Journal of Nusantara Studies 2024, Vol 9(2) 340-370
Universiti Sultan Zainal Abidin
ISSN 0127-9386 (Online)
http://dx.doi.org/10.24200/jonus.vol9iss2pp340-370

CHALLENGES AND COPING STRATEGIES OF AUTISM PARENTING: A SYSTEMATIC LITERATURE REVIEW OF PARENTS' AUTOETHNOGRAPHIES

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Received: 10.03.2024 Accepted: 30.06.2024

ABSTRACT

Background and Purpose: Parents of autistic children face caregiving challenges, yet there is a dearth of research specifically analysing parents' autoethnographies. This systematic literature review explores themes of challenges and coping strategies in autism caregiving, guided by the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984).

Methodology: Following Kitchenham and Charters' (2007) guidelines, a systematic literature search of autoethnographies by parents of autistic children was conducted using online databases. The search was guided by two questions: (1) What are the challenges faced by parents caring for their autistic children?; and (2) What are the coping strategies employed by parents in caring for their autistic children?

Findings: Twelve autoethnographies were analysed. Themes regarding challenges included parents experiencing fears, feeling despair and facing barriers and stigmatisation. Coping strategies identified included parents seeking answers, having hopes, and gaining empowerment besides providing support. Limitations and future research directions were discussed.

Contributions: This paper emphasises understanding challenges faced by parents of autistic children. It illuminates emotional and societal aspects of autism parenting, emphasising the necessity for tailored support systems. Additionally, it reveals parents' coping strategies, including empowerment and supporting others, indicating increased understanding of their children's autism and active facilitation of support networks.

Keywords: Well-being, Autism parenting, Autoethnography, challenges, coping.

Cite as: Bakar, R. A., Ghani, K. D. A., Aziz, N. I., & Mohamad, N. H. S. (2024). Challenges and coping strategies of autism parenting: A systematic literature review of parents' autoethnographies. *Journal of Nusantara Studies, 9*(2), 340-370. http://dx.doi.org/10.24200/jonus.vol9iss2pp340-370

1.0 INTRODUCTION

Autism Spectrum Disorder (henceforth, autism) impacts a substantial number of children worldwide. According to the World Health Organisation (2023), the global prevalence is 1 in 100 individuals. Autism is a widespread and intricate neurodevelopmental condition; individuals with autism exhibit a spectrum of symptoms and behaviours, including social challenges, communication obstacles, repetitive conduct, sensory sensitivities, and a strong reliance on routines and predictability (Bakar et al., 2022; Hazen et al., 2014). These differences, including unique learning styles and attention spans, present ongoing challenges affecting both the daily lives of autistic individuals and their parents who act as caretakers, especially as they navigate schools where autistic children are twice as likely to face exclusion compared to neurotypical peers, and encounter complexities in accessing healthcare services and additional support, leading to frustration and difficulties for parents (Rutter et al., 2024).

In previous research undertaken regarding autism and parents (Bakar & Bakar, 2019; Moshe et al., 2024), there is evidence that caring for a child with autism can be both challenging and rewarding. This is understandable, as raising a child with autism requires unwavering patience, dedication, and kindness (Penney et al., 2023; Tran, 2020). Although it is challenging, many parents find autism parenting rewarding as it allows them to take pride in their children's progress and growth, experience competence in caring for their children, develop a new outlook on life, and form better connections with others (Marsack-Topolewski et al., 2021).

To this end, the present study seeks to comprehensively examine and categorise the distinct challenges reported in parents' autoethnographies. By analysing autoethnographic accounts, including emotional, practical, and societal obstacles, this study aims to provide a nuanced understanding of the multifaceted difficulties faced by parents in autism caregiving. Secondly, by conducting a systematic literature review of autoethnographies, this study aims to identify a range of coping strategies employed by parents to manage the challenges associated with autism caregiving. By achieving these objectives, this study endeavours to contribute valuable insights into the lived experiences of parents raising autistic children. Understanding the challenges and coping strategies of autism parenting is essential for fostering effective support systems that empower and assist parents in providing optimal care for their children.

2.0 LITERATURE REVIEW

2.1 Challenges and Coping Mechanism in Autism Parenting

As studies conducted over time have documented, it is crucial to acknowledge that parents who raise children with autism confront diverse challenges (Gorlin, 2016; Gray, 2002; Liu & To, 2023; Srivastava et al., 2024). It starts with the early diagnosis and intervention process (Naicker et al., 2023). A significant amount of time and energy must often be devoted by parents in pursuit of a diagnosis for their children, a journey that can be both frustrating and emotionally exhausting, especially when they claim to not receiving enough information and guidance about autism support from professionals (Smith et al., 2023). This journey typically involves numerous appointments with professionals, including healthcare experts, specialists, and therapists. This can significantly impact parents' work routines and their well-being, leading to self-doubt, depression and anxiety, as has been observed by Giolo et al. (2023), who also emphasised the importance of a support system that may include family members and friends. Some parents of autistic children are fortunate to receive this support, while sadly, others encounter prejudice from those who do not fully grasp what autism is and the gravity of challenges in caring for children with autism (Abdullah et al., 2022).

Another challenge which lies in parenting children with autism is financial stress. The extensive costs associated with therapies, educational support, and medical expenses exert significant financial strain on these families who wish they could be supported financially or given more affordable options, yearning for lower fees and increased accessibility to therapy sessions that can better address their autistic children's needs (Jani et al., 2022). Given that financial strain represents a significant source of stress, it becomes crucial for parents of autistic children to acquire the skill of building resilience (Wu et al., 2023).

