres Extensive emotional preparation beforehand, coupled with the continual need for physical exertion implies that EL functions as an embodied endurance that requires persistence rather than a performance that requires an audience, and what marks the chronic nature of the phenomenon is the embodiment (Picardi et al., 2018). This finding necessitates the need for us to theorize co-occurring physical labour as a core feature of high-intensity family care, rather than treating it as a relatively minor consequence because the evidence fits with carer burden in so far as it is characterized by objective and subjective components, but that they are equally intertwined over time, thereby complicating the matter.

Objective indicators, such as hours of self-care assistance and frequency of behaviour management, should clearly map onto environmental demands and symptom severity (McStay, Dissanayake, et al., 2014) however, these objective demands are rarely encountered without subjective interpretation. For instance, Dababnah & Parish in (2013) argue that stigmatizing public encounters perceived as more burdening than objective burden would suggest, but that positive reappraisal facilitates emotional processing and mitigates burden without burdening carers with additional objective tasks According to some qualitative studies such as Dabrowska & Pisula, (2010) and McStay et al., (2015), the general feedback between the objective and subjective domain is highly repetitive and cumulative unless attended to as unmanaged fatigue heightens emotional reactivity, which heightens the perceived burden of any given task load, leading to spiralling, which the current linear theories and models fail to explain. Furthermore, sociocultural expectations about competent parenting or gender roles complicate dynamics that are currently very poorly captured by burden models as it is found that mothers experience disproportionate routine exposure to

burden and that fathers experience intermittent exposure to burden and participation in caring efforts for their child, which makes the burden and their emotional spikes more noticeable. This shows that the framework applications need to be revised to explicitly acknowledge differential responding of mothers and fathers to burden and that there is a need to incorporate temporal patterning (chronotypes) in addition to burden levels as the current relational patterning provide strong evidence for FST's claims of interrelated subsystems and episodic performance.

Dyadic-level effects, such as one spouse increasing night time caring in order to protect the other parent's ability to work, impact the emotional resources available to manage dyadic daily caring routines (Kütük et al., 2021). Circular causality is observed in cycles of escalating child behaviour prompting parental stress reactions that in turn influence behaviour. Our data further specify that these cycles are influenced by both physical capability and communicative patterns. Theoretical homeostasis is evident in households that maintain rigid role boundaries despite primary carer's fatigue (McStay et al., 2015). This highlights a systemic resistance to redistribute caring responsibilities despite acknowledgement of functional imbalance and, that there is evidence for convergence as families converge on similar adaptation levels through different configurations such as kin respite and structured co-parenting implying their adaptability within systemic constraints and in response to shifting contexts.

The data presented in the studies fit with intersectionality theories in so far as it highlights systematic differences that cannot be accounted for by family system or burden model, and that they extend the theory by showing that there is a multiplicity of systems involved. SES impacts formal service use and efficacy of particular coping strategies ((Papadopoulos et al., 2019; Buescher et al., 2014; Marshall et al., 2018). Highly resourced families may maintain engagement coping strategies for longer as they are able to outsource

some physical tasks. In contrast, low SES families utilizing similar strategies experience fatigue more quickly as interventions are required to be implemented directly by them (Wicks et al., 2022). Cultural background impacts how stigma is experienced. For example, religious groups who attribute their circumstances to the will of God experience less subjective burden despite experiencing high levels of physically demanding tasks (Hebert & Koulouglioti, 2010). Cultural discourses that place the blame for one's circumstances on others exacerbate both public and private stigma as they facilitate avoidance strategies (Dababnah & Parish, 2013).

Gender intersects with these, showing that mothers experience chronic and dispersed exposure leading to a gradual erosion of regulatory capacity, whilst fathers experience acute and episodic exposure that increases the risk for harm or reactivity even when global stress indices are equivalent (Dabrowska & Pisula, 2010). This implies that a more nuanced theoretical approach to applying stigma is required. The modified labelling theory posits that the anticipation of devaluation results in coping responses (e. g., disclosure management) regardless of actual discrimination experiences. Our analysis supports this position, and further suggests that for parents of children with ASD, such anticipation often involves modifying public routines to include novel physically demanding activities and strategic seating before events that are now the focus of psychological devaluation.

Different Ways to Explain and Understand

In light of the previously synthesised patterns, it is important to acknowledge that there are additional mechanisms which may contribute to explaining some of the correlations observed between needs for care, emotional outcomes and load profile. Once parents' experiences are contextualised within larger personal and situational contexts, alternative explanations emerge, though the prevailing explanations centre on direct burden processes involving roughly linear effects of symptom severity or service deficits. One (or a group of)

alternative explanations could be the contribution of prior mental health histories of parents before taking on autism spectrum disorder (ASD) caring responsibilities.

At times, a high frequency of depression or anxiety in parents is observed before diagnosis of the child (Ingersoll & Hambrick, 2011). The aforementioned conflicting previous findings provide evidence for this. These predisposing mental health vulnerabilities, where present, may shape emotional and physical stress responses to new caring situations, inflating subjective burden not due to the care task. This explanation does not necessarily diminish the importance of care, but does suggest that baseline mental health may mediate the experienced intensity of the task and the applicability of specific coping strategies whilst caring. Another alternative explanation arises when considering measurement frameworks which interpret objective features of the care task into subjective experiences. Cultural and religious belief systems held shape how the same physical care task is subjectively experienced as burdensome or tolerable, and even fulfilling, work. According to Hebert and Koulouglioti (2010), where parents believe that autism spectrum disorder (ASD) is part of a divine plan, they are less likely to self-blame and experience less emotional distress in the presence of the same care tasks. Here, the embedding of even the smallest tasks into a narrative that gives them meaning is associated with a reduction in subjective burden. Conversely, where societal level narratives attribute a child's behavioural problems to parent failure (Dababnah & Parish, 2013), even the smallest objective expectations can be heavily saturated with experiences of shame and maintaining a public image. A gender inequality reading can be done in relation to the distribution of work over time rather than just the total quantity, since, according to Dabrowska and Pisula (2010), the sustained engagement of mothers in dual-domain tasks of low-to-moderate intensity in daily routines results in chronic load. Chronic load is easier to see in qualitative descriptions such as a 'day in the life' narrative. It may be that the discrete but impactful caring tasks performed by fathers, such as

responding to public tantrums, are not captured by standard questions, but do evoke transient increases in emotional and physical load (McStay et al., 2015). It may be that theme synthesis is biased towards a single over-load pattern where insufficient sampling of males and the neglect of certain chronotypes are concerned. This will mean that an alternative pattern is missed. In this paper, Gabra et al. (2021) provide an alternative reading for the apparent contradictions in severity ratings and quality-of-life outcomes.

Clinician-rated severity scales measure observable behavioural symptoms, but the relation of the child's severity profile to contextual support influences parent experiences. Even with a high formal severity rating, a family can maintain roughly normative daily cycles if they are situated within a supportive school environment (Khateeb et al., 2019). Exclusionary schooling practices can make a family feel overwhelmed despite a moderate severity rating, as higher-level systems are offloading excessive regulation back down to the family system. The identified relations between coping and outcomes in several studies need to be revisited in the context of structural systems surrounding the family. Engagement-based coping strategies are commonly found to relate to superior outcomes, contingent on the availability of sufficient external resources to enable effective problem solving (McStay et al., 2015). According to Marshall et al. (2018), in low-resource families where the person has to enact interventions themselves because of financial or access constraints, engagement behaviours can become cycles of prolonged exposure reminiscent of models of occupational overwork, which negatively affect both subjective well-being and physical health. Conversely, so-called 'maladaptive' avoidance can at times be an adaptive response to a harmful situation. According to Tilahun et al. (2016), selectively avoiding highly stigmatising community settings can protect self-esteem and conserve energies for essential care tasks. The quantity of functional support provided is not the only mechanism determining the benefit of social support; perceptual framing can also operate in this way (Cohen & Wills,

1985; Ekas et al., 2010). According to Barkli and Doğan (2025), satisfaction ratings are more strongly related to reduced distress than the quantity of support provided, as emotionally congruent interactions reduce the cognitive effort of interacting.

This suggests that explanations purely in terms of network size may overstate protective benefits if they fail to account for the cognitive and emotional effort of educating or supervising unfamiliar carers regarding the unique needs of autism spectrum disorder (ASD). Parents have to put in additional effort to suppress irritation at poorly matched support when attending certain ‘support’ groups (Lodder et al., 2019). Perceived choice and control offer an alternative explanation for urban–rural stress differences in geographic comparisons beyond service density. According to Tilahun et al. (2016), waitlists in urban areas are experienced as frustrating because proximity is often related to availability.

