
ARTICLE REVIEW

Environmental Factors Related to Quality of Life of Parents of Children with Autism Spectrum Disorder: A Scoping Review

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ABSTRACT

Introduction	Concerns about the quality of life (QoL) of parents of children with autism spectrum disorder have been raised by previous study. Policy decision-makers and healthcare professionals can be better informed about the environmental factors associated with parental QoL, which will enhance outcomes for both parents and children. The objective of this review is to perform a comprehensive review that assesses the environmental relevant factors associated with quality of life (QoL) of parents of ASD children (under 18 years old).
Methods	To identify the environmental factors associated with parental QoL, a scoping review was conducted using the Arksey and O'Malley original and enhanced framework. Three electronic database (PubMed, Scopus & WOS) and reference list checks were used in the search.
Results	Social support, family support, residential condition, and access to services were all factors linked to the parental quality of life in this group.
Conclusions	The review highlighted environmental factors as one of the variables that have an association with parental QoL. The results of this analysis also highlighted potential areas of support that have implications on future policy and practices.
Keywords	Environmental Factors - Autism Spectrum Disorder - Quality Of Life - Parents - Children.

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INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disorder characterized by persistent impairment in social reciprocal communication and social interaction, and also restricted and repetitive patterns of behavior, interests, or activities.¹ American Psychiatric Association categorized autism into 3 different levels based on symptom severity which are Level 1 (mild), Level 2 (moderate), and Level 3 (severe), whereby each level requires different levels of support that reflect the challenges and strengths possessed by the autistic person. The United States of America observed an increasing prevalence of ASD among 8-year-old children between the years 2000 and 2014, with the prevalence increasing from 6.7 in 1,000 children¹ to 16.8 in 1,000 children.² Prevalence studies on children with ASD within the Asia Pacific region are limited to Japan and China, with an estimated median prevalence value of 11.6 in 10,000.³ Similarly, within the local setting, the lack of an ASD registry limits the knowledge of prevalence.

Previous scholars have reported several comorbidities associated with ASD in children, which include psychiatry and maladaptive disorders.^{4, 5} Other associated co-morbidities include poor eating, epilepsy, and gastrointestinal problems.⁶ The dynamic nature of the difficulties due to their child's developmental issues and various medical concerns faced by caregivers of children with ASD increases the likelihood of a reduction in their quality of life (QoL). Considerations about parental well-being have arisen because of research on the difficulties of raising a child with ASD. To provide a more comprehensive evaluation of parental adaptation, several recent studies have examined parental QoL of children with ASD. Consistently, throughout worldwide studies, they reported significant QoL alteration than parents of typically developing children and children with other disabilities.^{7, 8}

QoL is a complex and multidimensional concept that permits a comprehensive evaluation of positive and negative adaptation across multiple domains of functioning. World Health Organization

(WHO) defines QoL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns”.⁹ QoL measurement has played a critical role in evaluating the quality and outcome of health care and in influencing the allocation of resources by policymakers.¹⁰ Furthermore, assessing parents’ whole QoL could help us to better understand those aspects of life that extend beyond health, such as for example, education, marital relationships, and the social environment.

Research conducted on the quality of life (QoL) of parents of children with ASD has largely shown an adverse picture. The quality of life of parents of children with ASD is lower than that of parents of generally developing children, according to several studies.¹¹ Similar study has examined variables associated with QoL of parents of ASD children, including individual characteristics (demographic, biological, psychological) and contextual characteristics. However, a thorough study of parental QoL and environmental contributing components is lacking in the research. Therefore, identifying environmental factors affecting the quality of life of such parents is one of the important aspects to be included in planning and implementing future interventions.

Therefore, this review aims to examine and analyze studies measuring parental QoL, particularly to highlight environmental-associated factors with QoL. The key question provides focus for this review: What are the environmental factors influencing the QoL of parents of children with ASD?

METHODS

This scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension protocol for scoping reviews (PRISMA-ScR) guidelines.¹² The PRISMA-ScR establishes the fundamental elements to be included in a scoping review. The searching process is shown as in Figure 1.

