

A Systematic Literature Review of Qualitative Studies Exploring Parents' Experiences Post-Diagnosis of Autism

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Abstract

The global rise in Autism Spectrum Disorder (ASD), including Malaysia, has significantly impacted parents both mentally and physically. Creating a holistic support system for parents immediately following an ASD diagnosis is crucial, providing them with the necessary tools to navigate challenges, reduce stress, and make informed decisions for their children's future. Hence, this systematic literature review aims to explore parents' post-diagnosis experiences. Guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocol, this study selected articles from two databases namely Scopus and Web of Science. Based on the thematic analysis, three main themes were identified: (1) parents' emotions, (2) support systems and (3) treatments and school. Furthermore, this study aims to offer significant views and understanding of the challenges experienced by the parents. Future research suggestions were discussed to foster a more informed and supportive environment for the parents of the ASD children.

Keywords: Systematic Literature Review, Autism Spectrum Disorder, Parents, Experiences, Children

Introduction

The prevalence of Autism Spectrum Disorder (ASD) has seen a significant global increase from 0.5-0.7 cases per 10,000 people in 1970 to 100 cases per 10,000 people in 2022 (Talantseva et al., 2022; Jinan et al., 2022). Among children, the prevalence of ASD is 1 in every 100 children (Jinan et al., 2022). These trends indicate an expectant rise of ASD prevalence in Malaysia too. In 2016, there is an increase in the prevalence of ASD among children from 1.6 to 1.9 in every 1000 children (Kementerian Kesihatan Malaysia, 2014). According to a recent study, 47,000 children in Malaysia have been diagnosed with ASD, with an average age ranging from 6 to 17 years old (Razuan et al., 2023).

One of the factors that are frequently highlighted relating to the increased of ASD prevalence is the frequent changes of the diagnostic criteria (Zeidan et al., 2022). Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) categorized autism diagnosis from sub-types to spectrum. This reclassification expands the criteria and symptoms of diagnostic (American Psychiatric Association, 2022). However, Talantseva et al (2023) stated

that the evident increased prevalence is because of the public awareness of ASD and wider access to support and services. Obtaining a diagnosis is vital to ensure the child receives appropriate support and interventions. According to Crane et al (2016), children may receive their ASD diagnosis as early as 2 years old. Despite this, many studies reported that children were diagnosed late.

Makino et al (2021) reported that the process of diagnosis involved three phases: (1) pre-diagnosis, during diagnosis and post-diagnosis. These three diagnosis phases have different process and played its own important roles, as well as a deciding factor to the success of the next phase. During pre-diagnosis phase, parents decided when to bring their children to see a professional. During diagnosis phase emphasizes on the parents receiving an official diagnosis from professionals. Lastly, the post-diagnosis phase is vital in deciding the pathway of their children to acquire treatment with different goals and purposes such as behaviour, speech, social and life skills.

The evident increased prevalence of ASD in the past decades pressure relevant stakeholders especially, parents, families, children, and professional in ensuring receiving an accurate diagnosis at the right time (Low et al., 2024; Rogers et al., 2016). There were three aspects that were highlighted in the deliverance of the diagnosis from the professionals' view which were parents and caregivers understand the diagnosis given, delivering information that can be understood by the parents and caregivers and managing parents and caregivers' stress.

However, the parents' experiences and perceptions in receiving diagnosis are also important as they would understand their children and family's needs better. Parents play a critical role throughout the diagnosis process, including post-diagnostic phase. The experience of parents' post-diagnosis refers to their challenges, emotion and decision making after receiving their children's diagnosis (Befi et al., 2023; Beresford et al., 2020). This critical phase involved variety of emotions and feelings, seeking, and receiving support, deciding the intervention and therapy, and adapting in the new life of caring for their autistic child. With appropriate support, knowledge and self-motivation, parents are able to make a good decision to determine the future of their children. Such as the burdens and challenges faced by the professional, parents also experienced similar emotional challenges during the diagnosis period. Thus, it is important to explore and understand parents' experience holistically in the post-diagnostic phase.