A Comparison of the Structural Burden and Psychological Distress Perspectives: Points of Departure and Intersection

One theme evident in the interpretations of the studies is the separation between objective burden and psychological strain. While they are often both the subjects of the same analyses and often are measured by subscales within the same instrument, this systematic review points to the possibility that they are at least semi-separable components of the caregiving work, with different risk factors and drivers and responding to different forms of intervention.

Dependent variables generally included psychological distress, which was measured as parenting stress, depressive symptoms, anxiety, or emotional strain (Keenan et al., 2016; Kütük et al., 2021; Neijls et al., 2024; Picardi et al., 2018). Emotional strain was strongly related to child problem behaviour and caregiving burden (Chua et al., 2023; Picardi et al., 2018). Further, changes to environmental context, such as those experienced during the

COVID-19 pandemic, were associated with psychological distress and caregiving burden (Alshaban et al., 2024; Wang et al., 2021). Overall, emotional variables appear to be responsive to changes in child variables, as well as environmental factors.

In contrast, the operationalization of the structural domain of caregiving burden (i.e., time-dependence, supervision requirements, level of tiredness, and loss of freedom) was less uniform across the studies. Although few studies have measured these constructs, significant correlations with other variables of interest were found when they were assessed. Significant correlation was found between level of tiredness and lower QoL in mothers of children with ASD (Kara et al., 2025), for instance. In addition, increased levels of physiological indexes of stress in parents of children with ASD compared with a control group were also found (Padden & James, 2017), which suggests greater levels of stress regardless of perceived burden. However, direct measures of objective burden (e.g., number of hours of supervision per day, hours of sleep per day, and number of physical tasks) were rarely used. Therefore, the structural domain of burden seems to be less explored compared with the emotional distress one.

This measurement inequality has implications. Emotional labour is more often and better operationalised, whereas structural labour is more often measured indirectly. This means that psychological effects are more pronounced in the literature, not because they are more significant, but because they are more directly measured.

We find further evidence of the disconnect between structural burden and psychological distress by looking at the intervention literature. Parent-focused interventions (e.g., early intervention programs, digital parenting training) were associated with decreases in parenting stress and improvements in mental health (Estes et al., 2019; Liu et al., 2021).

These changes in psychological distress occurred in the absence of a likely substantial reduction in structural caregiving load (e.g., in the context of disrupted services during a pandemic) (Liu et al., 2021). This may indicate that emotional functioning is amenable to intervention in the context of coping, self-efficacy, and psychological flexibility even if objective burden is not reduced.

In contrast, structural burden outcomes (fatigue, time-dependence) did not consistently vary across the intervention studies. When assessed, structural burden was still associated with the current caregiving load (Kara et al., 2025). This might suggest a differential responsiveness of psychological distress compared to structural burden. While emotional burden may be alleviated by enhanced coping or perceived support, structural burden may be harder to reduce (e. g. by adjusting services, respite care, or caregiving structures).

Moreover, the results of the COVID-19 studies also shed light on the differences between the two constructs (Baweja et al., 2021; White et al., 2021). Emotional distress and burden were higher among the caregivers when the services were paused and daily routines were fewer (Alshaban et al., 2024; Wang et al., 2021). Although we cannot rule out the possibility that these results also capture the emotional part of the construct, it is plausible that they at least partly capture the structural part, as the burden may have increased, for example, due to more time spent on childcare, more constant surveillance or less help from others ((Sawyer et al., 2010; White et al., 2021). Yet, the intervention study by Liu et al. (2021) shows that emotional burden can decrease in a situation where the structural burden cannot decrease, that is, while services are paused. In other words, although related, the two dimensions do not overlap completely.

In the studies discussed, child behavioural complexity has both a direct (e.g., having to deal with difficult or unpredictable child behaviour increases the necessity for time and attention, Picardi et al., 2018; Chua et al., 2023) and indirect (e.g., experiencing and interpreting difficult or unpredictable child behaviour contributes to stress of parenting, Keenan et al., 2016; Neijls et al., 2024) effect on parenting. We assume the relationship between these effects is cyclical, but they should not be collapsed into a single construct.

Additionally, a difference is observed at the level of the caregiver. In terms of psychological resources, differences in coping styles, resilience, and psychological flexibility were related to differences in burden and distress (Rasoulpoor et al., 2023; Reich et al., 2025), which implies that the subjective appraisals of the caregiver influence emotional responses in the same objective structural conditions of care. Nevertheless, resilience-related variables were not correlated with structural objective variables, which implies the difference between perceived distress and objective workload.

Second, the majority of the studies used a cross-sectional design (Chua et al., 2023; Keenan et al., 2016; Rasoulpoor et al., 2023), and thus it is impossible to confirm the direction of relationship between the two groups of variables. For instance, we do not know if chronic structural burden led to psychological distress or vice versa, or if it was a bi-directional relationship. However, it is possible that these two domains could converge over time. For example, chronic fatigue or the need for constant monitoring could have resulted in reduced capability to cope, or chronic distress could have led to decreased productivity or self-efficacy, in turn increasing the felt workload.

Consequently, it is important not to confound the structural and emotional aspects of the caregiving experience when interpreting the results of interventions. For example, decreases in reports of stress in response to psychosocial interventions (Estes et al., 2019; Liu

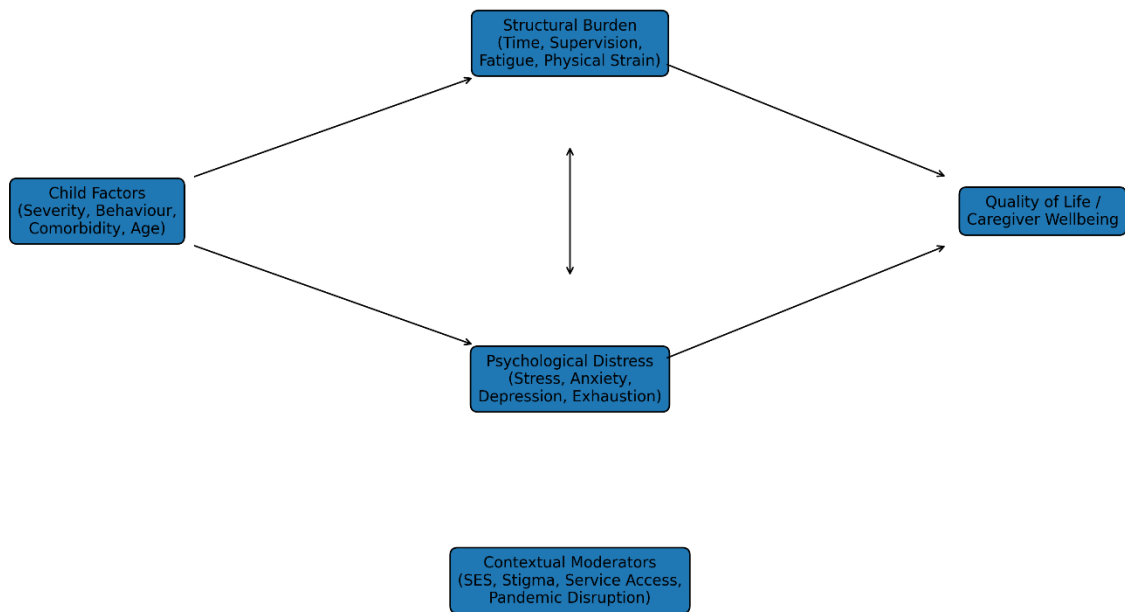
et al., 2021) do not necessarily mean that the caregiving burden has been alleviated, nor does stability in reports of fatigue or functional limitation necessarily mean that an intervention has been ineffective, but rather may suggest that the structural burden remains. It is crucial that the distinctiveness of the structural and emotional be acknowledged lest we inadvertently attribute outcomes across domains.

Finally, being able to distinguish between the diverging and overlapping aspects of the concepts will help resolve discrepancies in the findings in the literature. For example, some researchers found a significant relationship between child behaviour and burden (Chua et al., 2023; Picardi et al., 2018) which could be due to the fact that the instruments used tapped either the structural or emotional aspect or both depending on what the items consisted of. It is possible that the strength and breadth of the relationship vary when burden is measured in terms of both emotional and functional aspects.

Conceptual Model of Structural and Psychological Pathways in ASD Caregiving Labour

Figure 3

A hypothetical model that integrates the associations found in the studies.