Although having children with autism can pose challenges, it does have opportunities or positive aspects for parents. One is resilience. Resilience is the ability to recover from challenges while maintaining mental health and well-being; among parents of autistic children, it is found that resilience emerges when they understand autism, learn effective coping strategies, embrace acceptance, and seek support from others (Yaacob et al., 2022). Many parents of autistic children report personal growth and increased resilience as they navigate the challenges associated with autism (Waizbard-Bartov, 2019). Another aspect is that parents have been recognised for providing peer support to other fellow parents of autistic children (Bakar, 2019; Bakar & Bakar, 2019; Lee et al., 2023) due to their ability to empathise and relate to each other's experiences.

2.2 Transactional Theory of Stress and Coping

While many studies have extensively documented the impersonal and second-hand nature of parents' experiences through the lenses of other researchers, such as questionnaires (Giolo et al., 2023; Wu et al., 2023) and interviews (Abdullah et al., 2022; Bakar & Bakar, 2019; Gorlin et al. 2016, Gray, 2002; Liu & To, 2023; Smith et al., 2023; Waizbard-Bartov, 2019; Yaacob et al., 2022), there is a need to revisit this topic of autism parenting through reviewing the lenses of the parents themselves, that is through their autoethnographies. Given there is a current gap and limited understanding of parents' experiences through their lenses and noting the absence of a systematic literature review in relevant literature, it is imperative to explore firsthand autoethnographic stories provided by parents of autistic children to gain insights from their 'insider accounts' (Manning & Adams, 2015, p.350). In this research, autoethnographies are defined as published research articles and published master's or doctoral theses which were written by parents about their autistic parenting. A systematic literature review of parents' autoethnographies was presented to address this gap.

To the best of our knowledge, this is the first systematic literature review that synthesised and evaluated published research studies in the form of autoethnographies, which perpetuated parents' encounters and reflexivity through their writings while caring for their autistic children. Specifically, a systematic examination or review was carried out on the experiences and viewpoints of parents to identify the challenges and coping strategies of autism parenting, as described in their autoethnographies. This form of research could inform relevant stakeholders, such as academics in disciplines that include social volunteers, counsellors, family therapists, and society at large, about the emotional needs and the support that parents need.

The analysis of parents' autoethnographies was guided by the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984). It suggests that individuals continuously evaluate the situations they encounter in their environment. This process of evaluation leads to the experience of emotions. When these situations are perceived as challenging, threatening, or harmful (known as stressors), individuals experience distress, prompting them to employ coping strategies to either manage their emotions or directly address the stressors. These coping efforts result in changes to the person-environment relationship, which are then evaluated as favourable, unfavourable, or unresolved. Favourable resolution of stressors typically leads to positive emotions, while unresolved or unfavourable outcomes result in distress, motivating individuals to consider additional coping options to address the stressors.

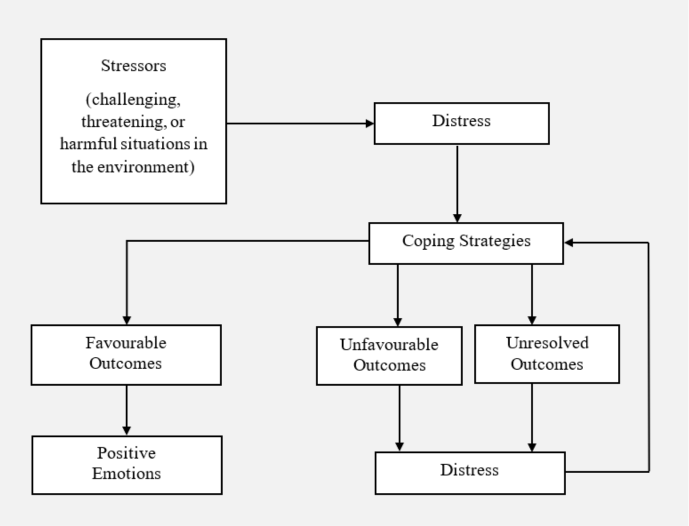

Figure 1: Transactional theory of stress and coping (Lazarus & Folkman, 1984)

This theory elucidates the dynamic interplay between individuals’ interpretations of stressors and subsequent emotional and coping responses. Specifically, this systematic literature review aimed to explain the dynamic interplay between parents' challenges or stressful incidents and their coping strategies. The theory was used with two main objectives: (a) to examine parents’ stressful challenges when navigating autism; and (b) to highlight parents’ coping strategies. This application highlights the theory's relevance in understanding the complex interplay between stressors and coping mechanisms in specific, real-life contexts.

2.3 Rationale for Reviewing Autoethnographies

Manning and Adams (2015) explain that autoethnography is a document in which writers or researchers (in this study, they are parents with autistic children) write about their personal experiences (auto-) to represent (-graphy) their cultural encounters (ethno-). In other words, autoethnography is often used to illuminate a researcher's experience or perspective within a broader cultural context. Bochner and Ellis (2022), eminent advocates of autoethnography, emphasise that this qualitative approach empowers writers cum researchers to share the experiences of living in a chaotic and uncertain world, offering insights for self-understanding and guidance on how to endure challenges, be resilient and move forward.

In this study, autoethnographies of parents with autistic children were reviewed for several reasons. Firstly, autoethnographies provide primary and detailed narratives that offer a wealth of qualitative information not captured in quantitative studies, such as those using questionnaires. Secondly, autoethnographies empower the voices of researchers who are also parents or primary caregivers of autistic children. This approach acknowledges their expertise and allows their perspectives to contribute to a more inclusive and representative body of knowledge on parenting autism. This review may offer an innovative method to represent parents' life experiences, potentially providing a fresh perspective that can intellectually and emotionally captivate readers' attention.

3.0 METHODOLOGY

This study is a systematic literature review of published autoethnographies in the form of journal articles, master's theses and doctoral theses written by parents of autistic children. Hence, formal consent from the ethics board is not required as the present study uses secondary data.