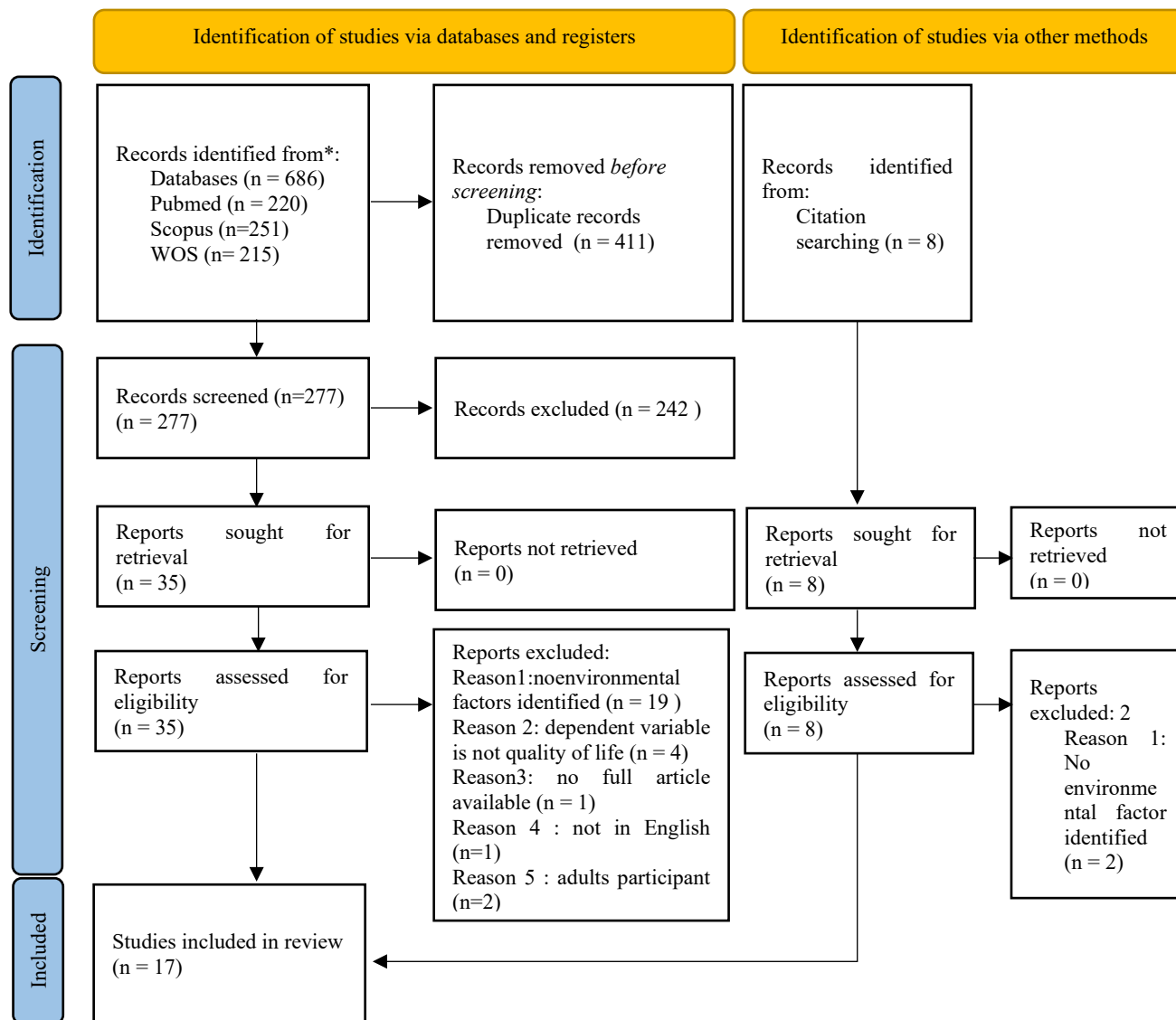


Figure 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

Research Question Formulation

The review question was developed based on the PICO (phenomena of interest, context) concept. The PICO (population, intervention, comparator/s, outcomes) framework has been widely used for evaluating the effectiveness of certain treatments in terms of their impact on outcomes, while the PICO concept is suggested for reviewing or synthesizing expert opinion, text, or policy regarding a certain phenomenon.¹³ Based on the PICO concept, the phenomena of interest refer to environmental factors, while context refers to quality of life among

the caregivers of ASD children. The main research questions are: (1) What are the environmental factors influencing quality of life of parents of children with ASD?

Data Source and Search Strategy

The Scopus, PubMed and Web of Science databases were searched from 1 January 2012 through to 31 December 2022. Table 1 lists the keywords used to search for relevant articles. A combination of index and mesh terms was used according to the requirements of each database.