In this model, a difference is made between the conceptual structural burden and the psychological burden, but the interplay of these two concepts in a multi-level system of care is visualized as well.

On the left side of the model are the child-level variables: behavioural complexity, symptom severity, comorbidity, and age. These are the primary parenting needs. Generally, all the studies we included found that greater problem behaviour and associated impairment are associated with greater parenting effort.

These childhood factors are then divided into two somewhat separate pathways. The first path is labelled structural burden. Structural burden encompasses the domains of supervision, time commitment, exhaustion, activity restriction, and physical strain. Structural burden denotes the objective load of caring activities. The model shows that structural burden

is directly related to child behavioural load and can be buffered by contextual variables such as service utilization, respite care, and general system stability (e.g., the effects of a pandemic). The model also suggests that structural burden may be less amenable to intervention based on psychological factors, except insofar as the situation of caring may be altered.

The second is psychological distress. Variables in this pathway include parenting stress, depressive symptoms, anxiety, and emotional exhaustion. Psychological distress is impacted by caregiving demand and a variety of caregiver-level factors, such as resilience, coping style, psychological flexibility, perceived social support, and parental efficacy. Interventions in the dataset indicate that this pathway can be more directly impacted in the short-term through interventions aimed at providing cognitive, relational, and skills support.

The model shows bidirectional pathways between the two variables, suggesting that they influence each other. It is possible that a heavier burden may lead to more distress or that more distress may lead to a heavier burden or reduced ability to manage a burden. While these longitudinal relationships cannot be tested with primarily cross-sectional data, the overall literature supports their connection. (Sedgwick, 2014; Levin, 2003)

Contextual factors including socioeconomic status, stigma, cultural values, access to healthcare services, and social context (e.g., COVID-19) are hypothesized to be moderators of both paths (Papadopoulos et al., 2019; Buescher et al., 2014; Wang et al., 2021).

Contextual factors are theorized to affect both structure and psychology. To the right of the figure are the caregiver outcomes of quality of life, health status, and continued well-being. Quality of life serves as a summary outcome measure that represents the totality of the structural and psychologic components.

Furthermore, the model shows that there are different intervention targets. The psychosocial interventions are likely to only affect the psychological route. In order to impact the structural burden, it will be necessary to implement policy and/or service level interventions. This may explain why changes in psychological outcomes do not necessarily result in decreases in fatigue or objective workloads.

The theoretical model is not suggesting directions of causality other than those that have been suggested by the empirical studies reviewed above. It is intended as a framework of integration for diverse research findings into an overarching explanatory framework. The model also stresses the importance of separating structural efforts and emotional strain in research and intervention design.

Consequences for Policy

Services to Help Parents

Based on the findings of the synthesis, it is proposed that support to parents of children with ASD should be seen as indispensable elements that impact on the sustainability of emotionally regulating and physically demanding life-long care-giving processes. If we want to do policy that makes positive changes in this arena, access, quality, suitability and sustainability need to be seen from a multitude of different vantage points. According to Lodder et al. (2019) unsuitable or inadequate service provision may do harm instead of good. There is a repetitive theme in the parent narrative of support services needing to address both labour domains simultaneously. Services that focus exclusively on promoting child outcomes (i.e. parent-mediated interventions) may indirectly increase physical labour burden, without reducing burden or providing relief or mental health support (Estes et al., 2019). They feel that without a concurrent reduction in other household or childcare duties, their endurance suffers (Marshall et al., 2018). Parents who follow a strict home-practice schedule report that

child skills improve, but also report that endurance declines when tasks are not compensated. Trained professional assistants can provide monitoring of high-intensity ASD-specific behaviours, reducing impression management and physical labour burden on outings (Barkli & Doğan, 2025). Services can address one domain, but the extent to which they reduce endurance burden in the other domain needs to be considered. The synthesis also highlights the importance of respite as a support type.

Respite that is well planned, professionally delivered and adapted for ASD symptomology, allows parents to recover and return to baseline functioning. However, the qualitative evidence also suggests that there are inequities in access based on SES, location and program eligibility (Marshall et al., 2018). Transportation costs to access respite may be a barrier for rural-dwelling families. There may be waiting lists for respite in urban centres, making services less reliable (Tilahun et al., 2016). Policymaking frameworks should allow for the provision of mobile respite services and fair financing strategies that adjust for regional variations in the cost-of-service delivery. If we do not consider how these distribution mechanisms function, our efforts may serve to create problems for those families that already have established connections, while leaving structurally disadvantaged families without any support. Another critical theme that emerges here is the need for service models that prioritize the mental health of parents.

There is evidence to suggest that parents who lack strong social support networks are more likely to experience depression, anxiety and burnout (Barkli & Doğan, 2025). The provision of free or subsidized counselling that addresses care-giving issues directly (i.e. coping with public stigma) may aid in alleviating chronic emotional overload, a concept that has received considerable attention in other contexts (Dababnah & Parish, 2013). These supports need to be culturally adapted. Parents whose explanatory models do not align with the Western bio-medical model may become completely disconnected if they are given

contradictory mental health messages (Hebert and Koulouglioti, 2010). The use of cultural broker positions on service teams may facilitate the alignment of intervention theoretical models with the explanatory models of parents, which may enhance service use and client satisfaction. Peer-led support networks are an essential, but oft forgotten ingredient, though not always (McStay et al., 2015). Parents prefer to interact with others who have had similar experiences to their own. In doing so, they can receive emotional support and learn strategies that reduce the costs associated with learning through trial and error. Facilitated groups, either face-to-face or web-based may serve as cost-effective adjuncts to existing programs. However, they require moderation and protection to avoid the creation of negative group dynamics such as comparative competition (O'Donovan et al., 2019).

That would be counter-productive. Policymakers can capitalize on the availability of community groups by providing funding for peer-facilitators to receive group process training and ensuring ASD-specific knowledge is accurate. In so doing, it will become easier to couple the emergence of grassroots networks with the accountability that is required in funded programs. The results are clear. Support systems need to integrate navigation into their programming. Navigating fragmented health, education and social care systems require a tremendous amount of hidden paperwork. Many attribute these efforts to stress and burnout (Russell and Norwich, 2012). There is a need for hidden paperwork. It may be that those in case manager type positions on interdisciplinary teams will assume the responsibility of coordinating scheduling across different departments. Not only will this ensure that information is transmitted in a timely fashion, but it will also mean that parents are not required to commit an inordinate amount of time to the task (Currie et al., 2023). In situations where there is an absence of formal infrastructure, and thus, limited resources, NGOs may serve as the intermediary between parents and credentialed providers in addition to serving material provider functions. According to Tilahun et al. (2016) targeted investments can

enhance the efficiency of these intermediary functions, particularly in situations where there are limited services. Moreover, there is qualitative evidence to support the use of flexibility in service delivery as a policy lever.

For some, fixed-hour therapy programs are inaccessible because they must work or attend to other siblings. To effectively translate the synthesis into policy responses at the workplace and economic level, the financial commitments and employment constraints commonly described by parents must be addressed. The vignettes demonstrate how labour market arrangements, firm policies and social protection arrangements all play a significant role in sustaining emotional regulation and physical caring over time. For example, parents of children with ASD report greater psychological distress as a result of inflexible employment conditions including inflexible scheduling, limited paid leave and limited control over work schedules (Seymour et al., 2018). In line with the extensive evidence linking inflexible work schedules with increased parenting stress, particularly with respect to responsibilities such as attending appointments, it makes sense that fathers with limited access to flexible work hours or parental leave report increased stress, while fathers with greater access report reduced stress. In the absence of such provisions, carer absences may result in reduced income security, employment insecurity or career standstill, thus further compounding the financial strain associated with out-of-pocket costs for medications and services (Rogge and Janssen, 2019). Poverty is a key driver of these strains.

Finally, for many families, the problem is not that they necessarily want to do less paid work, but that inflexible, non-standard service hours require them to do so (Falk et al., 2014). This poses a particular problem for many families. For many women. As a result of the gendered division of unpaid work, which assigns one member of a couple responsibility for both physical caring work and emotional work, women are more likely to reduce their working hours or drop out of the labour market (Dabrowska & Pisula, 2010). Given that

women are more likely to be the primary carers of their children, this often means that they are more likely to drop out of the labour market. The gendered division of unpaid work may explain the gap that some studies have found in certain quality-of-life outcomes between mothers and fathers (Gabra et al., 2021). As such, there is significant scope for policies that address the gendered division of unpaid work. In particular, there is scope for a greater use of paid family leave policies that include long-term, complex care rather than only infant care or short-term care in the case of acute need to share the responsibilities of care more equally and prevent labour market drop out.