The methodology employed for this research involved conducting a systematic literature review following Kitchenham and Charters' (2007) guidelines. This approach includes a protocol delineating specific phases, such as formulating the research questions, designing a search strategy, establishing inclusion and exclusion criteria, and conducting data abstraction and analysis. The search commenced by identifying autoethnographies through a systematic mapping of previously published works. Quality criterion questions were established to refine the selection of autoethnographies for the systematic literature review, along with inclusion and exclusion criteria. Two research questions were formulated to guide the analysis of the autoethnographies.

3.1 Research Questions

The initial step involved identifying themes relevant to the challenges experienced by parents of autistic children in caring for their children, and the strategies they used to cope with these challenges. Two research questions were identified, and potential schemes for categorising themes were analysed based on existing autoethnographies. The two research questions that guided the present study are as follows: (1) What are the challenges faced by parents of autistic children?; and (2) What are the coping strategies employed by parents of autistic children?

3.2 Search Strategy

In conducting this systematic literature review, a search strategy was used to map previously published literature, specifically focusing on published autoethnographies. The search strategy, which considers important search criteria, is outlined in Table 1.

Table 1: Search strategy

Element	Search Criteria
Database	Web of Science, Scopus, Science Direct, Emerald Insight and Google Scholar
Key searched terms	<autism>, <autism spectrum disorder>, <ASD>, <parent>, <autism>, <parenting>, <experiences>, <challenges>, <opportunities>, <autoethnography>
Types of records	Published journal articles or published master's or doctoral theses written as autoethnographies (including collaborative autoethnographies) by parents addressing autism-related challenges and coping strategies; the records are not book series, books, book chapters or conference proceedings
Language	English
Location	Globally
Duration	January 1990 to October 2023
Other quality criteria	The records are not duplicates; they are parents' autoethnographies addressing topics related to autism rather than other cognitive and developmental challenges; and they are not studies conducted by other researchers about the parent(s).

The search strategy encompassing the search criteria is explained. The databases chosen for the literature search were Web of Science, Scopus, Science Direct, Emerald Insight and Google Scholar. The literature search was conducted by the researchers from September to October 2023. The five databases were considered appropriate and diverse for identifying relevant literature; notably, Scopus is touted as the largest database of abstracts and citations (Kitchenham & Charters, 2007). It is recommended that at least two relevant databases be chosen to ensure a comprehensive exploration of a topic (Green et al., 2006). Secondly, the key terms were used to search for published literature. Relying on previous studies and thesaurus, keywords similar and related to autism, autism spectrum disorder, ASD, parent, autism parenting, experiences, challenges, opportunities, and autoethnography were chosen (see Table 1). Boolean operators were employed with these keywords (Kitchenham & Charters, 2007; Wanden-Berghe & Sanz-Valero, 2012) in all database searches. The searches from all five databases produced 231 records: (a) 3 records from Web of Science; (b) 3 records from Scopus; (c) 9 records from ScienceDirect; (d) 16 records from Emerald Insight; and (e) 200 out of 1780 records from Google Scholar. It is suggested that only the initial 200 records should be included from Google Scholar (Muka et al., 2020; Xiao & Watson, 2019). The searches were stopped when they resulted in fewer and the same records with no new findings (Levy & Ellis, 2006). The initial number of collected records identified from the databases was 231. Thirdly, based on the 231 records that emerged from the search process, the following quality criteria were considered for selecting the records to be included in this systematic literature review. They are as follows:

a) The record is an autoethnography (including collaborative autoethnography) written by parent(s) addressing autism-related challenges and discussing coping strategies while caring for their autistic children; this autoethnography can take the form of a published journal article or a master's or doctoral thesis;
b) The record is not any book series, book, book chapter or conference proceeding, ensuring that the chosen record has undergone a thorough review;
c) The record is written in the English language, which is understood by the authors of the present study, to avoid any confusion or difficulties associated with translation (Mohamed Shaffril et al., 2020);
d) The record is written by parent(s) across the globe, offering diverse cultural perspectives and experiences related to autism caregiving;
e) The record is written between January 1990 and October 2023; taking into account the increasing popularity of autoethnography, especially during the late 20th century and particularly in the 1990s (Ellis et al., 2011);
f) The record is not a duplicate;
g) The record pertains to autism and not other cognitive and developmental challenges; and

h) The record is an autoethnography written by the parent(s) of autistic child(ren), rather than a study conducted by other researchers about the parent(s).

Collectively, records that did not meet the quality criteria outlined above were excluded (n = 213). Those records that met these eligible criteria remained for analysis (n = 18).

3.3 Inclusion and Exclusion Criteria

The criteria for inclusion and exclusion should align with the research questions of the systematic literature review (Kitchenham & Charters, 2007). For this systematic literature review, the selection of autoethnographies was limited to autoethnographies written by parents of autistic children, sharing their experiences of autism caregiving. The review further excluded autoethnographies pertaining to speech therapists and schoolteachers dealing with or teaching autistic children. Finally, 12 records or autoethnographies were left to be analysed in the systematic literature review. Figure 2 illustrates the systematic literature review process for obtaining parent-authored autoethnographies related to autism caregiving, focusing on their challenges and coping strategies.