Table 1 Keywords search used in the screening process

Databases	Search Strings
Scopus	(TITLE-ABS-KEY (caregiver OR carer OR parent OR family OR father OR mother OR caretaker OR "informal carer") AND TITLE-ABS-KEY ("environmental factor" OR "environmental predictor" OR "environmental determinant" OR "social environment" OR "living arrangement" OR "housing factor" OR "family factor" OR factor* OR predictor* OR determinant*) AND TITLE-ABS-KEY ("children with autism spectrum disorder" OR "children with autism" OR "autistic children") AND TITLE-ABS-KEY ("quality of life" OR "well-being" OR "family quality of life" OR "family well-being") AND PUBYEAR > 2011 AND PUBYEAR < 2023
Web of Science	caregiver OR carer OR parent OR family OR father OR mother OR caretaker OR "informal carer" (All Fields) and "environmental factor" OR "environmental predictor" OR "environmental determinant" OR "social environment" OR "living arrangement" OR "housing factor" OR "family factor" OR factor* OR predictor* OR determinant* (All Fields) and "children with autism spectrum disorder" OR "children with autism" OR "autistic children" (All Fields) and "quality of life" OR "well-being" OR "family quality of life" OR "family well-being" (All Fields)
PubMed	(caregiver OR carer OR parent OR family OR father OR mother OR caretaker OR "informal carer") AND ("environmental factor" OR "environmental predictor" OR "environmental determinant" OR "social environment" OR "living arrangement" OR "housing factor" OR "family factor" OR factor OR predictor OR determinant)) AND ("children with autism spectrum disorder" OR "children with autism" OR "autistic children") AND ("quality of life" OR "well-being" OR "family quality of life" OR "family well-being") Filters: from 2012 – 2022

Study Selection

The study inclusion criteria were: (1) studies had to include parents of children with ASD (2) published in 2012 – 2022; (3) original article, case study, and report (4) articles related to environmental factors influencing parents' QoL, and (5) the age of the child had to be below 18 years. The exclusion criteria were: (1) no full article; (2) article in a language other than English; (3) unrelated to QoL among parents (4) review articles. During the article selection, the authors screened the titles and abstracts of all potentially eligible articles. The screened articles were divided randomly among all authors. Two authors reviewed each article independently and interchangeably. Disagreements were resolved through discussion and consensus between the two authors and/or input from a research team leader.

Data Extraction and Synthesis

Data were extracted from the included articles using a standardized data extraction form and organized using Microsoft Excel. The information collected in the form included: (1) author/publication year, (2) references, (3) country, (4) study design, and (5) results/findings. The findings of all included articles were synthesized using a narrative synthesis. Study quality was not appraised due to the nature of the scoping review

Patient and Public Involvement

There was no involvement of patients or the public in either the design, conduct, or reporting of this scoping review.

RESULTS

A total of 686 articles were identified from the literature search of the three electronic databases with inclusion criteria limited to publication year (2012–2022), English language, and publication type (original article, case study, and report). A total of 411 duplicate records were removed, leaving 277 records for title screening (Figure 1). 242 articles were removed during the screening, leaving 35 articles for full-text screening. Disagreements among the researchers were resolved through discussion to reach a consensus. Of the 35 articles, one was excluded due to inability to obtain the full-text article, another one was excluded as it was not in English, nineteen were excluded as they did not examine the environmental factors, four studies excluded due to the dependent variable is not related to QoL, and two articles were not included due to adults with ASD. Eight articles were identified via other methods, which is citation searching. Only six articles were included. The final 17 articles were included in the full-text assessment following the rigorous selection screening, as shown in Figure 1. Table 2 depicts the descriptive summary of the study locations and study designs of the 19 studies. Table 3 summarizes the points on environmental factors influencing the parental QoL of ASD children. Table 4 presents the detailed findings from the 17 studies included in this scoping review. The 17

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studies were from the USA, China, Spain, Turkey, Saudi Arabia, Malaysia, France, and Australia. All

studies were cross-sectional studies published in English.