Problem Statement

The diagnosis process is often associated with a long and stressful journey for parents (Eggleston et al., 2019). According to the diagnosis model, to obtain an ASD diagnosis requires detailed and in-depth observation and screening by professionals. This process requires thoroughness and possibly prolonged observation to arrive at a conclusive diagnosis. In special cases, some professional require taking more time and several more observations to issue a diagnosis report, as well as seeking opinions from other professionals or colleagues to avoid misdiagnosis and missed diagnosis (Freeman & Paradis, 2023).

The long journey of obtaining a diagnosis can be overwhelming for parents. On average, parents took at least 6 months to 4 years and see more than 4 professionals to get an ASD diagnosis for their children (Bent et al., 2020; Crane et al., 2016). Nevertheless, parents reported a sense of relief and calmed after receiving the diagnosis of their children. They stated that getting an ASD diagnosis further explained their concerns about their children's development (Bent et al., 2020). Parental challenges do not end after getting a confirmed

diagnosis. Post-diagnosis is also an important phase to determine the direction of their children to get specific and best intervention or therapy. Parents voiced their tiredness and lamentation upon realizing that their battle continued into the post-diagnosis phase (Russell & Norwich, 2012). Parents often face uncertainty about the long-term prospects for their children, the most effective interventions and therapies, and the future in terms of educational and social opportunities. This uncertainty can contribute to stress and have a negative impact on parents' mental health (Bent et al., 2020).

Many parents expressed that they do not receive enough support to guide their journey (Jacobs et al., 2020). Furthermore, parents voiced their dissatisfaction with the support given (Eggleston et al., 2019). Lack of proper support can impact family dynamics and even life satisfaction. Additionally, the costs linked with ASD interventions, therapy and special education services can impose a significant financial strain on families (Makino et al., 2021). According to Makino et al (2021) systematic literature review, there were only 25% of past studies examining parents' experiences in the post-diagnosis phase of ASD, and even fewer past studies examining parents' experiences when receiving a diagnosis (Makino et al. 2021). On the other hand, 75% of previous studies examined parents' experiences pre-diagnosis. These findings indicate that there is a lack of studies examining parents' post-diagnosis experiences and contribute to an insufficient understanding of the support parents and their families need.

Government officials and professionals should consider the experiences and views of the parents during the post-diagnosis phase. This consideration can facilitate a smoother journey for parents and enabling the implementation of effective measures to access intervention and therapy for their children. Therefore, this study aims to summarize and synthesize studies about the experiences of parents' post-diagnosis.

Methodology

The present study was guided by PRISMA model based on figure 1. PRISMA or Preferred Reporting Items for Systematic Review and Meta-Analysis is a publication protocol or standard of reporting to aid the research in evaluating quality and accuracy of the literature review (Hayrol et al., 2019). Furthermore, the PRISMA model provides a transparent and systematic approach to synthesizing data, allowing readers to review and appraise the findings appropriately (BMJ, 2021). Referring to the PRISMA model, there are four main phases in selecting articles for the systematic literature review namely identification, screening, eligibility, and included (Hayrol et al., 2019).

