Stigma among Parents of Children with Autism: An Integrative Review

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Abstract: The number of children diagnosed with autism is increasing around the world. The role of parents is vital in caring for children with autism, but stigma is a challenging and prevalent aspect that families face in raising and caring for them. This integrative review, undertaken by nurse researchers in 2022, synthesized the existing knowledge of current studies about stigma status and the factors relating to stigma among parents of children with an autism spectrum disorder. The electronic databases searched included PubMed, CINAHL (EBSCO), EMBASE, and Scopus, using the keywords "stigmatization," "parents," and "autism."

Thirty-six studies without time limits were included in this review, 16 qualitative, 15 quantitative, four mixed-method, and one interventional study. The results indicated that stigma was common among parents of children with autism in all studies. However, there was a difference related to cultural stigma among parents with autism in Western, Asian, and Middle Eastern countries. Both modifiable and unmodifiable factors were associated with the stigma, for example, parents' age, marital status, child's behavior, and social support. Further longitudinal studies on stigma should be conducted in low-resource areas with different caregivers in large sample sizes to identify the prevalence of stigma and stigma changes among parents of children with autism. This review's results provide evidence for further intervention studies that address factors related to reducing stigma among parents of children with autism. Moreover, healthcare professionals, including nurses working with these families, should assess the level of stigma among these parents to provide timely support.

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that lasts a lifetime caused by differences in the brain.[1] Children with ASD illustrate difficulties in language and communication, socialization, restricted interests, and repetitive behaviors.[1] In recent years, the rate of children with ASD has increased significantly, but this may be partly due to improved diagnostic methods. In 2000, the rate of children with ASD in the United States was 1 in 150 children. By 2014, this number had increased to 1 out of 59 children.[2] According to the most recent

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survey in the US in 2016, the prevalence rate was 1.85%, meaning that 1 in 54 children has ASD, and the rate of boys is 4.3 times higher than girls.[3] In Vietnam, several studies show that the prevalence of ASD ranges from 0.4 to 0.7%, the rate in male children is higher than in female children, and children in urban areas are more affected than in rural areas.[4]

Parents play an essential and irreplaceable role in directly educating their children. For children with autism, parents are usually the first people who notice unusual behaviors in their children. The main point in treatment is that there is an unknown cure for ASD. Therefore, early intervention is crucial for children with ASD.[1] Early intervention depends on whether parents perceive stigma or not.[5] Parents also play a critical role in helping children integrate into the community.[6] However, meeting the healthcare needs of children requires parents to spend a lot of time, effort, and patience. In addition, many parents face financial problems, high services costs, or lose their jobs or quit because they spend a lot of time intervening with their children. Therefore, the parents of these children often experience much stress in life.[5,7] An important factor affecting stress and difficulties for these parents is the stigma against their children and themselves.[8]

According to Goffman, stigma is the adverse effects of negative attitudes and behaviors from the public on discredited individuals.[9] Groups experience stigma in various ways, including labeling, prejudice, alienation, emotional reactions, dislocation, and discrimination, often from the community because of abnormal behaviors or communication with other people.[7,10] Stigma affects not only children but also their parents. Previous studies have shown that experiencing social stigma is common among parents of children with ASD.[11,12] Stigma is a key risk factor for mental health issues.[13,14] Stigma also reduces the quality of life,[15,16] increases the healthcare burden[16] and reduces the intention to seek medical support or intervention for children.[5] As a result, children with ASD are delayed or not receiving early interventions, which leads to consequences for the child and family.[5]

There are various factors related to stigma. The child's factors include age,[17] sex,[18] the severity of autism, and behavioral problems.[5,8,11,12,18,19] Factors related to stigma against parents can be age,[12] sex,[18,20] ethnicity,[12] education level, income,[21] caregivers,[22] number of children with autism,[5,17] lack of knowledge about strategies to deal with stigma,[10] social support,[22,23] marital status,[24] number of hours for sleep,[25] social awareness of autism,[26] self-responsibility, self-blame,[27,28] and perceived benefits of raising children with disabilities.[29] Some factors are modifiable to reduce stigma for parents, such as knowledge of strategies to deal with stigma, social support, and social awareness about autism.