Table 2 Summary of study locations and study designs

Study location	Authors
Australia	Arora S. et al (14), Willet M et al, ¹⁵ Parson D. et al ¹⁶
China	Feng YS et al, ¹⁷ Ji B et al, ¹⁸ Lei XM et al, ¹⁹ Zeng S et al, ²⁰ Zeng ST et al. ²¹
Malaysia	Asahar S.F et al, ²² Ismail MF et al. ²³
France	Derguy C et al, ²⁴ Baghdadli A et al. ²⁵
Saudi Arabia	Alenazi D et al. ²⁶
Turkiye	Meral BF et al, ²⁷ Mello C et al, ²⁸ Ozgur BG et al. ²⁹
USA	Hsiao YJ et al. ³⁰
Study Design	
Cross sectional (n=17)	Arora S et al, ¹⁴ Willet M et al, ¹⁵ Parson D et al, ¹⁶ Feng YS et al, ¹⁷ Ji B et al, ¹⁸ Lei XM et al, ¹⁹ Zeng S et al, ²⁰ Zeng ST et al, ²¹ Asahar SF et al, ²² Ismail MF et al, ²³ Derguy C et al, ²⁴ Baghdadli A et al, ²⁵ Alenazi D et al, ²⁶ Meral BF et al, ²⁷ Mello C et al, ²⁸ Ozgur BG et al, ²⁹ Hsiao YJ et al. ³⁰

Table 3 Summary on studies based on points related to environmental factors

Environmental Factor	Studies
Social support	Arora S et al, ¹⁴ Feng YS et al, ¹⁷ Hsiao YJ et al, ³⁰ Ji B et al, ¹⁸ Lei XM et al, ¹⁹ Ismail MF et al, ²³ Mello C et al. ²⁸
Family support	Meral BF et al, ²⁷ Zeng S et al, ²⁰ Derguy C et al, ²⁴ Zeng ST et al, ²¹ Ismail MF et al. ²³
Residential condition	Asahar SF et al, ²² Alenazi D et al, ²⁶ Parson D et al. ⁽¹⁶⁾
Access to intervention services/ school/ training session	Ozgur B.G et al, ²⁹ Asahar SF et al, ²² Derguy C et al, ²⁴ Willet M et al, ¹⁵ Baghdadli A et al. ²⁵

Table 4 Summary on environmental related factors from each study

Author	Year	Country	Study Design	Summary on environmental related factors
Arora S et al ¹⁴	2020	Australia	Cross-sectional study design	Social support
Asahar SF et al ²²	2021	Malaysia	Cross-sectional study design	1)Housing type 2) Training session- access to service
Feng YS et al ¹⁷	2022	China	Cross-sectional study design	Social support
Hsiao YJ et al ³⁰	2016	USA	Cross-sectional study design	Social support
Ji B et al ¹⁸	2014	China	Cross-sectional study design	1) Social support 2) Family support
Lei XM et al ¹⁹	2021	China	Cross-sectional study design	Social support
Willet M et al ¹⁵	2018	Australia	Cross-sectional study design	Service access
Zeng ST et al ²¹	2021	China	Cross-sectional study design	Family support
Alenazi D et al ²⁶	2020	Saudi Arabia	Cross-sectional study design	Housing tenure
Derguy C et al ²⁴	2018	France	Cross-sectional study design	1)Family support 2) Service access
Zeng S et al ²⁰	2020	China	Cross-sectional study design	Family support

Ozgur BG et al ²⁹	2018	Turkiye	Cross-sectional study design	School access
Baghdadli A et al ²⁵	2014	France	Cross-sectional study design	Intervention access related to duration of intervention
Parson D et al ¹⁶	2020	Australia	Cross-sectional study design	Living area related to regionality
Ismail MF et al ²³	2021	Malaysia	Cross-sectional study design	Social support
Meral BF et al ²⁷	2013	Turkiye	Cross-sectional study design	Family support
Mello C et al ²⁸	2019	Turkiye	Cross-sectional study design	Social support

DISCUSSION

QoL and Environmental-Related Factors

This theme discusses the environmental factors that participants interact with, which may act as facilitators or barriers to their lives. It includes 'support, relationships and attitude', and 'services'. 'Support and relationships' describe the support provided to participants by their close relatives, friends, peers, professionals, community, and their attitude. The 'Services' subtheme describes the health, social, and other services that are designed to meet the needs of participants.