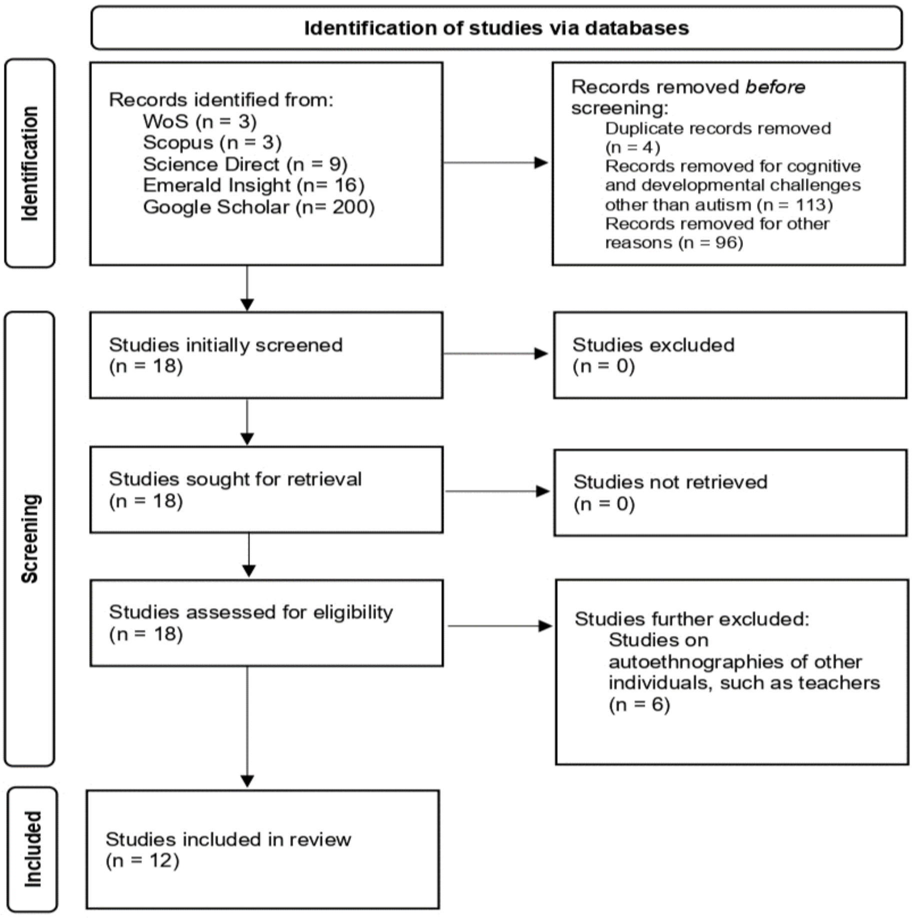

Figure 2: The systematic literature review process

3.4 Data Abstraction and Analysis

The remaining 12 records or autoethnographies underwent comprehensive assessment and analysis, focusing on studies that addressed the formulated research questions. In these autoethnographies, the authors are the parents, providing firsthand perspectives on challenges and coping strategies adopted while caring for their autistic children. Each autoethnography refers to the parent(s) concerned when discussing relevant information. The extracted details from the autoethnographies included authors' names (with parents as authors), publication years, countries of studies, types of publications, sample sizes (with parents as participants), parents' ethnicities, parents' educational backgrounds, and parents' experiences in caring for autistic children. This information is summarised in Table 2. Next, scrutiny involving data extraction through a meticulous review of abstracts and a more detailed examination of the full articles to discern pertinent themes and sub-themes was carried out. The data were systematically entered into an Excel spreadsheet, adhering to the recommendation by Muka et al. (2020). Qualitative analysis methods outlined by Bogdan and Biklen (1992) and Merriam and Tisdell (2015) were employed to identify themes related to parents' challenges and coping strategies in caring for their autistic children. This involved the systematic identification, coding, reduction, and collapsing of common themes based on the regularities and patterns observed in the data.

Subsequently, a focused data reduction process, following Bogdan and Biklen's (1992) guidelines, retained only significant excerpts from all types of data. A collaborative approach was adopted to ensure the accuracy and consistency of the analysis and synthesis of results. All authors meticulously examined and endorsed the identified themes within the established thematic typology. The process of identifying, coding, and reducing themes, followed by their systematic consolidation, laid the groundwork for the subsequent narration of these themes within the results section. This comprehensive methodology allowed for a thorough exploration and interpretation of the data, enhancing the robustness and reliability of the study's findings. The collated information in the form of consolidation of final themes, key themes, sub-themes, and their explanations is succinctly summarised in Appendix 1.

4.0 RESULTS

A total of 12 autoethnographies, which were in the form of published journal articles and published master’s and doctoral theses written by 17 parents, underwent review collectively. The autoethnographies were written by Alcock (2016), Britton (2013), Clasquin-Johnson and Clasquin-Johnson (2018), Dorman (2019), Hall et al. (2022), Hannon (2017), Kavsak (2022), Lowenstein and Jones (2020), McMahon et al. (2020), Mitra (2022), Taylor (2019), and Vlcek (2023). The majority of these parents were from the United States (25%) and Canada (25%), followed by the United Kingdom (16.7%) and Australia (16.7%). A smaller percentage originated from Japan (8.3%) and South Africa (8.3%). They all held either master's degrees, advanced degrees, or doctoral degrees. The parents included in the review represented a diverse array of ethnicities, with 11.8% identifying as African, 5.9% as Asian or of European descent, 5.9% as Black, 5.9% as Mexican American, and 17.6% as White. However, ethnicity data were not provided for some individuals, accounting for 52.9% of the sample.

The review resulted in six key themes and 25 sub-themes related to challenges experienced by parents with autistic children and their coping strategies. Three key themes addressed challenges faced by parents, answering the first research question (i.e. What are the challenges faced by parents caring for their autistic children?): (a) experiencing fears (seven sub-themes), (b) feeling despair (four sub-themes), (c) facing barriers and stigmatisation (three sub-themes). The other three key themes focused on parents' coping strategies, answering the second research question (i.e. What are the coping strategies employed by parents in caring for their autistic children?): (d) searching for answers (four sub-themes), (e) having hopes (four sub-themes), and (f) empowerment and providing support to others (three sub-themes).