From the literature, some existing reviews have been found related to this topic. For example, a literature review on stigma[30] reported that stigma was experienced and perceived by parents of children with autism. However, this review focused on behaviors of autism and the severity of symptoms as a factor affecting stigma without synthesizing the other factors. In addition, this review described stigma experiences across social-cultural settings without a clear comparison of stigma between different cultures. An existing integrative review on the experiences of families of children with autism[31] emphasized experiences that lead to an increase in the level of stress and anxiety in the family without focusing on stigma among parents of children with autism. A knowledge gap was therefore identified to support a review of the topic.

Study Aim

This integrative review was undertaken to synthesize stigma status and related factors. The results will provide information that assists nurses in delivering holistic care for families of children with autism and identifying stigma-related factors for further prevention through intervention programs.

Method

Design: This integrative review followed Whittemore and Knafl's methodology,[32] and used the PRISMA guidelines to write this report.[33]

Data Collection and Analysis: The researchers conducted five steps in the methodology: problem identification, literature search, data evaluation, data analysis, and results interpretation.[32]

Problem identification: Three nurse researchers were the reviewers in this study and set up the research questions: "What is the stigma status among parents of children with autism?" and "What are the factors related to stigma among parents of children with autism?"

The literature search: In this step, a research librarian completed comprehensive, systematic investigations of the following databases: PubMed, CINAHL (EBSCO), EMBASE, and Scopus. Keywords used were "stigma," "parents," "children," and "autism." Each database used a language filter to locate studies written in English or Vietnamese. The search process was undertaken between December 2021 and January 2022. The inclusion criteria were parents of children with autism related to the issue of stigma without any limitation on publishing date and study methodology. Review articles, doctoral dissertations, master's theses, editorials, and commentaries were excluded.

After removing duplicates, all articles were assessed by two reviewers. Each reviewer screened the title and abstract independently. Full-text papers that passed the title and abstract stage were continuously screened separately by these two nurse researchers. Discord in the initial assessment was reviewed by the third nurse researcher and resolved through collaborative discussions among the three via email and video conference.

Data evaluation: The risk of bias in the selected studies was assessed using the Joanna Briggs Institute (JBI) Critical Appraisal Tools.[34,35,36] The JBI checklists for qualitative, cross-sectional, descriptive, and intervention research (randomized control trials) were used to evaluate qualitative, quantitative, and interventional studies. These checklists included questions about the selective report and the overall risk of bias, for example, "What is reported to have happened in the study?" Then, the response options were provided to assign a judgment related to the risk of bias to each item. The response was a "Yes," "No," "Unclear," or "Not applicable" statement indicating a low risk, a high risk of bias or some concern depending on the question content. The three reviewers performed this step, where articles were rigorously evaluated for quality based on the JBI tools.[34,35] The first reviewer completed the assessment, and the second confirmed it. Both reviewers assessed each study independently. The results were discussed among team members, and disagreements were resolved through consensus. At least two reviewers agreed on the final decision of quality appraisal for each study. Each "yes" response achieved by the study corresponds to 1 point; the higher the total score of the criteria, the better the research quality. Before the critical appraisal, the reviewers agreed that out of the total score, if a study got at least 50%, this was considered a good quality study. If the study got all "yes" responses was considered an excellent quality study. An article having less than 50% "yes" answers to the criteria was excluded from the review.

Data analysis: Using Microsoft Excel, two reviewers independently extracted data from articles, including the first author's name, year of publication, location, study design, participant, sample size, sampling methods, stigma definition, stigma types, measurement of stigma, main finding, recommendation or limitation of included studies as well as the quality of studies.