Seven studies discussed the relationship between the availability of social support, including professional support, and QoL. Social support was discussed in terms of parental engagement in social interaction with others, including friends and neighbors in the community. All studies reported a significant positive association between social support and QoL. Parents who experienced more social support demonstrated higher QoL. In contrast, one study reported the utilization of support was not consistently associated with increased parental QoL.¹⁹

Family support is also correlated with parental QoL in five reviewed studies. Parents received informal support from family members in terms of sharing the caring burden, helping with housework, and providing emotional support. A significant positive association was reported between family support and QoL in all studies. Two out of five studies emphasized emotional support as the most significant predictor of QoL in families to improve their overall positive orientation to life.^{20, 27} Parental QoL seems to be determined by the quality of the family interactive process used in a family through family support, communication, listening, and others.²⁴

Three studies provided separate results regarding housing and residential areas. A significant association was found between the type of house lived by the parents of ASD children with their QoL in parents staying in an apartment/flat reported lower QoL compared to parents staying in a single-storey house.²² In contrast, no significant association was found between housing type and

impaired QoL in one of the studies.²⁶ Another study did compare parents who live in a different geographical area with their QoL; however, found that parents with ASD children residing in a rural area in Western Australia have no association with their QoL as compared to those living in urban areas.¹⁶

Five studies assessed the relationship between QoL and participation or access to intervention, school, or services to meet their need. Parents who attended more training sessions reported higher QoL compared to those who attended training sessions only once.²² Training sessions become intervention for parents to break from their child's behavioural challenge cycle that later may improve their psychological outcome. Two studies reported a significant positive association between access to school and intervention therapy to ASD children with parental QoL.^{24, 29} Parents reported better QoL when their ASD children attend school session and have access to psychoeducational intervention. The more hours of intervention children received, the more likely their parents were to detect a significant or moderate positive impact on their emotional QoL.²⁵

Social Support

The aim of this review was to identify the factors associated with quality of life of parents with ASD children focusing on environmental predictors. Four main areas emerged from the analysis that affect parental QoL from environmental perspectives. These areas were social support, family support, housing-related, and access to school, intervention therapy or training session. Results from this review highlighted the importance of social resources on improving parental QoL. Specifically, higher levels of social support were positively associated with parental QoL in which social support is regarded as a critical protective factor of health outcomes among families of children with ASD.³¹ This review highlighted the value of social relationships and social interactions to parents who continue to face demanding challenges throughout the caregiving process. It is common for families caring for children with ASD to feel unsupported or lack

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understanding from family and friends.³² This was demonstrated in feelings of loneliness and social isolation expressed by many participants when losing the ability to sustain relationships or engage in social activities due to feelings of social stigma from their surroundings. With more subjective support, particularly emotional support from their social circle, parents could express their emotions more effectively and take more effective coping measures, thus improving their QoL. Besides that, the importance of social support was highlighted in reducing negative outcomes such as depression and anxiety.³³ Since it is hard to improve the social support system in a short time, this finding further highlights the need to first identify those at risk of feeling socially isolated and second provide increased access and utilization to appropriate services such as support groups for better satisfaction with QoL.²⁰ Supporting families of children with ASD in improving their social connectivity by seeking different types of social support and resources in order for them to cope with stressful situations has also been targeted by many initiatives recently.³⁴ Collectively, it is clear from the evidence reviewed that there is a need to increase parental access to support in this area and understand barriers and facilitators to access support services. There is also a need to further understand strategies used by parents to cope with social difficulties.

Family support

It is also important to acknowledge that this review highlighted family support as the other area in which parents require support. Family support has a positive association with promoting QoL and helps to buffer the negative psychological effects deriving from raising a child with ASD. Spouses and extended family members were the source of family support for parents.³⁵ Informal support from family members is the common support of choice compared to friends or other's support. Families can help parents to get brief breaks physically, mentally, and financially such as taking care of their autistic child for parents to have a short vacation.³⁶ The importance of considering the relationship within the couple and within other family members (parent-grandparents dyad) to better understand the parental adjustment has been underlined based on study of the family support effect. Previous scholars have highlighted the association between ASD in children and difficulties in interaction and communication within the couple and the extended family.^{37, 38} Parental QoL seems to be determined by the quality of interactive process used in the family communication, listening, understanding, cooperation, support, and problem-solving methods as part of marital relationship aspect. The good quality of interaction implies defining and

acknowledging the role of each family member, equal sharing, and the absence of domination relationship, thus contributing to better QoL. Therefore, if robust family support is available to meet the demands associated with parenting a child with ASD, it may not only alleviate parental stress but may also change their perception of QoL. Parents of children with ASD have emphasized the importance of learning from other parents' experiences. Sharing information and experiences with each other will contribute to opportunities for parental adjustment toward positive outcomes in their daily life. Given that information, more efforts should be made to develop and strengthen family support networks within families for families with children with ASD. The authorities, in collaboration with non-governmental organization (NGO) could expand more support group networks so that parents can connect to each other and to professionals.