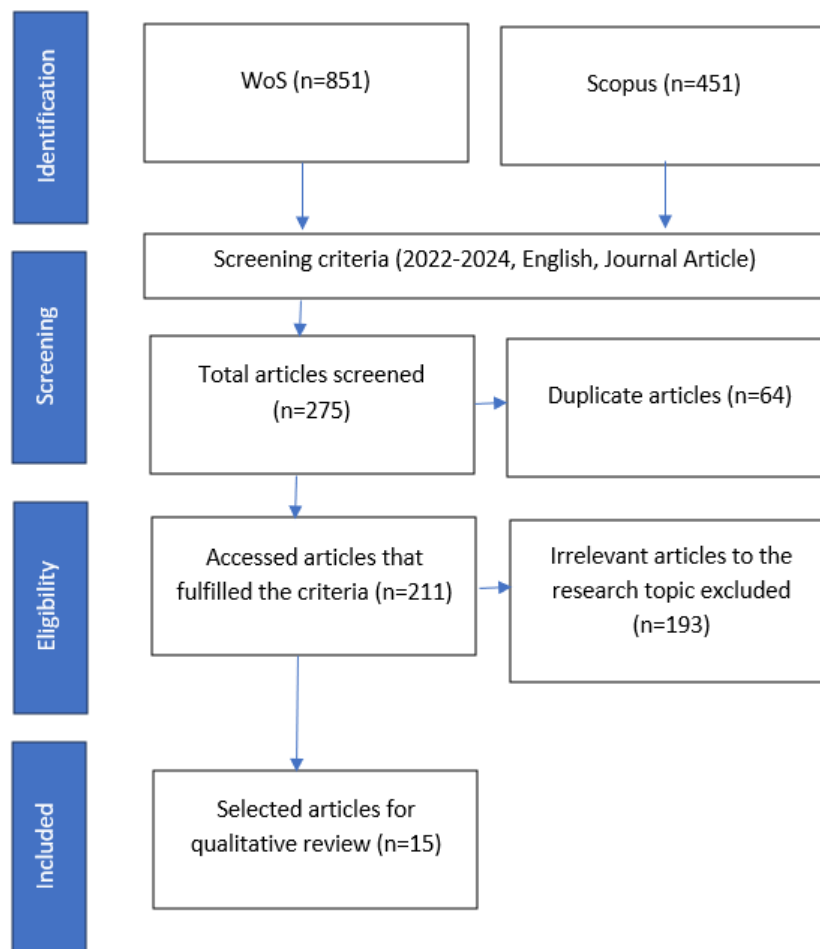


Figure 1 PRSIMA flow chart

Definite Introductory Phase

Identification

Identification process involves the selection of main keywords, a critical step in ensuring only articles relevant to parents' experience post-diagnostic are identified. A full keyword strings were developed using the Boolean Operators to facilitate the searching of studies on two databases, Scopus and Web of Science (Table 1). Four keywords were selected, parent, experience, diagnosis, and autism. To ensure an efficient identification of studies relevant to children with ASD, the Boolean Operator "NOT 'adult'" was added. The two databases that were used offered peer-reviewed publications from globally and comprehensive. Furthermore, the advanced searching functions allowed a systematic finding as it provided publisher list, publication year, journal types, and journal lists options (Bramer et al., 2017; Mengist et al., 2020). The searching process on these two databases was conducted on February 25, 2024 and have resulted of 1339 articles (Figure 1).

Table 1

The search string and findings.

Search String	Database	Search Limitations	Findings
TITLE-ABS-KEY (“diagnosis” AND “parent*” AND “experience*” AND “autism” AND NOT “adult*”)	Scopus	Journal articles 2022-2024	488
TS=(“diagnosis” AND “parent*” AND “experience*” AND “autism” NOT “adult*”)	Web of Science	Journal Articles 2022-2024	851

Screening

This study screened all 1339 articles by choosing the inclusion and exclusion criteria. The inclusion criteria were articles published in journals, English, between 2022 and 2024, and with empirical data. The reason for limiting the search from 2022 and 2040 was to ensure only the most recent articles were included in this review. Furthermore, no inclusion criteria were determined for the countries to offer a global view. This process excluded 1027 articles automatically following the determined inclusion criteria and removed 64 duplicated articles. A total of 211 articles remained to process in the eligibility phase.

Table 2

Criteria set in the filtering phase

Criteria	Qualifications
Type of literature	Journal (Study article)
Language	English
Year of publication	2022-2024
Index	Scopus & WoS
Country	All

Eligibility

The third phase involves authors to manually assess the screened articles, ensuring all the 211 articles fit this study criteria. After reading the title and abstract, authors excluded 198 articles that were not focus on parents’ experience post-diagnosis of ASD. Most of the articles that were removed focused on parents’ experience pre-diagnosis of ASD. Next, three articles using quantitative method were also excluded to ensure a fair of consistent review. Overall, there were only 15 selected articles.