Data were synthesized using a categorization system based on the research questions.[32] The categories were discussed through multiple rounds to reach a final agreement. In addition, each category had subcategories based on quality assessment supported by evidence to ensure scientific validity. The subcategories endorsed the description of categories in detail and identified similarities and differences between researchers.

Thematic analysis was carried out to identify critical and recurrent themes of the qualitative findings. The text findings in all included studies were coded, and then themes were developed by the first reviewer. Two reviewers then discussed these themes to achieve consensus on the data interpretation. For quantitative designs, the variety of settings, study designs, and measurements made it inappropriate to use meta-analysis. Therefore, narrative synthesis was used to analyze the data, including synthesis by stigma concepts, type of stigma, measurement of stigma and evidence grouped by social and cultural context.[37]

Results interpretation: The results were described under four primary categories: literature characteristics; stigma status; related factors; and quality of studies.

Results

Characteristics of included studies

Initial searches captured 379 records across all databases, and an additional 52 articles were sourced by searching through reference lists. Duplicated references were removed, and 161 citations remained for screening. Rayyan, a cloud-based web screening tool, was used.[38] A total of 56 papers were selected for full-text assessment. After this stage, 20 articles were excluded because they included various mental health issues. Figure 1 shows the PRISMA Flow Diagram of the search, screening, and selection process.[33]