The vast majority of the financial costs of caring for a child with ASD come from lost productivity. With lost income and unpaid care time estimated to account for up to 89% of total family ASD costs in Australia (Rogge & Janssen, 2019), it is clear that lost productivity is a key driver of estimated lifetime costs per child, when using estimates from a number of high-income countries. This economic footprint suggests there is scope for targeted financial interventions such as tax credits for dependent care when support needs are high, subsidies for qualified in-home care workers and expansion of mandated insurance coverage to cover a broader range of services so that families do not have to absorb these costs entirely and without compensation (Buescher et al., 2014). All of these suggestions are a response to the significant economic footprint. These strategies would directly reduce the objective burden and indirectly reduce the subjective burden by reducing the risk that individuals will have to undertake physically demanding tasks regularly. Even in the context of rising care demands, positive work conditions, autonomy over working practices, perceptions of job security and moderate levels of stress exposure seem to persist, when some studies have employed measures of job quality (Seymour et al., 2018). This would be more sustainable if employment norms included these dimensions. This could involve mandating reasonable adjustments from larger employers for employees with ongoing caring responsibilities,

enshrining the right to request flexible working arrangements without penalty and establishing carers leave as a specific leave entitlement in its own right, rather than a form of generic sick leave.

In the absence of these measures, parents are often required to informally adjust their working hours (e.g. taking carers leave to attend appointments), which makes it harder for parents to combine work and care for their child and undermines the trust of parents in their employment relationship. Furthermore, there are important sectoral differences. According to Rogge and Janssen (2019), parents in precarious or hourly wage employment may be particularly vulnerable, as any absence related to care immediately results in lost income, rather than income through flexibility. In order to prevent the situation of low-wage and professional carers from deteriorating further, there is a need for legislation that extends the right to flexibility beyond white-collar workers. Similarly, the provision of public or subsidised respite care tied to working hours may enable part-time carers to undertake paid work, without the risk of having to cancel shifts at the last minute due to a lack of childcare options. Beyond formal entitlements, workplace culture is crucial. As a consequence of firms signalling that they recognize an employee also has the role of an intensive carer and that it is important that this role is balanced against their role as an employee, parents feel less inclined to hide stress and disguise their needs (Seymour et al., 2018), according to some qualitative research. In contrast, non-supportive environments impose an additional burden of emotional labour such as disguising one's tiredness during meetings, managing the concerns of co-workers about requests for leave and managing the implicit stigma attached to one's level of commitment. In these cases, training managers about what it is like to care for a person with a disability may help, which may also ensure that supportive policies are applied consistently across teams.

Consequences for Practice

Training for Professionals

The curricula of pre-service education and continuing professional development should be restructured to reflect the realities of emotional and physical caring work in ASD. This systematic review makes clear that much of the burden experienced by parents is caused not only by what is required from them in terms of response to their child's needs, but also the nature and quality of interaction with professionals in education and other services (Dababnah & Parish, 2013). Professionals' knowledge, attitudes and responsiveness are central to whether services make the caring work of parents easier or harder. Without education in the specific family context of ASD, such as the intersection of emotional regulation and physical caring, the experience of services may leave parents feeling not understood or that they need to do more explaining or advocating (Marshall et al., 2018). A clear feature of the literature that we reviewed is that the capability of professionals must extend beyond the domain of diagnosis to include skills for supporting parents in their two-domain experiences. Social workers, teachers, therapists and health professionals need to be aware that advice to increase the frequency of therapy at home can have the unintended consequence of decreasing the endurance of parents if not offset by other relieving mechanisms (Estes et al., 2019).

Programs should include instruction on how to assess the total load of a career, in terms of objective load (the amount of hands-on caring activities undertaken on a daily basis) and subjective load (the degree of associated emotional distress and stigma), and how to adjust interventions accordingly. This is in line with findings from intervention studies that applied teaching was not sufficiently adapted to the context of families which lead to drop-out from an otherwise evidenced-based intervention (O'Donovan et al., 2019). Cultural capability is a critical dimension. Shifting explanatory models of autism can influence

engagement and satisfaction with intervention, as has been found in multicultural contexts (Hebert & Koulouglioti, 2010; Jegatheesan et al., 2010). There is a need for training to equip practitioners to engage respectfully with the belief systems of their clients, working together to make adaptations that do not compromise the essential objectives of interventions but also respect the wishes of parents. In the absence of such capabilities helpful interventions may be rejected or only partially implemented because their value is not recognized (Damschroder et al., 2009). The use of role-play and reflective supervision using real case scenarios can help practitioners to refine this complex negotiation, developing awareness of culturally specific standards of adequate care (Khateeb et al., 2019). In addition, there is a need to equip oneself to work effectively with highly stressed families.

Russell and Norwich (2012) argue that the empirical literature details many instances where poor planning of multi-agency involvement increases the bureaucratic burden on parents by requiring them to provide information on a regular basis. Training may go some way to addressing this issue by teaching professionals how to communicate effectively with each other, by ensuring that all parties understand their role as a health practitioner, teacher or social worker, and by demonstrating an understanding about how to utilize collaborative planning tools that facilitate the management of paperwork. Such intersectoral strategies reduce unnecessary effort that parents must expend while at the same time conveying that they understand the time constraints they face. Social support has been identified as a factor associated with positive outcomes for carers (Barkli & Doğan, 2025). As such, professionals should be equipped with the skills to support individuals to build networks, rather than providing a direct service. Necessary skills include the ability to link families with peer groups or respite services that have been vetted for proficiency in ASD (Bonis, 2016), understanding eligibility criteria for financial benefits or assistive technologies (Marshall et al., 2018), and oversight of their use without facilitating inappropriate services that may

exacerbate emotional regulation challenges by exposing families to unwanted challenging situations (Lodder et al., 2019). Findings further highlight the importance of professionals in supporting the reduction of stigma-related constraints which serve to increase both forms of caring burden.

Professionals should teach parents to use rights-based language when encountering discrimination (Dababnah & Parish, 2013). This would involve strategies for promoting the inclusion of children in public spaces, working with educational or recreational settings to ensure inclusion of all, and teaching parents such language. By modelling inclusive practice, professionals can influence the meso-level contexts (such as clinics and schools) which affect the daily caring pressures experienced by parents that are discussed in this synthesis paper. Finally, a clear message from parents about their experiences of musculoskeletal strain associated with frequent lifting or the need to physically restrain, is that training should include an understanding about physical ergonomics (Neijs et al., 2024). The care of adult patients with disabilities is already included in allied health curricula however there is a need to adapt these to include children with neurodevelopmental disorders who may exhibit unusual movement patterns or behavioural resistance. This should include instruction about safe positioning during personal care, injury-preventive de-escalation techniques, and strategies for environmental set up to reduce the risk of dangerous lifting within home environments, to foster a prevention approach which reduces the likelihood of long-term caring injuries. Another capability for professionals is the need to understand the temporal aspects of family life. They need to appreciate that the daily chronic exposure of mothers and punctuated acute exposure of fathers will require different forms of support (Dabrowska & Pisula, 2010; McStay et al., 2015). Rather than utilizing generic strategies for supporting parents, training should enable practitioners to engage reflexively with different 'role chronotypes' and to offer load-balancing strategies that respond to the particular stressors

faced by each parent. In reality, this might mean finding relief staffing to cover periods of known high-load conditions or distributing skill teaching evenly between co-parents regardless of who uses the clinic most often.

We believe that the impact of capacity building programs should extend beyond university academic curricula. Systematic review evidence such as the current review could be used in practice update modules of continuing professional education programs. Such modules would demonstrate how practitioner responsiveness interrupted the cycle of emotional strain and task burden through behavioural responses, adjusting dosages of interventions and understanding the validity of parents' responses. Lastly, to ensure that practitioners can be effectively prepared, it is essential that systems are in place at the organizational level to enable trained practitioners to perform their roles effectively. It would be futile to raise awareness of caregivers' experiences among practitioners if organizational workloads constraints meant they could not commit sufficient time to work together to establish policies and procedures. The quality of family care outcomes is directly linked to policy issues to advocate for manageable workloads of direct care practitioners. Practitioners would profit from learning about advocacy skills to articulate these systems needs up the chain of their respective organizations in the context of needed to maintain ethical practice with highly demanding caregiving populations.