Residential condition

This review also highlighted the effects of housing typologies on increasing or alleviating QoL associated with having a child with autism at home that have been investigated from the perspectives of the families. This was demonstrated in a study that found the main caregivers of children with ASD living in an apartment/flat were negatively associated with QoL as compared to those living in a single-storey house. One study demonstrated the negative effect of housing type,²² others have reported no effect on housing tenure when there is a child with ASD⁽²⁶⁾. Professionals acknowledge that houses (attached or detached) are preferable to apartments for meeting the needs of people with autism and their families.³⁹ The comments of surveyed families in phase two confirmed that living in a detached house is the most preferable option, whereas living in an apartment is the least preferred. This finding is consistent with the literature that correlates housing type to the mental and emotional well-being of inhabitants which suggested that residents of single-family detached homes typically have better mental health than those living in multiple dwelling units.⁴⁰ A small size in the apartments or flats are more likely to have lack of privacy for family members and lack of space for family activities and to meet the needs of their children with autism. Besides, the overcrowding of a small space also contributes to increasing sensory stimulus, such as noise and clutter, and therefore, increases autism-related behaviours. These reasons place a high priority on unit size among autism-friendly housing characteristics. The importance of a spacious home environment that can accommodate therapeutic home modifications for both patients and caregivers thus have a detrimental effect on QoL.

Access to intervention services/ school/ training session

This review also showed that despite caregiving challenges faced, many parents found that access to services, including intervention therapy, school, and training session have an impact on their QoL. This is demonstrated by access to those services and is another important factor associated with a good quality of life for the parent. It is important that parents and caregivers have sufficient access to support and services to help manage the challenges of providing care and ultimately maximize their QoL. This includes formal services provided by the organization to address parents' medical and psychological needs. These findings from the review indicated that activity targeting handling stress as well as ASD difficulty symptoms and behaviour might be able to reduce child-related parenting stress, which may, in turn, improve QoL. Access to school and intervention therapy contributes to better functionality of the children and gives parents the ability to set aside time for themselves when the child on therapy. Furthermore, attendance at school increases the likelihood of benefiting from support systems, including education and healthcare services, thus providing positive impact to the child in developing their independence skills.²⁹

Strength and Limitations

Several limitations need to be borne in mind when examining the results of this study. All studies in the review were cross-sectional and therefore inferred an association and not a causal relationship.⁴¹ The presence of convenience samples, the absence of assessment of confounding variables, and the absence of professional verification of ASD diagnosis are likely to have compromised the internal and external validity of the research and influenced the review's conclusions. The concept of quality of life is a further factor. QoL is a complex concept with numerous assessment methodologies and definitions. The examined studies comprised a variety of quality-of-life metrics whose theoretical conceptualizations varied slightly. These issues must be considered when evaluating existing findings, as they make comparisons between studies challenging. However, limiting the search to studies employing the same QoL definition and measurement would have drastically reduced the scope of the evaluation and removed pertinent studies. In addition, because the goal of this review was to explore the QoL of parents of children with ASD, studies that evaluated parents of children with other diagnoses, such as comorbid learning disability, Fragile X, or Down syndrome, were omitted. And finally, certain studies that could have qualified could not be accessed within our institutes. Therefore, we are uncertain of how much the

conclusions of these unreachable studies may have influenced the results.

Despite these limitations, the current review is the first to examine the environmental factors related to quality of life (QoL) of parents of children with ASD and can offer some circumstantial evidence about the connection between ASD and parental QoL. Despite its limitations, this review contributes to understanding that this population may have poor quality of life by highlighting some of the environmental elements discovered in the body of literature that may enhance or impair parental quality of life. Future research should aim to assess whether parental interventions targeting these factors result in improved QoL outcomes.

CONCLUSION

The main findings emerged from this review highlighted the environmental variables that influence parental QoL within this group. Findings from this review may inform the development of future interventions and influence healthcare, policy and funding decisions related to environmental associated factor.

Ethical approval

Institutional review board (IRB) approval was not applicable for this scoping review.

Author contribution

Amy Azira Hamis contributed to conceptualization, methodology, analysis, interpretation, drafting, reviewing, and editing the manuscript. Roszita Ibrahim contributed to conceptualization, supervising, reviewing and critically revised the manuscript, gave final approval, and agrees to be accountable for all aspects of work ensuring integrity and accuracy. Mohd Hasni Ja'afar contributed to reviewing and gave final approval.

Conflict of interest

The author declares no conflict of interest.

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