Following the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), which posits that individuals evaluate stressful situations and develop coping strategies to manage them, the six identified key themes were intricately interconnected. Through the analysis of parents' autoethnographies, it became evident that they employed coping strategies in response to stressful situations. Indeed, autoethnographies serve as a medium for writer-researchers to share their experiences of navigating a tumultuous and uncertain world, providing insights for self-discovery and guidance on overcoming challenges, fostering resilience, and progressing forward (Ellis et al., 2011). Consequently, the authors decided to consolidate the six key themes into only three distinct main themes by merging themes (a) with (d), (b) with (e), and (c) with (f). This consolidation effectively outlines the stressors and coping strategies within the final three themes. The final three themes are outlined as follows:

1. Experiencing Fears but Simultaneously Searching for Answers;
2. Feeling Despair but Having Hopes; and
3. Facing Barriers and Stigmatisation yet Resulting in Empowerment and Providing Support for Others.

The findings offer an in-depth analysis, presenting a comprehensive understanding of parents' perspectives on the challenges associated with raising autistic children and the coping strategies they undertook. The summary of the consolidation of final themes, key themes, sub-themes and their explanations can be found in Appendix 1.

Table 2: Summary of various aspects of the autoethnographies

No	Author(s)	Country in Which Study is Based on	Publication Type	Sample (N)	Ethnicity	Parent's Educational Background	Parent's Experiences in Caring for the Autistic Child(ren)
1	Alcock (2016)	United Kingdom	Journal article	1	Data not provided.	Data not provided but affiliated to a university.	Facing bureaucracy by disability services.
2	Britton (2013)	Canada	Doctoral thesis	1	Data not provided.	Doctorate.	Appreciating autism, coming to terms with oneself and cultivating qualities such as humility and compassion.
3	Clasquin-Johnson & Clasquin-Johnson (2018)	South Africa	Journal article	2	a. African. b. African.	a. Doctorate. b. Doctorate.	Incurring high costs of diagnosis, existing intervention and support approaches.
4	Dorman (2019)	Japan & USA	Journal article	1	Data not provided.	Data not provided.	Building a community that supports autism through crowdfunding, social networking and volunteers.
5	Hall, Hoxie,	USA	Journal article	3	a. Asian and European descent.	a. Doctoral student.	Prioritising children. Making professional sacrifices.

	Grundon & Cordero (2022)				b. Mexican American.	b. Master’s degree.	Undergoing professional training is an asset in caring for children. Facing biases in professional contexts.
					c. White.	c. Doctorate.	Facing obstacles in maintaining parent-professional roles.
6	Hannon (2017)	USA	Journal article	1	Black.	An advanced degree.	Negotiating with school teachers and staff about his autistic son’s educational plan.
7	Kavsak (2022)	Canada	Master’s thesis	1	Data not provided.	Master’s degree.	The experiences of planning for her autistic children’s literacy skills shape her own learning and mind shift.
8	Lowenstein & Jones (2020)	USA	Journal article	2	a. White.	a. Doctorate.	Experiencing work-life tensions as mothers, teachers and scholars.
					b. White.	b. Doctorate.	Aspiring to become advocates for people and families with disabilities.
9	McMahon, Wiltshire, McGannon & Rayner (2020)	Australia	Journal article	2	Data not provided	Data is not provided but they are affiliated to universities.	Experiencing stigma. Facing lack of provisions for parents and their autistic children in sport and physical activity contexts. Living through discrimination.

10	Mitra (2022)	United Kingdom	Journal article	1	Data not provided	Doctorate	Engaging with professionals leads to traumatized experiences, stress and pressure.
11	Taylor (2019)	Canada	Master's thesis	1	Data not provided.	Master's degree.	Experiencing challenges in accessing autism services.
12	Vlcek (2023)	Australia	Journal article	1	Data not provided	Doctoral student	Experiencing disequilibrium in the multiple roles of being a mother to two autistic children, a doctoral student, a teacher and a research assistant.

4.1 Theme 1: Experiencing Fears but Simultaneously Searching for Answers

While parenting autistic children, parents have undergone experiences filled with fears. Parents often had a continuous stream of questions that either mirrored or led to their fears. Asking ‘why?’ had been part of their parenting journey (Alcock, 2016; Dorman, 2019). The questions of why the autistic child(ren) did not utter words, withdrew, made no eye contact and did not point at objects caused confusion (Dorman, 2019). They grappled with the mystery of why their children’s speech development lagged behind other neurotypical peers, resulting in a delay in their ability to communicate effectively (Alcock, 2016; Hall et al., 2022; Hannon, 2017).

Parents experienced grief which encompassed anger, sadness, shock and confusion. This emotional stress set in as their children started receiving medical diagnoses as they were unable to comprehend what was happening to their children and unsure about the future (Alcock, 2016; Hannon, 2017). They were helpless to notice variations in their children’s behaviours and could not help but ponder the underlying causes of these variations (Alcock, 2016; Hannon, 2017).

The journey through parenthood was further complicated by uncertainty (Alcock, 2016), as parents crossed the challenge of determining the most suitable educational plans (Hannon, 2017; Kavsak, 2023) for their children. Along this path, they encountered a bewildering array of jargon from experts, which left them unnecessarily confused (Alcock, 2016; Britton, 2013) or desperate because of the absence of solid advice from speech professionals (Dorman, 2019).

The prospect of making professional sacrifices to prioritise their children’s well-being was tinged with the ever-present worry of financial instability (Clasquin-Johnson & Clasquin-Johnson, 2018; Hall et al., 2022). The provision of care for autistic children imposed a significant financial burden.