Interventions in the Community

Taken together, the findings in the studies that were reviewed here suggest that community-level interventions are an essential vehicle for bridging between individually tailored, specialist services and wider socio-environmental factors which are a part of the daily life of parents of children on the autism spectrum. First and foremost, they are best positioned to address issues that, although outside the clinic or classroom, have a significant impact on both the need to engage in emotion regulation, as well as the demands of

physically demanding childcare tasks. Effect sizes for these are comparable to the other practice domains and depend on not only de facto provision but also relevance to the family setting, sensitivity to cultural beliefs and the embedding of supports within daily routines to reduce the burden on the carer rather than adding to it (Li et al., 2024; Beach et al., 2005; Damschroder et al., 2009). Well-designed community programs can address a number of the issues with care-giving at the same time. In addition to removing the need for constant childcare supervision, autism-friendly public spaces, adapted sports clubs, sensory-sensitive playgroups and inclusive recreation facilities can also remove the anticipatory anxiety associated with stigma (Dababnah & Parish, 2013).

Group activities run by experienced staff or volunteers mean that parents are free to relax or to interact with other family members, removing the need for constant alertness to potential child behaviour (Barkli & Doğan, 2025). Resources to train local staff, particularly parents, to channel discussion in a productive way and to ensure that there is guaranteed inclusion will go some way to addressing these issues. Community-level interventions are also a key way to buttress the resource-delivery functions with which formal services are most commonly associated.

The establishment of sensory equipment loan schemes, drop-in clinics run by healthcare specialists and transportation co-operatives has made it easier for families in rural areas to access transport (Tilahun et al., 2016). The amount of labour involved, the time required to seek out and/or purchase equipment and the distance that has to be travelled to access therapy are all successfully reduced by them. By indirectly acknowledging care-giving tasks, community supports emotional functioning. According to Bonis (2016), these processes demonstrate the potential for even modestly sized logistical supports at the community level to break the circular reinforcement loops around fatigue and reactivity that were identified in other parts of the synthesis. Cultural adaptation is a key enabler for many

of the ethnographic studies. Programs led by cultural brokers enhance interest and engagement in communities where there is a strong stigmatization of disability or where explanatory models depart from the bio-medical (Jegatheesan et al., 2010). Participation can be enhanced by the provision of therapies within valued community settings such as mosques or dedicated community centres for specific diaspora groups. This both reduces the need for trust-building and the emotional effort required. The inclusion of religious leaders and elders on design teams ensures that messages are congruent with community values.

This renders participation a virtue, rather than a stigma (Hebert and Koulouglioti, 2010). Even well-resourced interventions can collapse if they enable people to opt out in order to protect their family's reputation (Dababnah & Parish, 2013). Such calibration is necessary. A second tier is how community-level programs articulate with other programs in order to prevent duplication and enhance reach. Parents commonly report that one of the most significant sources of bureaucratic burden is the need to maintain separate enrolments and reports for different programs (Russell & Norwich, 2012). Operational efficiency and ensuring that participation in one program facilitates participation in another can be enhanced by the allocation of coordination functions within community organizations and the designation of staff to connect participants to relevant school provision, healthcare services and respite care schemes. This can also help to reduce extant bureaucratic burdens on families. Whilst there is potential for community-level digital platforms to enhance this brokering function when these are designed with access in mind, deficits in infrastructure and issues around digital literacy remain, which can serve to exclude those who stand to benefit the most (Jegatheesan, 2011). A second facet commonly identified in parent reports of what modes of support are either enabling or disabling is the ability to adjust the program schedule. In terms of the potential to provide scheduling that fits with family routines, community-level actors far surpass statutory provision. For example, activity groups may be scheduled out of

regular working hours or parent groups scheduled to coincide with concurrent children's provision in order to provide simultaneous support to both generations (Estes et al., 2019).

The latter format has been lauded for making it easier to organize transportation and reducing the guilt that parents feel when they have to abandon their child in order to attend to their own needs in isolation. Mobile distribution schemes and activity schemes that rotate across different neighbourhoods may help to make it easier to access goods and services in situations where there is a lack of availability of public transportation. This would enable visible inclusion practices to spread further across a given geography. The training of local actors in both knowledge about the program content and contextual realities that families face on this journey can enhance the effectiveness of the intervention. This includes: safe lifting techniques for older children engaged in sports, early behavioural signs that might suggest an escalation and the application of de-escalation techniques to reduce the need for trauma prevention and physical restraint. As such, resources for the training of local volunteer capacity should be allocated at the planning stage. The professional competencies outlined above should be equivalent to these trainings, in order to ensure consistency of service provision regardless of who provides it. The improvement of the quality of evaluation data collected in communities around the country is a necessary step if programs are to be evidence rather than rumour based. The use of mixed-methods feedback loops such as parental stress inventories to monitor change post-intervention and qualitative interviews to assess the degree to which perceived gains are relevant to cultural context (Picardi et al., 2018) present a strategy that renders it easier to support continuous improvement over time.

This analysis relies on the social constructivist assumptions that meaning is created at the interface of actors and program. I find that the adaptive management theoretical framework is useful because it gives us a framework to do just that. Finally, many of the evidence-based community interventions have an advocacy element, in that public facing

efforts to promote the inclusion of neurodiversity gradually influence attitudes to reduce stigma. They have dual benefits, in that they offer immediate enjoyment and respite benefits, but in doing so, gradually influence the way in which community members encounter autism as a feature of life (Khateeb et al., 2019). Examples include: inclusive festivals, open-house days at adaptive recreational facilities, and joint initiatives between parent groups and local government. Changes in macro-attitudes have been found to lead to changes in micro-attitudes, which in turn reduce the extent to which carers experience stress in public interactions. This analysis has shown this relationship to hold. Failing to incorporate an outward facing element may mean interventions miss opportunities to leverage some of the most powerful upstream variables influencing carer stress, as was observed in a number of instances.

In summary, well-designed community-based interventions have the potential to act as integrative hubs addressing multiple variables that concurrently influence carer stress, because they can concurrently address multiple variables. Stigma free environments, adaptive coping resources via culturally sensitive peer networks, access to formal services with minimal bureaucracy, local capacity to respond to the unique needs of people with ASD, and longitudinal shifts in social attitudes are ways community programs address emotional challenges. Across the studies reviewed, community-based interventions integrating professional input with informal support are identified as potentially reducing caregiver burden by facilitating delegation, improving access to vetted peer networks, and removing stigma related barriers to participation (Clay et al., 2017; Lambert et al., 2017; Papadopoulos et al., 2019; Chua et al., 2023).

Methodological Limitations of Included Studies

When considering the results of this systematic review, it is essential to keep in mind the common methodological shortcomings present in the studies. Firstly, the cross-sectional nature of a large number of studies (e.g., Chua et al., 2023; Kara et al., 2025; Wang et al., 2021) makes it difficult to determine the direction of the relationship between variables. Though longitudinal studies were identified (e.g., Chetcuti et al., 2020), they were less frequent.

The majority of studies used caregiver self-reported measures. Instruments measuring emotional burden (e.g., PSI-SF, DASS, SDS) and proxy measures of physical burden (e.g., time-dependence, fatigue, musculoskeletal symptoms) commonly used self-report questionnaires (Chua et al., 2023; Wang et al., 2021; Trembath et al., 2019). However, self-report measures are susceptible to response bias and common method bias.

Many studies used convenience or clinically referred samples (e.g., Clay et al., 2017; Papadopoulos et al., 2019). These sampling methods may disproportionately represent families who are already accessing services and may exclude harder-to-reach populations of carers. Fourthly, the diversity in operational definitions across studies poses challenges for comparison. Different tools and subscales were used to measure ostensibly the same concepts. Furthermore, only a small proportion of studies utilised objective measures (e.g., Kara et al., 2025; Padden & James, 2017).

The quality and comprehensiveness of reporting of intervention studies was varied. Though some studies used a RCT design (e.g., Trembath et al., 2019; Gentile et al., 2022), others used a pre-post design, or a non-RCT design. Adherence, treatment fidelity and follow-up periods were also inconsistently reported (Chukwuemeka & Obioha, 2024). Finally,

attrition and missing data were not consistently reported across studies, which may introduce bias if loss of participants was related to the level of burden experienced. In summary, the extant literature is most robust in relation to the consistent associations between caregiving burden and carer-related outcomes. However, it is less robust in terms of establishing the direction of relationships and the long-term course of burden.