Included

Through the described phases above, a total of 211 articles were identified from both databases and further screened following the inclusion criteria. 15 articles were analysed (Figure 1).

Data Analysis

The present study used a qualitative method, namely thematic analysis. According to Kiger and Varpio (2020), thematic analysis is a powerful and suitable method to analyse abstracted

data set in exploring and understanding experiences. Five steps were adopted in this study (Braun & Clarke, 2006; Kiger & Varpio, 2020). Firstly, all the 15 articles were read thoroughly and repeatedly, paying more attention on the abstract, results and discussions sections. This is to ensure familiarization with the data. Next, initial codes were generated and applied across the data set. Thirdly, themes were actively searched by analysing, combining, and finding relationship between the codes. Patterns and similarities were identified, and themes emerged. Further analysis revealed sub-themes. Then, the themes were reviewed to ensure that each code was placed appropriately and relevant to the results of the review. Lastly, names were given for each theme and sub-themes, producing a total of 3 themes and 7 sub-themes.

Findings

Background of the selected articles

Location of Studies

Analysis of data revealed that out of the 15 articles that were selected, two studies were conducted in these countries, India, Iran, and United Kingdom and one study was conducted in these countries, Australia, Chile, Ireland, Malaysia, Malta, South Africa, Tunisia, Turkey and Venezuela (Table 4). The data showed international interest in regards on the topic.

Table 4

Country by study location

Country	Number	Author
India	2	Ranjan et al. (2023); Malhi et al. (2022)
Iran	2	Hossinpour et al. (2024); Gholipour et al. (2023)
United Kingdom	2	Hasson et al. (2024); Milosevic et al. (2022)
Australia	1	Smith et al. (2023)
Chile	1	Martinez, Davidoff, & Briceño. (2023)
Ireland	1	Twomey (2022)
Malaysia	1	Abdullah et al. (2022)
Malta	1	Camilleri (2022)
South Africa	1	Mnono & Clasquin-Johnson. (2023)
Tunisia	1	Abid et al. (2022)
Turkey	1	Rfat, Koçak, & Uzun (2023)
Venezuela	1	Montiel-Nava et al. (2024)

Year of Publication

Studies were tabled by year of publication (Table 5), showing two articles were published in 2024, six articles published in 2023 and seven articles published in 2022. The figures indicating there is a decrease of publication between year of 2022 and 2023.

Table 5

Number of articles by publication year

Year of Publication	Number	Author
2024	2	Montiel-Nava et al.; Hasson et al.
2023	6	Rfat, Koçak, & Uzun; Smith et al., Mnono & Clasquin-Johnson; Ranjen et al., Martinez, Davidoff, & Briceño.
2022	7	Camilleri, Milosevic et al., Abid et al., Hossinpour et al., Gholipour et la., Abdullah et al., Twomey; Malhi et al.

Study Sample

Most of the studies focused on the parents' experience of children with ASD aged 2-10 Abdullah et al (2022); Abid et al (2022); Nava et al (2023); Malhi et al (2022); Martinez et al (2023); Mnono & Clasquin-Johnson (2023); Ranjen et al (2023); Smith et al (2023) and some studies were children ranging from 2 to 14 years old (Rfat, Koçak, & Uzun, 2023; Gholipour et al., 2023; Camilleri, 2022; Milsevic, et al., 2022). Two studies didn't reveal the full data of the children's age (Hossinpour, et al.a, 2022; Twomey, 2022). Also, experiences of mothers Abdullah et al (2022); Abid et al (2022); Mnono & Clasquin-Johnson (2023); Montiel-Nava et al (2024) and fathers of children with ASD (Camilleri, 2022).