To eliminate fear and seek answers to the uncertainties surrounding autism, parents searched for avenues to access information to enhance their understanding of autism. The internet (Hall et al., 2022) served as a repository of shared experiences and support networks, offering a glimpse into the challenges and coping strategies many other parents employed and shared. Some parents participated in special education programmes to understand effective teaching strategies, the unique language and culture of special education, and the legal frameworks surrounding special education to provide optimal care for their autistic children (Hall et al., 2022).

Some parents read research extensively to better understand aspects of autism caregiving, including dietary considerations and vitamin therapies (Alcock, 2016; Hall et al., 2022). However, not all parents could perceive a direct relevance of research to their situations due to the vast diversity in how autism affects individuals (Hall et al., 2022). Another parent cautioned that there are multiple therapeutic approaches for addressing autism, none of which can universally accommodate every case or align with the lifestyle choices of families (Dorman, 2019).

Parents' own experiences in the field of education offered a personalised perspective in dealing with the challenges they faced (Hall et al., 2022). Parents emphasised the importance of moderating the pursuit of knowledge, avoiding the potential pitfalls of information overload, and allowing room for human connection that underlies the parental journey in caring for autistic children (Alcock, 2016; Dorman, 2019).

4.2 Theme 2: Feeling Despair but Having Hopes

The challenges and emotional turmoil that parents experience while caring for their autistic children are multifaceted. Parents frequently confront intense stress and a sense of loneliness, further compounded by the lack of sufficient extended family support (Hall et al., 2022). Managing challenging behaviours and frequent emotional outbursts of autistic children often landed them in persistent stress, driving them to emotional exhaustion (Hall et al., 2022; Lowenstein & Jones, 2020; Mitra, 2022; Taylor, 2019). The emotional exhaustion went beyond affecting their personal lives within the home. It also substantially impacted their roles as employees at their workplaces. Multitasking has certainly led to burnout and a sense of failure as parents and professionals (Hall et al., 2022; Vlcek, 2023).

For these parents, the quest for balance was complicated by the need to provide specialised attention to their autistic children and excel in their careers; consequently, they would not mind forgoing promotions as they reached a point where they could not take on more responsibilities (Hall et al., 2022; Vlcek, 2023). The perpetual concern about who would support their autistic children when they were no longer able added another layer of apprehension to their emotional burden (Alcock, 2016; Taylor, 2019).

The difficulties mentioned above do not end there. They are further compounded by external factors. It is not uncommon for parents of autistic children to experience frustration when they encounter professionals who may misunderstand or misrepresent the unique needs of their children (Hall et al., 2022), leaving them with a sense that the situation has been twisted (Mitra, 2022) to downplay the severity of the challenges they had been facing.

When considering the economic aspect, it becomes evident that autism is one of the most expensive disabilities to care for (Alcock, 2016; Clasquin-Johnson & Clasquin-Johnson, 2018). The financial burden of providing appropriate care and therapies for autistic individuals can be overwhelming for parents.

However, in the face of obstacles, these parents exhibited resilience backed by supportive networks. Family members and other neurotypical children often emerged as pillars of strength for these parents (Hall et al., 2022; Mitra, 2022). Their support made a difference in mitigating the challenges posed by autism. Likewise, life partners, whether husbands or wives are pivotal in providing emotional and practical support (Hall et al., 2022). A strong and empathetic partnership can significantly alleviate the burden, fostering a sense of unity in facing the unique demands of autism caregiving.

Interestingly, the concept of support extends beyond human relationships. It was found that the presence of a beloved pet offered a source of solace and comfort, providing a unique form of therapeutic companionship (Britton, 2013).

Parents with autistic children also learned the importance of flexibility and adaptability (Hall et al., 2022; Kavsak, 2023). Modifying daily routines and expectations became essential, allowing for a more harmonious environment for autistic children and their families.

Parents often hope to receive counselling or therapeutic assistance to reduce their stress levels (Lowenstein & Jones, 2020; Mitra, 2022). This signifies a proactive approach to self-care and mental well-being, highlighting the importance of addressing the emotional toll of autism caregiving. Ultimately, this journey prompted parents to come to terms with themselves and cultivate humility and compassion (Britton, 2013). They aspire to become better individuals as caregivers and compassionate human beings who embrace the challenges and rewards of caring and providing love for their autistic children.

4.3 Theme 3: Facing Barriers and Stigmatisation yet Resulting in Empowerment and Providing Support for Others

In their autoethnographies, parents openly conceded that they faced discrimination and biases. When seeking advice and guidance about autism, parents felt that they met with professionals who exhibited a lack of understanding and empathy, and did not provide the right advice (Clasquin-Johnson & Clasquin-Johnson, 2018; Hall et al., 2017; Taylor, 2019). Some attributed this to their non-white ethnicity (Clasquin-Johnson & Clasquin-Johnson, 2018; Hall et al., 2022; Hannon, 2017).

Parents also reported feeling excluded and frustrated as they claimed experiencing biased attitudes within professional contexts (Hall et al., 2022; Hannon, 2017). They explained that they often had to hide their parental status in autism research in workplaces as there was a common misperception that parents with autistic children had limited contributions to make and did not possess the same expertise as other academic researchers in the field of education and autism. This discrimination, they deplored, highlighted a systematic bias against parents in professional settings, especially those who had valuable, distinctive perspectives to share. They claimed they were not seen as valuable assets but as burdens, extending a cycle of marginalisation.