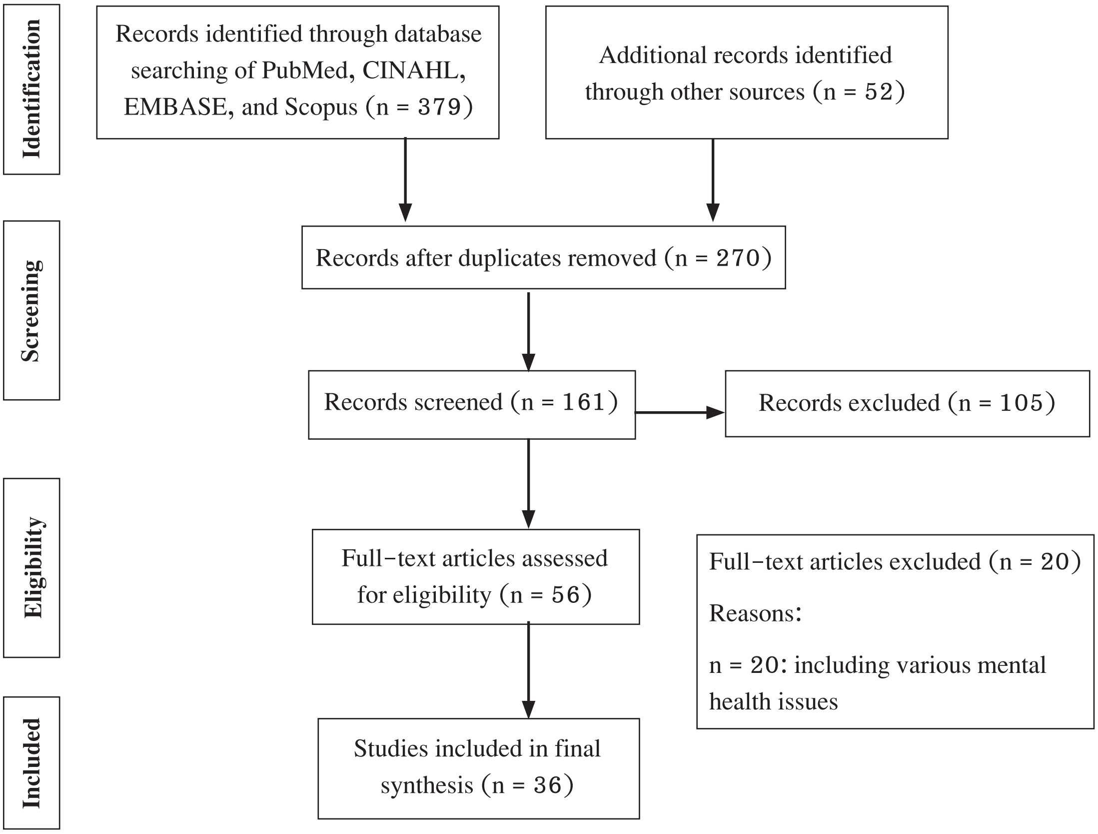

Figure 1. PRISMA Flow Diagram

Finally, 36 studies meeting the inclusion criteria were included, and there were 16 qualitative studies, 15 quantitative studies, four mixed method studies and one intervention study. All articles were published in English. These studies were from various regions of the world: Australia (n = 5), UK (n = 4), USA (n = 5), Ireland (n = 2), Egypt (n = 1); Serbian (n = 1), China (n = 7), India (n = 1), Iran (n = 1) and Israel (n = 4), Nigeria (n = 1), Pakistan (n = 1), Ethiopia (n = 1), Saudi Arabia (n = 1) and Vietnam (n = 1). Most studies included parents of children with ASD, except five focused on mothers only.[24,26,39-41] The results are presented in **Appendix Table 1.**

Quality of included studies

All qualitative studies demonstrated appropriateness between research methods and questions/objectives, data collection method, analysis, presentation of results, and interpretation of results. However, only eight studies presented the concordance between theory and research methods.[20,24,26,29,39,42-44] Six out of 16 studies did not provide information regarding ethics panel approval.[20,24,26,42,43,45] All qualitative studies were of good quality, of which four were excellent.[19,26,39,44] Regarding the quality of quantitative studies, all demonstrated the following criteria: Risk factors and outcomes were ensured its validity and reliability with appropriate statistical analysis methods. However, only six studies solved the problem of identifying confounding factors and providing ways to deal with these.[8,12,13,22,25,46] The quantitative studies were generally good quality, especially the three studies that achieved maximum scores.[13,22,46] Four studies using mixed methods were evaluated using eight criteria for quantitative research and ten for qualitative research. Moreover, one randomized controlled trial (RCT) was assessed well in most criteria, except for two: the people delivering treatment and the data collectors were not blinded to the study. The detailed scores for each criterion are shown in **Appendix Table 2.**

Stigma status among parents of children with ASD

Stigma is a complex concept that has been defined differently in previous studies.[9] However, Goffman's stigma model has been used as the primary theoretical foundation for analyzing the stigma among parents with ASD children and as the most basic definition in studies[8,10,12,20,21,42] However, we found no clear definition of stigma among parents with ASD children in the studies reviewed. There were different terms for this type of stigma, such as affiliate stigma/courtesy stigma/associative stigma/family stigma. Findings in this integrative review showed 12 studies with clear definitions of affiliate stigma.[8,10,14,16,18,21,25,28,40,43,47,48] In comparison, others used the term courtesy stigma[14,15,20,24,49] and only two studies defined affiliate stigma and courtesy stigma as the same.[18,23] In general, affiliate stigma/courtesy stigma is defined as the experiences of social stigma due to the association with a person who is stigmatized.[8,13,18,23,25]

There were different types of stigma categorization among parents of ASD children in reviewed articles. However, stigma among parents with ASD children can be split into three main types. The first type of stigma was perceived stigma (other terms as public stigma/social stigma/perceived ASD stigma/perceived public stigma/perceived stigma/felt stigma/ perceived courtesy stigma/perceived family stigma, affiliate stigma/courtesy stigma/associative stigma/family stigma), which was defined as the parent's feelings when they interacted with society and was the result of parents' inference or understanding of a particular behavior or attitude towards them.[11,20-22,43,50] A substantial proportion (83.5%) reported perceived stigma in the study of Oduyemi et al.[21], while other studies showed that the prevalence of perceived stigma ranged from 16% to 59.3%.[11,12,17] The second type was self-stigma/affiliate stigma, defined as parents internalizing stereotypes and prejudices into their thoughts and using thoughts against themselves. During this internalization process, parents believed in the stereotypes (or stigmas) that society intended for them[13,28,47,48] and felt a lack of confidence in their self-abilities and worth.[50] Several studies revealed that self-stigma accounted for 33.7% and 34.5%.[12,18] Finally, enacted stigma was defined as negative experiences such as discrimination by people in society against parents with ASD children.[11,20-22,43] About half of the parents in the study of Gray[20] experienced adverse treatment from others, and more than half of parents (53%) in Nigeria were discriminated against by society in the study of Oduyemi et al.[21]