The Themes and the Sub-themes

Three themes emerged from the thematic analysis: (1) emotions and feelings, (2) support system and (3) treatment and education. Further analysis of the themes has resulted in seven sub-themes. These themes are presented in Appendix Table 6.

Emotions and Feelings

Out of the 15 articles selected, 12 studies in this review reported themes relevance to the emotional aspect of the parents' experience in the post-diagnostic phase. The emotions and feelings were divided into three sub-themes namely individual, family and community. There were consistent reports of parents' emotional challenges following their children's diagnosis (Abdullah et al., 2022; Abid et al., 2022; Camilleri, 2022; Malhi et al., 2022; Mnono & Clasquin-Johnson, 2023; Montiel-Nava et al., 2024; Rfat et al., 2023; Smith et al., 2023). Parents described their experience during the post-diagnostic phase as disappointment, sadness, helpless, and grief.

There were also different emotions and feelings experienced by both mothers and fathers. Burden of caring the children were heavier on the mother's side (Hossinpour et al., 2022; Malhi et al., 2022; Rfat et al., 2023). They revealed that fathers generally distanced themselves from them and their children. Besides that, mothers reportedly to observe changes in their working life and career advancement which resulted in disappointment, unlike fathers (Abdullah et al., 2022; Rfat et al., 2023). On the other hand, fathers experienced overwhelming emotions to ensure they are able to provide their children financially, which lead to stress and spending less time with their children and families (Camilleri, 2022).

Emotions and feelings were also attributed to the parents' family including spouse and extended family. The diagnosis affected their marital relationship both positively and negatively. Some studies reported that each partner and spouse found support and strength in each other, resulting to a closer bond as a couple (Camilleri, 2022; Montiel-Nava et al., 2024). However, some studies highlighted that they have been some problems in their marital relationship which led to divorce (Abid et al., 2022; Hossinpour et al., 2022; Malhi et

al., 2022). Besides marital relationship, parents also experienced judgment from their extended families, primarily being blamed for their children's diagnosis and their 'bad parenting' (Camilleri, 2022; Malhi et al., 2022; Mnono & Clasquin-Johnson, 2023; Montiel-Nava et al. 2024; Ranjen et al., 2023)

Stigma and discrimination by the community towards the parents was revealed in this review. Parents often faced judgment and social isolation from the community (Abid et al., 2022; Hossinpour et al., 2022; Malhi et al., 2022; Mnono & Clasquin-Johnson, 2023; Ranjen et al., 2023; Smith et al., 2023). Some studies revealed that the community treatment towards them resulting them to withdraw from the society to avoid potential conflicts and difficulties (Abid et al., 2022; Malhi et al., 2022; Ranjen et al., 2023). Culture and religion also played a vital role in this situation, whereby mothers are expected to conform to the traditional roles and were commonly blamed for their children's diagnosis (Mnono & Clasquin-Johnson, 2023; Smith et al., 2023). Some studies contested that lack of awareness contributed to the stigma and discrimination faced by the parents (Hossinpour et al., 2022; Renjen et al., 2023). Despite these challenges, some parents showed resilient in overcoming their difficulties. Over time, they became acquainted with their children's diagnosis and able to navigate themselves to put their children's needs as their priority (Abid et al., 2022; Camilleri, 2022; Milosevic et al., 2022; Mnono & Clasquin-Johnson, 2023).

Support System

Research focuses on support system was less compared to the other two themes (n=5). Support pathway remained unclear in most studies (Milosevic et al., 2022; Smith et al., 2023; Twomey, 2022). Support systems were described as poorly coordinated in which parents described they were being referred to different places. Some studies revealed there is a myriad level of support following their children's diagnosis, primarily the lack of continuity (Gholipour et al., 2023; Milosevic et al., 2022; Twomey et al., 2022). However, parents consistently reported positive reactions towards informal support, involving parents support groups, non-governmental organisations, and charities (Abdullah et al., 2022; Milosevic et al., 2022; Smith et al., 2023). They found seeking information and guidance from parents with similar situation were more effective and insightful in comparison through formal channels.