Limitations of the Present Review

Although this review followed best practices in searching for literature and reporting systematic reviews (Page et al., 2021), several caveats should be borne in mind. Firstly, the review focused on peer-reviewed literature in the English language from 2015 onwards, so may have missed pertinent studies published before this date, or non-English language studies, or grey literature, and may be prone to publication bias. Secondly, there was considerable heterogeneity amongst included studies in terms of measurements, samples and study designs (Jüni et al., 2002; Egger et al., 1997). Given that outcomes were measured in differing ways and operationalised using different definitions, a narrative synthesis was undertaken rather than a meta-analysis in line with recommendations for combining heterogeneous data (Popay et al., 2006). As such, this review does not provide pooled quantitative estimates. Thirdly, the majority of studies were cross-sectional in nature, which precludes inferences about the direction and/or causality of the associations.

Where possible longitudinal studies were also sought but were less frequently identified. Fourthly, the results are only as good as the quality of reporting in the included studies (Page et al., 2021). This review did not involve a reanalysis of primary data. Fifthly, the evidence comes from diverse cultural and socioeconomic contexts, and may not be equally applicable to a single health care system. Finally, the framework of emotional and physical labour was used as a conceptual framework for this review, but some outcomes

could arguably fall under both (e.g., fatigue, economic strain). These should be interpreted as rough heuristic categories. (von Elm et al., 2007; Schulz et al., 2010)

Transferability and Extent of Results

The generalisability of the results is determined by the generalisability of the samples and the generalisability of the results across contexts and across different types of carers.

In terms of generalisability to different locations, the literature was mostly conducted in countries with greater resources for carers. There may therefore be limited generalisability to locations with fewer resources for assessment, education or respite. The literature conducted in countries with greater stigma and/or fewer resources for carers reported greater restriction of social activities and more problems accessing services (Papadopoulos et al., 2019; Chukwuemeka & Obioha, 2024). Resource limitations also influenced the burden on carers and access to services (Chua et al., 2023).

In terms of generalisability across different types of carers, a number of studies focused solely on mothers of children with autism, and there was a dearth of literature on fathers and other carers. Where distinctions were made between mothers and fathers, there were differences in terms of carer burden and wellbeing between them (Wang et al., 2021), and so it may not be possible to extrapolate findings from studies using a sample of mothers to other types of carers.

Many of the results concerning interventions will be context-dependent, as they depend on the availability and affordability of the intervention and how easily it can be integrated into the daily routine. For example, the effectiveness of respite care depended on how easily accessible it was (Lambert et al., 2017; Kara et al., 2025) and disruption to services (e.g., as a result of the COVID-19 pandemic) resulted in greater burden (Alshaban et al., 2024). Remote or digital interventions may increase accessibility where access to services

is a problem, although benefits may be muted where structural demands remain the same (Gentile et al., 2022; Trembath et al., 2019).

Heterogeneity of measurement also limits the generalisability of the results in terms of the size of any effect. The various components of emotional burden and physical burden were measured in multiple ways across the different studies, and objective physiological measures were only included in a minority of studies (e.g., Padden & James, 2017). The review can therefore be said to provide more robust evidence for patterns across studies than for direct comparison of the size of effects across studies.

Overall, associations between increased demands of caring and poorer carer wellbeing were reported across a variety of contexts, and the relevance of accessing services, stigma and greater access to financial resources were also noted (Chua et al., 2023; Papadopoulos et al., 2019; Clay et al., 2017). However, recommendations for specific services may need to be tailored to the specific context in terms of resources and stigma, as well as the carers in question.

Directions for Future Research

Although a large number of synthesised studies are available, several subpopulations of parents remain relatively underrepresented. As such, it is difficult to know whether the synchronized changes in emotional and physical labour identified in this review apply to all ASD parent households, and these knowledge lacunae are in need of urgent addressing in order to further diversify the knowledge base. One common limitation of qualitative ASD caregiving research, is the underrepresentation of fathers compared to mothers (McCafferty & McCutcheon, 2020). In most qualitative studies, the proportion of fathers does not exceed 20 of the sample (McStay et al., 2015). As such, it is difficult to explore the concept of father-specific role chronotypes of caregiving, characterized by condensed periods of exposure to

high-intensity caregiving events (e.g. attending clinics, going out with the child, or dealing with a major behavioural meltdown) over a limited time. Underrepresentation of fathers has precluded awareness of how differences in coping styles and stress responses may be due to time in role rather than time of caregiving (Dabrowska & Pisula, 2010). It is also difficult to assess the extent to which findings of equality in terms of stress (Ha et al., 2014) reflect genuine parity in experience or simply differences in the distributions of exposure, given the underrepresentation of fathers and intact two-parent households with relatively equal roles.

Another important gap concerns the complete absence of representation of non-binary parents or non-maternal female caregivers (e.g. grandparent as primary caregiver). As such, little is known about the roles of non-traditional parents and non-maternal caregivers in the intra-household division of emotional and physical labour. A second major knowledge gap concerns lower SES households outside the reach of formal professional services. Although evidence suggests SES gradients in burden (Marshall et al., 2018), many studies fail to report socioeconomic status or include samples solely drawn from support groups or intervention programs, which leaves out households requiring intensive support but without regular professional support. These families are hypothesized to engage more in compensatory substitution, in that parental provision of tasks typically provided by formal personnel (Wicks et al., 2022). Here, both forms of labour may be more heavily influenced by system-level factors than child characteristics alone, with coping strategies focused more on conservation than engagement, as a function of continuous exposure without opportunity for relief. Studies including direct sampling of these scenarios would provide insight into the relationship between systemic insufficiency and trajectories of family resilience and burnout. The geographical spread of samples also varies, with Anglophone high-income countries with formal diagnostic services being overrepresented (Khateeb et al., 2019). According to Tilahun et al. (2016), rural low- and middle-income countries are underrepresented. These families

face particular challenges including limited access to diagnostic facilities, absence of specialized care, and exertion needed to travel long distances to access care. The majority of research on rural populations has been conducted in high-income countries where basic resources remain available even if at a distance. As such, it may not capture the full range of adaptive enhancements or attritional effects that emerge in the context of home-based care as the only available option over the course of multiple years (Sawyer et al., 2010; Vitaliano et al., 2003). Inequities within countries are also relevant to consider: although living in close proximity to care facilities, urban poor families may share many of the same limitations as rural families, due to access barriers relating to cost or bureaucratic factors (Rogge & Janssen, 2019).

Cultural and ethnic heterogeneity of sample is sometimes not fully reported beyond description, and heterogeneity is not consistently reported. According to Jegatheesan et al. (2010), immigrant parents in bicultural settings (e.g. South Asian or Somali parents living in Western host countries) face unique constellations of system uncertainty, explanatory model incongruence and stigma, which directly affect public-oriented emotion management. Systematic comparative research on immigrant groups is relatively rare, despite a wealth of qualitative research which has more directly investigated these dynamics (Jegatheesan, 2011). In addition, while there is evidence that these factors influence reflective functioning and acceptance-based coping, intra-cultural variation (e.g. differences among Arab parents in terms of religiosity or geographic location) has received little attention (Hebert & Kouloughlioti, 2010). Future samples should therefore actively seek to sample intra-group variation within broad cultural groupings in order to identify subgroup-specific moderators of emotional-physical labour balance. Given that evidence suggests that the absence of a second caregiver exposes parents to greater frequency of peak-load episodes and reduces the capacity to swap tasks in order to mitigate sleep disturbance associated with overnight care, another

group which is underexamined concerns single-parent households (Ha et al., 2014). Here, the dual pressure of impression management under conditions of stigma in conjunction with sole responsibility for physically-demanding tasks (e.g. lifting, physical restraint during a behavioural meltdown) may generate a unique strain signature compared to two-parent households, where tasks can theoretically be swapped. A similar analytic oversight concerns blended or extended families, where multiple adults are present who can assume caring responsibilities.

Such family structures are more common outside of the Western nuclear family ideal, and may reduce the physical burden of care, although complicating interpersonal dynamics associated with emotional labour. Finally, in terms of longitudinal qualitative research on transitions across different stages of development, very few studies have focused on the aforementioned underrepresented groups (Da Paz et al., 2018). For example, a father's part-time role in early childhood may give way to fulltime daily involvement as employment opportunities shift; likewise, a single parent may move in and out of informal support networks as the availability of extended family support ebbs and flows. Extrapolation from cross-sectional short-term studies may distort resilience and burnout trajectories if life-course considerations are not taken into account in these populations. A final population essential to the current review which is almost entirely absent from the qualitative literature concerns parents of children with ASD and other comorbid medical conditions (Lee & Barger, 2022; Vitaliano et al., 2003). Although common comorbidities such as ADHD or intellectual disability are prevalent enough to identify thematic links to increased burden (McStay, et al., 2015), relatively few narratives have addressed experiences at the intersection of ASD and a medical comorbidity requiring ongoing management (e.g. uncontrolled epilepsy).