Various instruments had been developed in previous studies to measure stigma status among parents of children with autism.[5,13-18,21,22,25,27,28,40,46-48] Among 36 studies, most used a modified scale to assess stigma without validation in the context of cultural aspects. Twelve studies used the Affiliate Stigma Scale (ASS) developed by Mak and Cheung[51] in 2008.[13-15,17,18,25,27,28,40,46-48] This scale consists of 22 questions using a Likert scale from (1) strongly disagree to (4) strongly agree and is divided into three parts (affective, cognitive and behavior). A higher mean score indicates a higher degree of affiliate stigma/self-stigma.[51] Other instruments used in the reviewed studies included the Devaluation of Consumer Families Scale (DCFS) to measure courtesy stigma;[14,15,27] the Parental Perceptions of Public Attitudes Scale (PPPAS) to measure parents' perceptions of public attitudes;[17] the Self-stigmatizing Thinking's Automaticity and Repetition Scale (STARS) to measure the self-stigma process[16]; the Perceived Caregiver Stigma Scale (PCS) to assess perceived caregiver stigma[22]; and other scales developed by researchers.[5,11,12,21] In addition, the qualitative studies regarding parents' experiences of raising and nurturing a child with autism reported stigmas such as blame, shame, exclusion, and discrimination.

There were cultural differences relating to cultural stigma among parents of children with ASD in Western, Asian, and Middle Eastern countries. In Western cultures, 15 studies[5,8,10,12,15,17,20,22,24,25,29,42,43,52,53] reported that parents experienced common aspects of the stigma of "felt blamed" or "judged" for parental competence, or as bad parents because of their children's behavioral problems,[52] shame because their children with ASD had a normal appearance but inappropriate behavior problems,[40] social isolation,[20,42] discrimination in various social settings, especially schools and public systems like parking spaces for people with disabilities[24] or shopping centers.[53] In addition to similar studies from Eastern cultures, there existed different beliefs about children with autism and their families relating to the traditional religions of countries such as Vietnam, China, India, and Latin. Autism was considered by Vietnamese society and culture as a "disease" or a family problem caused by "karma" or bad behavior in the past instead of a neurodevelopmental disorder.[44] Some studies mentioned that parents hid the disability problems in their own homes from other family members.[54] Additionally, discrimination occurred significantly in social environments, especially schools. This stigma surfaced as difficulties in enrolling children[44] or bad attitudes of schoolteachers towards children's integration.[54] Two studies in China also described a high degree of self-stigma among parents of children with ASD.[13,27] In Middle Eastern cultures, three out of nine studies described parents' beliefs that having a child with ASD was God's will, a blessing and a gift. They had a strong religious belief in God and hope for their children, which helped them accept their child's disability.[39,41,49] However, social isolation and stigma persisted among parents of children with ASD in these Middle Eastern societies. Similar to Western and Eastern cultures, some aspects of stigma emerged in studies as "felt blamed,"[49] "embarrassed,"[21,41,49] "isolated,"[21,23,39,41,49] and "discriminated against."[38,41,47,49] Mothers in a Bedouin community reported exclusion in all aspects of life, including the right to know their child's problems and the right to make decisions.[39] In addition, many mothers also shared that they sacrificed their personal lives to care for their children, felt completely isolated from family and society,[39] and hid their child's status from others[49] even from family members, except their husband.[39] These mothers also felt discriminated against by the community in various settings such as restaurants and bus stations.[49] More details of stigma status are shown in Table 1.