Treatment and Education

Following their children's diagnosis, parents constantly seek treatment and school options for their children. Parents' experience towards intervention, therapy, and school for their children were reported in this review (n=12). There are mixed findings regarding parents' view to treatment. Some studies reported that parents perceived interventions and therapies as inadequate in providing appropriate support for their children (Gholipour et al., 2023; Hossinpour et al., 2022; Milosevic et al., 2022). The lack of specialized facilities and service providers were highlighted (Gholipour et al., 2023; Montiel-Nava et al., 2024; Hossinpour et al., 2022). Some studies revealed that parents appreciated professionals who provided treatments for their children, as they offered valuable guidance on managing their children's behaviours (Smith et al., 2023; Twomey, 2022).

Financial burdens were also revealed in many studies, displaying a common challenge faced by parents from different countries in seeking treatments (Abdullah et al., 2022; Abid et al., 2022; Gholipour et al., 2023; Hossinpour et al., 2022; Malhi et al., 2022; Rfat et al., 2023). Interestingly, one of the studies mentioned the lack of efficient insurance in covering their children cost of treatment (Hossinpour et al., 2022). There were only 6 studies reported

parents' experience with school. Overall, this review also indicates the parents' dissatisfaction in the school system (Martinez et al., 2023; Montiel-Nava et al. 2024;). Many parents expressed that the school weren't supportive and there was lack of preparation and resources to accommodate their children's special needs (Milosevic et al., 2022; Montiel-Nava et al. 2024). In Venezuela, special education for autistic children isn't available in comparison to United Kingdom. Parents highlighted that poor communication between the school and them negatively impacted their relationships, which extended to their children's mental health (Hasson, et al., 2024). Three studies revealed that some schools rejected enrolling their children upon learning their diagnosis (Abdullah et al., 2022; Malhi et al., 2022; Martinez et al., 2023).

Discussion

The present study synthesized and summarized the body of research on parents' experiences during the post-diagnosis phase using a systematic literature review. Global interest remains on this research topic, not only focusing on America and Europe, providing view from high-income countries to low-income countries. However, the number of studies published remains low compared to studies focusing on pre-diagnosis stage (Makino et al., 2021). Three main themes were found in this review: emotions and feelings, support system, and treatment and school. Notably, many articles included in this review studied parental emotions after receiving diagnosis, aligned with Makino et al (2021) findings which stated over half of the studies reported parental emotions and reactions towards diagnosis. Parents revealed to experience difficult emotions, consistent with past studies (Makino et al., 2021). However, the current study provided a perspective of the parents' experiences towards parental role. Although parents shared similar emotional experience, they seem to face different challenges in their parental roles. For the past decades, mothers remain the primary parent in charge of children's lives and fathers assume the breadwinner role (Roskam & Mikolajczak, 2020). These gender roles impacted both parents' mental health.

Moreover, mothers reported to have quit their jobs to assume the caregiving role completely, leaving the financial aspects to the fathers. Stay-at-home mother isn't a foreign concept as it is studied across field of research (Johnstone & Lucke, 2021; Odenweller & Rittenour, 2017). According to Johnstone and Lucke (2021), mothers acknowledged that their choices to stay at home were influenced by the socioeconomic factor of their lives and generally satisfied with their choices. However, mothers may themselves returning to work. Future research should consider exploring working and stay-at-home mothers to children with ASD. Moreover, the parents resilient are worth nothing in caring their children with ASD. Despite the challenges, most studies revealed that parents focused on the positive outcomes of the post-diagnostic phase which resulted in the increased family closeness. This indicates that many parents were able to overcome their challenges with support from their close ones. In contrast to the studies reviewed emphasizing on the lack of awareness of ASD within the community, studies have showed that there has been increased of awareness of ASD in the past decades (Gómez-Marí et al., 2022; Talantseva et al., 2023). Despite these findings, parents and their children were continued to be stigmatized and discriminated by the society. Parents revealed cultural and religious factors as contributors to the stigma and discrimination. These two factors have a strong influence on an individual's beliefs, perceptions, understanding and acceptance of someone (Foege, 2019). In this case, society beliefs of parental roles as well child upbringing led an individual to negatively judged the parents of the children with autism. These misconceptions of ASD contribute to frequent

stress and frustration parents faced in social settings and should be addressed. The power of social support from spouse, family, community, and professional should be the centrepiece of the arising emotional challenges faced by parents.