Furthermore, parents of autistic children frequently encountered exclusion and resentment in social and educational settings due to the unique challenges their children presented. Bitterness and alienation were apparent when parents grappled with the repercussions of their children's emotional outbursts and dangerous behaviours, such as kicking, grabbing, scratching, or punching (Alcock, 2016; McMahon et al., 2022; Mitra, 2022; Taylor, 2019). They detailed how they were stared at, given disapproval looks and verbal 'tisk', and accused of bad parenting style and troubled familial relationships by parents, teachers, schools and the communities who were not fully aware of the difficulties that these parents battled with every day in trying to cope with their autistic children's tantrums. They were excluded from social gatherings, and required to home-school their autistic children, who were also barred from any class or sports activities until they were 'well-behaved'. They also reflected on how siblings of autistic children were also affected, having to grow up prematurely, behave extremely well, and endure chaotic outings due to societal misconceptions about autism. As these experiences accumulated, these parents faced a bitter reality where their challenges were often met with blame game and exclusion, highlighting the urgent need for greater societal awareness, empathy, and support.

However, these parents believed that empowering themselves through transformational learning was a resolution in caring for their autistic children (Hall et al., 2022; Kavsak, 2023). This process involved equipping parents with the knowledge and tools through which they could learn effective strategies and approaches to better understand and support their children's unique needs. Some went for their master's and doctoral degrees to empower themselves and advocate for their children, besides helping other parents with similar children and situations (Hall et al., 2022). Accordingly, Kavsak (2023) described her experience as an educator, which was marked by a substantial learning curve, prompting her to engage in extensive reading and video research to effectively implement a strategy to support her two autistic sons. This deliberate effort not only broadened her understanding of instructional techniques but also facilitated the exploration of suitable book genres, which were also recommended to special education teachers and fellow parents to be used with other autistic pupils and children.

Another resolution to improving their autistic children's lives was coaching other parents to participate actively in inclusive education (Hall et al., 2022). This type of coaching empowered the parents to advocate for their children, emphasising this role's rewarding and educational aspects. Their coaching philosophy extended to fostering a positive attitude among young teachers regarding emphasising the value of parental involvement. They also stressed the importance of taking a long-term perspective in encouraging young teachers to develop goals that hold enduring social values which could positively impact autistic children throughout their lives.

Parents of autistic children were determined to build a sense of community, share knowledge, and foster empathy within their network and the broader community. They believed that with the community's help, parents could better confront the challenges of caring for their children because emotional support and empathy were present (Dorman, 2019; Hall et al., 2022). This, in turn, could lead to knowledge sharing within the community, contributing to a collective wisdom that informs best practices in autism care, education, and advocacy.

5.0 DISCUSSION

While every effort was made to objectively synthesise parents' experiences in autism parenting into themes of challenges and coping as guided by the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), it is important to acknowledge that these individual voices cannot be readily generalised to the broader society.

Despite these limitations, their stories still have meaning. It is found that there is a dynamic interplay between parents' challenges or stressors and coping strategies. Parents faced emotional turmoil due to worries about their autistic children's developmental traits, speech delays, educational plans, spectrum of autism, and financial strain. This turmoil was intensified by a lack of extended family support, leading to emotional fatigue and isolation. Parents faced hurdles in career progression as they grappled with the dual demands of parenthood and profession. Parents, too, faced discrimination, biases, and a lack of support from professionals and communities, exacerbating feelings of exclusion and desperation. Despite the turmoil, parents exhibited resilience, flexibility, and a desire for mental well-being with spouses' and neurotypical children's support and embracing the challenges and rewards of caring for their autistic children.

The challenges mentioned are not new, as similar ones were reported by Giolo et al. (2023), Lilley (2013), Marsack-Topolewski and Church (2019), Myers et al. (2009), Ng and Ng (2022), and Smith et al. (2023). The coping strategies reviewed are also similar to those reported by Barrett (2022), Kapp and Brown (2011), Waizbard-Bartov (2019), Yaacob et al. (2022), and Zhao and Fu (2022). However, a noteworthy discovery is that these parents, who were also writers cum research respondents, openly discussed discrimination in their autoethnographies without concealing their identities. This suggests that these parents are unafraid of conflict when they expose the unseeming attitudes of others towards them. This is the opposite of the findings of Dobai and Hopkins (2022), who stated that respondents conceal their identities to avoid conflict when they expose other people’s attitudes. It also indicates that these parents dare compromise their reputation when people who are the most open in conveying information still maintain a form of boundary (McLeod & Leshed, 2011). This could imply that their self-disclosure is undertaken to uphold marginalised communities, a similar finding reported by Davidson and Henderson (2010), indicating that individuals with autism disclose their identities to educate others and create a supportive community. Thus, future research could focus on understanding why biases and discrimination persist in certain developed countries, including those from which the parents in this study originate, despite their reputation for fair social systems. Additionally, further exploring the motivations behind parents’ disclosure behaviour would be beneficial.

5.1 Limitations

While this systematic literature review contributes valuable insights, it is essential to acknowledge certain limitations. Firstly, a limitation of this review is that we only used Web of Science, Scopus, ScienceDirect, Emerald Insight and Google Scholar to search for studies, which may have limited the number of potentially eligible studies. Furthermore, the stringent criteria of a systematic literature review may constrain the exploration of the broader scope (Collins & Fauser, 2005; Ferrari, 2015) of autism parenting. Next, although autoethnographies can provide insights into parents' unique lived experiences in caring for their autistic children and contribute to a deeper understanding of certain cultural phenomena and social issues, it is important to note that autoethnographies are inherently subjective. Consequently, interpretations derived from autoethnography can be highly personal and may not easily be generalised to broader populations. In addition, we only examined articles published in English, which may have limited the diversity and inclusivity of perspectives and experiences represented in the review. By excluding non-English publications, valuable insights and findings from studies conducted in other languages and cultural contexts may have overlooked valuable insights and findings from studies conducted in other languages and cultural contexts. This limitation suggests that our findings may not fully capture the breadth of knowledge available, particularly from non-English-speaking regions or communities. Future research should aim to incorporate a more diverse range of literature, including studies published in other languages, to ensure a comprehensive understanding of the topic.