Similarly, the specific ways in which the physical labour of clinical care intersects with the manual labour of emotional care may generate distinct emotional

surveillance/embodiment dynamics not evident in the sample populations utilised for the illustrative quotations above. In addition to the ‘missing’ individuals highlighted above, the existing samples also fail to ‘see’ those interviewees who are interviewed in a language other than the researcher’s, with interviews translated into the researcher’s language and treated as if conducted in that language; immigrant mothers who participate in majority mother groups without the data being thematically coded separately; and working class, urban fathers who participate in mixed-sex samples which are not analysed by gender due to small sample size.

While samples would remain small, we would need to deliberately oversample these populations at the design stage, and use stratified analysis at the analysis stage to bring them into view. These methodological blind spots can only be addressed through analytically precise inclusion strategies. In order to sample the as yet unexamined low-SES carers, for example, we may need to sample through non-service gatekeepers; work with cultural gatekeepers to establish trust in historically excluded communities; provide flexible interview timing (evenings/weekends/remote interviewing) in order to accommodate shift-working fathers; utilise nested longitudinal case series to explore changing divisions of domestic labour over years rather than months; employ translation services to avoid erasing the nuances of minority language accounts and adequately capture culturally inflected enactments of enacted stigma; and stratify by family structure in order to unpick more nuanced redistributive mechanisms within different household configurations. By systematically broadening the research net to incorporate these as yet unexamined carer populations, we can explore whether the dynamics described here are consistent or context dependent on SES, ethnicity, family type, and/or service type (Khateeb et al., 2019; Marshall et al., 2018; McStay et al., 2015).

Longitudinal Viewpoints

Investigating longitudinal effects is crucial for mapping how requirements for emotional labour and physical labour evolve over the life course of an ASD child and are affected by system changes. Much of the available data is cross-sectional, representing parents at one moment in time, which may obscure a transient spike in burden that is mistakenly assumed to represent an equilibrium. Examining longitudinal or multi-wave studies from the past suggests that the state of the caregiver is not fixed and is likely to shift as children enter new school settings, as they go through behavioural changes that accompany puberty, or as they transition to legal majority (Da Paz et al., 2018). The balance between emotional labour tasks and embodied labour tasks may need to be recalibrated at each of these junctures. Identifying these transitions can help identify periods of cumulative overload or periods of effective intervention that can prevent future overload. Longitudinal work has already begun to identify these patterns.

According to McStay et al., (2014), longitudinal research has already demonstrated that some components of subjective burden decrease over time as families adapt to circumstances or as they learn more effective behavioural management techniques, but other components of burden increase as children grow older and more physically independent or strong, requiring more intensive monitoring for safety. Since the person is larger and less predictable, tantrums become more dangerous and more physically taxing in these situations even if daily living skills are better (Ferrara et al., 2023). These phenomena explain why cross-sectional data may underestimate the risk: a caregiver may be managing well at the moment a child is nine but may be more at risk by the time the child is fifteen. The relatively small number of longitudinal studies also underscores that outcomes for families are not uniform or linear. While some families experience a loss of resilience as acute stressors give rise to chronic fatigue syndromes or depressive symptoms (Neijs et al., 2024), others

experience reduced distress over time as coping improves and support networks expand (McStay et al., 2015). The consistency of social support (Barkli & Doğan, 2025), the consistency of service provision, and macro-level policy changes that affect the provision of relief may all be contributing factors to differential outcomes. When services are reduced or eligibility criteria become more stringent after a decade of parenting, parents have to resume tasks they previously off-loaded: this heightens both their physical labour and impression management activities.

Longitudinal designs are essential for examining the bidirectional effects between caregiver well-being and child outcomes. Data from repeated measurements suggests a bidirectional influence: chronic parenting stress at one time point predicts poorer observed parent-child interaction quality at a later time point, whereas child behavioural functioning contributes to later parenting strain (McStay et al., 2015). By accounting for temporal bidirectionality, researchers can avoid drawing an overly unidirectional model of causality that does not take into account the fluctuating nature of caretaker capacity as it affects the child's developmental environment. By tracking families longitudinally, we can identify how families adapt or fail to adapt their coping strategies over time as their circumstances shift. For example, while problem-focused coping is associated with positive adjustment in young children, it may become maladaptive in the adolescent years if there are too few cycles of relief (Shepherd et al., 2020); conversely, selective disengagement, which served as an adaptive strategy for conserving energy during the intensive treatment phase, is likely abandoned as children attain greater independence. These longitudinal adaptations cannot be observed unless one follows people over time (Smith et al., 2012; Sedgwick, 2014). To capture this, study designs will need to incorporate fixed-interval follow-ups as well as sensitivity to life-course events (e.g., school transitions, changes in household structure) theorized to impact role distribution (Dabrowska & Pisula, 2010). Longitudinal research is

also important for capturing downstream effects that cannot be observed in a one-time snapshot (Smith et al., 2012; Sedgwick, 2014). For example, reductions in self-blame are associated with improvements in life satisfaction among mothers eighteen months later (Da Paz et al., 2018), suggesting that interventions that target maladaptive cognitions may have benefits over time rather than in the moment; similarly, parents who make sense of their circumstances through acceptance-oriented cultural or religious meanings may experience a sustained decrease in subjective burden for years until environmental stressors, the loss of informal supports, or economic recession erode those cognitive buffers (Hebert & Koulouglioti, 2010).

In the absence of longitudinal depth, those vulnerabilities are invisible until they become apparent. Longitudinal designs can also bring cohort effects to the fore that are tied to shifts in the policy environment. Families who enter the diagnostic system after a major policy expansion often report that the process was easier and timelier compared to families whose early years were spent navigating a more fragmented system; however, when traced longitudinally within cohorts, satisfaction appears to eventually equalize if new cohorts experience service attrition over time. This suggests that for initial gains to be sustained, investment in support services must be ongoing rather than a one-time infusion. To strengthen the methodological integrity of longitudinal research, future longitudinal studies should prioritize the inclusion of diverse participants along all of the dimensions discussed in the previous sections to ensure the adequate representation of fathers, low-SES families outside of the formal service system, rural families who face substantial barriers to accessing care (Tilahun et al., 2016), and ethnically diverse families who are navigating complex dynamics around bicultural stigma (Jegatheesan et al., 2010). The use of stratified sampling frames would enable researchers to test whether longitudinal trends, such as the observed increase in physical labour during adolescence, are universal or intensified under particular structural

conditions. The integration of mixed-methods designs into longitudinal frameworks can facilitate their explanatory power: repeated quantitative measurements (e.g., standardized stress inventories) can be contextualized against unfolding qualitative narratives that illuminate how families reproduce and reconfigure coping strategies over the life course (McStay et al., 2015). This dual tracking can help clarify whether apparent stability on quantitative outcomes obscures a series of adaptations that trade off of one another; for example, an increase in physical labour may be offset by a decrease in emotional labour due to stigma resulting from greater inclusion in their communities. Finally, longitudinal approaches are a necessity for evaluating the long-term efficacy of interventions intended to alleviate dual-domain burdens (Barkli & Doğan, 2025; Da Paz et al., 2018).

Studies that compare cultures

The results reviewed in the previous sections of this review already gave some indication of the themes and contexts in which research has been done. Building on these themes and contexts, there are ample opportunities for further research that uses a cross-cultural comparative design that could confirm, complement and even contradict the findings of research reviewed here. Qualitative single-case studies in non-Western, immigrant or ethnic minority contexts have already been very useful in identifying culture-specific coping strategies, stigmatization experiences and ways of navigating the system of care (Dababnah & Parish, 2013; Hebert Koulouglioti, 2010; Jegatheesan, 2011). However, these single-case studies are often published as stand-alone results rather than being presented alongside other systematically comparable single-case studies in different cultural contexts. In the absence of such systematic comparison, it is still unclear which problems and changes in the caregiving process are universal among parents of children with ASD and which problems and changes are context-dependent in terms of dominant social norms, policies or levels of resource availability.