This study also indicates that parents found the formal support system unhelpful, contributed to persistence stress and frustration long after diagnosis. However, parents revealed that the informal support groups to be more informative and insightful. Past studies have showed similar findings that parents engaged with parents of similar situation to find answers (Lee et al., 2023; Milosevic et al., 2021; Truong et al., 2023). The different perceptions towards these support channels should be further studied to address the gap of the unmet challenges faced by parents in formal support system. Researchers should study the informal support that parents seek as it was reported to be helping them. Studies showed that parents' value one-to-one support and speaking to parents with similar challenges were more comforting and helpful (Lee et al., 2023).

Aligned with past studies, the diagnosis of the children remains a significant driving factor for the parents' decision to seek intervention and therapy for their children (de Verdier et al., 2019; Jacobs et al., 2020). However, their challenges continue in finding the best treatment available. It has been highlighted that the lack of quality intervention and therapy centres contributes to the parents' dissatisfaction towards the services. Concerningly, schools have outright rejected children with ASD. Rejection of children's enrolment because of their differences are conflicting with United Nation's call for inclusive education (United Nation, 2006). Respective countries are encouraged to monitor and provide the resources and facilities for children with ASD, ensuring the children are included in every level of education. There is in dire needs of more trained staff and teachers in special education, especially following the increase prevalence of ASD among children.

Suggested future research should consider studying different sample such as single mothers and parents of older children with ASD. Provided the different challenges faced by mothers and fathers, a new insight may be emerged from single mothers as they would need to juggle between caring and providing for their families. Moreover, this review revealed that most studies focused on the parents of younger children. Future research should consider parents of adolescent as older children pose different needs, especially involving their journey to adulthood.

Conclusion

This review aimed to discuss the parents' experience post-diagnostic ASD. Based on the result and discussion above, the three themes proposed gave an overview of the experiences and challenges that parent encountered after receiving their child's diagnosis. Post-diagnostic phase involves different aspects and continue throughout parents and their children's lifetime. The lengthy process impacted the parents' emotions and feelings, their marital relationship and family, and how the community treating them. Moreover, parents revealed that the formal support systems were unable to address their challenges. In fact, the unclear pathway added a burden on their shoulders, which created a sense of distrust towards the government. Searching for suitable treatments and schools were also posed different challenges. Overall, parental emotions during the post-diagnosis phase have been studied in-depth, but there were still lacking in comparison to the pre-diagnosis period. Future researchers should consider exploring different populations and aspects described above to provide a further understanding of the parents' experience and challenges through the long post-diagnosis period.

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Appendix

Table 6

Articles by themes studied

Year	Author	Emotions and Feelings			Support System		Treatment and Education	
		Individual	Family	Community	Formal	Informal	Intervention and Therapy	School
2024	Montiel-Nava et al.	√	√				√	√
2024	Laurence Hasson et al.							√
2023	Frat, Koçak, & Uzun.						√	
2023	Jodie Smith et al.	√		√	√	√	√	
2023	Mnono & Clasquin-Johnson.	√	√	√				
2023	Ranjan et al.		√	√			√	
2023	Martinez, Davidoff, & Briceño.	√	√					√
2023	Gholipour et al.	√						
2022	Camillieri				√	√	√	√
2023	Milosevic et al.	√	√	√			√	
2022	Abid et al.	√	√	√				
2022	Hossinpour et al.				√		√	
2022	Abdullah et al.	√				√	√	√
2022	Twomey				√			
2022	Malhi et al.	√	√	√			√	√