Additionally, a noteworthy limitation pertains to the geographical focus of the articles under review. Given that biases and stigmatisation are reported among parents, particularly those who are not white, it is imperative to address a notable limitation in the geographical focus of the articles under review. The predominant concentration of studies in regions such as the UK, US, Canada, and Australia, with minimal representations from Japan and South Africa, accentuates a significant lack of regional diversity. This limited regional diversity may constrain the findings' generalisability, as parents' experiences from other cultural contexts may not be adequately represented. The paucity of variation in cultural perspectives underscores the need for caution when extrapolating the results to a broader global context. Future research should strive for a more geographically diverse selection of studies to enrich the understanding of parents' experiences across different cultural landscapes.

6.0 CONCLUSION

This systematic literature review has highlighted the importance of understanding the challenges faced by parents with autistic children. Fears, despair, and stigmatisation are significant themes requiring careful consideration. Exploring these experiences sheds light on the emotional and societal aspects of parenting a child with autism, emphasising the need for tailored support systems. In response, parents have adopted coping strategies. Based on the reviews, the authors identified patterns like empowerment and supporting others. This not only implies parents gaining insights into their children’s autism but also actively coaching and forming communities to help other parents. This collaborative approach highlights the potential for mutual support and shared experiences to enhance coping within the community of parents raising children with autism.

The review suggests several recommendations for future studies. First, it is important to delve into the factors that sustain biases and discrimination within certain developed countries, including those of origin for the parents in this study, despite their recognised commitment to fair social systems. Secondly, a more in-depth exploration of the motivations shaping parents’ disclosure behaviour emerges as a valuable area for further investigation.

These research trajectories hold the potential to deepen our insights into the perpetuation of bias and discrimination within ostensibly equitable social structures, as well as unravel the intricate dynamics guiding parents' disclosure practices. On this note, future assessments should be conducted to comprehend various facets of caregiving within diverse cultural contexts, aiming to address issues such as parental challenges in the intervention process and the development of effective support and service packages tailored to diverse cultural needs.

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APPENDIX 1

Consolidation of final themes	Key theme	Sub-theme	Explanation

Experiencing Fears but Simultaneously Searching for Answers	a. Experiencing fears	Having continuous questions when children do not exhibit certain developmental traits	Parents ask 'why?' Why is there loss of words? Why is there withdrawal? Why is there no eye-contact? Why is there no pointing at object?
		Delayed speech development	Parents grapple with autistic children's delayed speech development
		Emotional turmoil	Parents undergo grief, uncertainty, and emotional turmoil as diagnosis on autistic children is carried out
		Educational plans	Parents face challenges in determining suitable educational plans for autistic children
		Lack of guidance	Parents are overwhelmed by expert jargon and a lack of concrete guidance from professionals
		Diversity of Autism	Parents acknowledge the diverse impact of autism on individuals, making research less directly relevant for some cases of their children
		Financial instability	Parents need to prioritise their children's well-being but face complicacy by financial worries and the prospect of making professional sacrifices
	d. Searching for answers	Value of academic programmes	Participation in master's and PhD programmes offers a structured and evidence-based foundation for understanding autism care
		Personalised perspectives	Parents' own experiences in the field of education contribute to their understanding of the challenges they face
		Balancing knowledge acquisition	Parents emphasise the need to moderate the pursuit of knowledge and prioritise human connection in caring for autistic children.

		Multiple therapeutic approaches	Parents recognise the existence of multiple therapeutic approaches, each varying in its applicability to different cases
Feeling Despair but Having Hopes	b. Feeling despair	Profound stress	Parents face profound stress and a sense of loneliness, compounded by a lack of extended family support. Managing challenging behaviours and emotional outbursts of autistic children also leads to emotional exhaustion
		Impact on employment	Parents feel excluded by employers and office-mates in work delegation aspects, leading to challenges in professional advancement
		Juggling roles	Parents struggle to balance their roles as parents and employees, experiencing guilt and failure both as parents and employees
		Concern for children's future	Parents worry about who will support their autistic children when they are no longer able to do so
	e. Having hopes	Resilience and support	Despite obstacles, parents show resilience and are supported by family, life partners, and even pets
		Flexibility and adaptability	Parents learn the importance of being flexible and adaptable to create a harmonious environment
		Mental well-being	Parents express the hope for counselling sessions or therapeutic assistance to reduce stress levels and emphasise the importance of addressing the emotional toll of caregiving
		Personal growth	The journey prompts parents to cultivate qualities such as humility and aspire to become better individuals, embracing the challenges and rewards of caring for their autistic children
	c. Facing barriers and stigmatisation	Discrimination and biases	Parents often encounter professionals lacking understanding and empathy, especially for non-white parents. Biased attitudes in professional contexts perpetuate feelings of exclusion and frustration

Facing Barriers and Stigmatisation yet Resulting in Empowerment and Providing Support for Others		Stigmatisation	Parents face exclusion and resentment in social and educational settings due to their children's challenging behaviours, leading to bitterness and alienation
		Lack of Support	Institutions and communities fail to provide appropriate support and understanding, contributing to isolation and desperation among parents
	f. Empowerment and providing support to others	Empowerment through learning	Parents empower themselves through transformational learning to gain valuable insights into effective strategies and approaches for supporting their children's unique needs
		Coaching and advocacy	Parents become active participants in inclusive education, advocating for their children and fostering a positive attitude among young teachers regarding parental involvement
		Building a community	Parents aim to build a sense of community, share knowledge, and foster empathy within their network and the broader community, contributing to collective wisdom in autism care, education, and advocacy