Cross-cultural comparison offers a way to test the robustness of some of the concepts that were central to this review, such as the interplay between physical and emotional demands, across different interpretative frameworks. For example, research in several Arab countries has shown how attributing the child's disorder to the will of God may decrease feelings of burden despite high objective burden (Hebert Koulouglioti, 2010; Khateeb et al., 2019). In contrast, research among East-Asian mothers has pointed to a higher sensitivity to the judgment of others, resulting in more extensive anticipatory regulation before going out into society (Yamane, 2021). Systematic comparative designs could examine whether these relations still hold when controlling for differences in disease severity, SES and service use. This could help clarify which effects are primarily shaped by cultural interpretations of disability and which effects are primarily the result of a relative lack or surplus of institutional support. Well-prepared multi-country samples could help examine whether relations between stigma and emotional/physical labour are equivalent across different cultural scripts. In collectivistic cultures, people's behaviour in public is often viewed as a representation of their family (Dababnah Parish, 2013). As such, parents may be more likely to invest in the behavioural management of their child in public, than having to use their hands to intervene at all times. In individualistic cultures, where accountability to others is lower and daily interactions with strangers are more common, impression management may require a more rapid reframing of incidents rather than a more sustained avoidance (Tilahun et al., 2016). A cross-case comparison may clarify whether these differential emphases alter the overall amount of labour over time or merely shift the emphasis from one domain to another. Such studies could also be conducted in contexts like Somali immigrant communities, where a lack of knowledge among co-ethnic networks is coupled with a mistrust of mainstream services, resulting in a unique reliance on informal support (Jegatheesan et al., 2010); comparisons could focus on the manifestation of similar processes

in other immigrant groups, caught between two cultural worlds. Another objective could be to clarify how cultural values impact the extent to which the provision of services responds to the needs of carers. In rural, low-income countries, parents have to take on the role of full-time therapist because services are lacking (Khateeb et al., 2019). This situation increases both physical and emotional labour but may go hand-in-hand with cultural values that deem extensive familial care as a norm rather than a problem. In urban, high-income countries with an abundance of formal services but long waiting lists for interventions (Tilahun et al., 2016), feelings of anger about bureaucratic procedures may exacerbate the situation even when objective burden is reduced.

Comparative studies could examine whether equalising service density across different contexts reduces inequalities in subjective burden or whether culturally embedded expectations around the role of parents continue to produce diversity even when service provision levels are equivalent. Another cross-culturally interesting research avenue is language use in the family context. In multilingual families that receive monolingual care recommendations from dominant-language services (Jegatheesan, 2011), parents face a double challenge: they have to maintain the intergenerational transmission of their heritage language for reasons of cultural continuity and they have to implement care in a second language for reasons of adherence to clinical protocol. A comparative study contrasting these patients to controls from monolingual families at equivalent levels of severity could clarify the additional cognitive-emotional burden that is caused by the need for ongoing negotiation around language use on top of the burden of standard care routines. Comparative studies should take into account intra-national cultural diversity that is often masked in aggregated country-level samples. For example, in pluralistic societies, differences between urban, middle-class families and rural, working-class families in terms of mentalizing capacity (Reich et al., 2025) and attitudes towards coping mechanisms (Reich et al., 2025) may be just

as large as the differences observed between countries when these are directly compared. In the same way, distinctions within dominant religious groups in terms of frequency and type of religious service attendance may reveal gradients of acceptance-oriented coping that are associated to religious doctrine around disability (Hebert & Koulouglioti, 2010).

Future research designs should explore multi-site studies within countries to distinguish between “culture” defined as relatively stable values and “context” defined as relatively dynamic service availability and climate of stigma. Comparing cases using these cross-cultural studies will need to address the methodological challenges that are implicit in the limitations of the present analysis including: the relative absence of fathers in most samples (McStay et al., 2015), the lack of consistency in reporting SES to account for the intersectionality of carer and child variables (Marshall et al., 2018) and the heterogeneity in defining the severity to limit the ability to understand the association of symptom burden in other contexts (Gabra et al., 2021). Standardizing sociodemographic variables, accounting for the relative distribution of carer gender, using severity scales that are psychometrically equivalent across languages and using qualitative measures that have been adapted to the context are several strategies that could improve the confidence of results that the cases are different because of differences in samples rather than selection bias or non-equivalent instrumentation.

However, qualitative researchers should maintain some level of epistemological humility to ensure that the requirements of standardization for comparability are balanced with an appreciation for emic concepts that are not in codebooks that are salient to dominant cultural ontologies. Adding a longitudinal component to cross-cultural comparative research can offer insights including: whether the benefits of processes for making meaning, such as religiously accepting are sustained or diminished as a function of long-term exposure with no corresponding change in structural demands across cultures, whether changes in de-

stigmatization practices result in a more direct observable change in emotional labour in one cultural context compared to another or how chronotypes change over time as a result of importing egalitarian care incentives into a cultural context with a more differentiated gender divide (Papadopoulos et al., 2019; Beach et al., 2005). The impact of policy level change on carer division of labour in the household is an ideal policy change for cross-national comparative research given the large discrepancies in carer leave, respite care and inclusion policies across countries (Khateeb et al., 2019). Finally, cross-cultural comparative research should include a discussion of researcher positionality similar to what is included in the methodology section of this synthesis (Neely-Barnes et al., 2011).

Cross-national comparative research may be particularly vulnerable to interpreting differences from the majority world with a deficit perspective when the construct is not from the perspective of the participants regarding what should be measured as the most important indicators of successful adaptation within the context. Using local co-investigators and a carer advisory board may offer a way to mitigate cultural bias that can be left out of interpreting results without considering the experiences of carers in terms of their ability to be successful careers and the value of caring. In sum, cross-cultural comparative studies can offer a meaningful contribution to the current literature by providing more than a few descriptive comparisons of activities of caregiving labour. Rather, a cross-cultural comparative study can offer an explanatory theory for how different cultural meanings of disability and national structural factors are associated with different levels of carer burden. Accounting for the structural context in which carers live and understanding the cultural values of disability can offer more information about which intervention strategies are universally needed and which strategies need to be adapted by country to translate research into policy that takes embodiment in a particular socio-cultural context into account

(Dababnah & Parish, 2013; Hebert & Koulouglioti, 2010; Jegatheesan et al., 2010; Jegatheesan, 2011).

Chapter 5: Conclusion

This is a comprehensive systematic review of the qualitative evidence on the emotional and physical labour of parents caring for children with autism spectrum disorder. It highlights the ongoing and recursive nature of both types of demands, highlighting that caring is not only about discrete acts, but involves emotional labour and chronic physical strain (Grandey, 2000; Vitaliano et al., 2003). The findings indicate that caring is not a static phenomenon, but a process that is shaped by the evolving needs of the child, family dynamics and wider social, cultural and structural contexts. The review lends support and expands theoretical explanations by demonstrating that emotional and physical caring cannot be treated as separate domains (Vitaliano et al., 2003; Hayes & Watson, 2013). It shows how parental strategies of pre-emptive coping and resigned withdrawal operate in complex feedback loops that are influenced by factors such as stigma, resource access and cultural representations of disability. Social support emerges as a key mediating variable, with the quality and appropriateness of support being more important than its quantity. This underscores the importance of carer synchrony in mitigating stress. The synthesis also finds that considerable variation exists within and across different demographic and contextual parameters. For instance, there are differences in division of labour between men and women, in accounts of burden between socioeconomic groups, and in stigma management between cultural groups. These variations suggest that one-size-fits-all approaches are inapt, and that more nuanced, context-sensitive interventions are needed that accommodate differing family systems and belief systems. The time dimension is critical. Longitudinal studies indicate that parents' needs and coping mechanisms evolve with the child's growth and changing family circumstances.

The policy implications arising from these observations advocate for integrated support services that address both emotional and physical caring needs. This includes

improving access to culturally sensitive respite care, facilitating work-from-home options, and promoting integrated, family-centred care pathways to reduce bureaucratic hassles.

Professional training should focus not only on technical skills, but also on cultural awareness and the embodied nature of care work (Beach et al., 2005; Papadopoulos et al., 2019).

Community-based initiatives have the potential to generate supportive environments that combat stigma and offer practical support; however, these initiatives require careful planning to ensure accessibility and relevance. Finally, the review notes methodological limitations in terms of sample representativeness, geographical location and method diversity, underscoring the need for future research to increase the participation of under-represented groups such as fathers, non-traditional carers and families from low resource settings. There is a particular need for longitudinal and cross-cultural studies to enhance the understanding of caring trajectories and intervention options. Overall, the review provides a rich and utilitarian framework for supporting families in managing the persistent challenges of caring for a child with autism. It highlights how emotional resilience and physical sustainability are intertwined in diverse lived experiences.

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