Factors associated with stigma among parents with ASD children

From the literature review, many factors relating to children's stigma variables were non-modifiable factors such as age,[42] genders,[18] the severity of autism, symptoms of autism,[18,20,42] modifiable factors such as behavior problems[5,8,11,12,18-20,26,39,40,43] and child's health insurance.[5] Additionally, children with ASD at different ages had diverse characteristics and difficulties, which might change the stigma level among their parents.[42] Regarding non-modifiable factors, parents of a girl with autism reported higher stigma than parents of a boy with autism.[18] In addition, the parents of children whose challenging behaviors were more likely to experience enacted stigma.[18,20,42] About modifiable factors, the more severe challenging behaviors children had, the more likely their parents got a higher stigma score.[5,8,11,12,18-20,26,39,40,43] Regarding child health insurance, parents with public health insurance experienced more stigma than parents with private health insurance.[5]

Regarding parent variables, non-modifiable factors consist of parents' demographics such as the number of children with ASD,[5] genders of parents,[18,20] education level, income,[21] places of residence,[5,13] marital status,[24,25] family structure, family function[5] and modifiable factors, such as sleeping time,[25] community awareness related to ASD,[23,26] positive perceptions about raising children with autism,[10,29] social support,[22,23,27] perceived responsibility,[27] perceived controllability,[27] self-blame,[27,28] proneness to shame,[13] compassion,[48] and participation in family and community activities[46] also were found to be correlated with stigma. The non-modifiable factors such as the number of children with ASD, mothers, low education level, low income, rural area, single mothers, and low family adaptability are related to higher stigma scores. About parents' modifiable factors, less time for sleeping, lack of awareness associated with ASD, lack of social support, perceived responsibility, self-blame, and proneness to shame was associated with higher stigma score. In addition, perceived responsibility was negatively correlated with stigma.[27] Moreover, the engagement of children in two particular activities: children's hygiene and physical activities in the community, correlated significantly with the parents' affiliate stigma.[46]

Discussion

This study examined stigma status and factors among parents of children with ASD based on findings in the available databases. The JBIs criteria assessment,[34,35,36] was suitable to ensure the quality of review articles because of the criteria's published validity, reliability and usability. Accordingly, the articles included in this review were high quality in the appropriateness between research methods and research questions/objectives, data collection method, analysis, presentation of results, and interpretation of results.

Studies synthesized in the literature review were conducted in different countries, resulting in various stigma concepts. Most studies came from Western cultures, and only three were sampled across two countries, but this review did not compare culture-related stigma. Therefore, conducting studies in low-resource areas and comparing stigma among various cultural settings is necessary. Regarding the study participants, there was skewed gender distribution across samples of parents, except for five studies focusing on mothers only. The health-related stigma was commonly considered to be differed by gender, especially the experience of social stigma relating to the perception of caring roles of men and women.[30,55] This is consistent with previous reviews indicating that mothers accounted for most of the sample size.[30] To comprehensively understand the stigma on parents of children with ASD, different approaches should be carried out to collect data on stigma in different genders of caregivers.

Even though findings indicated common types of stigma, including self-stigma/affiliate stigma, enacted stigma, and perceived stigma, the definition and the categorization of stigma were still vague and varied in different settings due to socio-cultural factors among reviewed articles. Stigma among parents of children with ASD is similar to stigma in other health situations. The definition may vary and differ from culture to culture and is permanently embedded in social structures of class, command, gender, and ethnicity.[56] This aligns with previous reviews indicating that stigma concepts were complex and differently categorized.[30] To deeply understand parents' experiences and effectively implement social support and intervention programs, it is imperative to conduct further studies regarding the specific social norms and perceptions of stigma self-reported by caregivers.

Measurements of stigma are inconsistent across studies. Specifically, 18 studies used validated stigma scales, such as ASS, DCFS, PPPAS, STARS, and PCS. Among these scales, the ASS developed by Mak and Cheung[51] was the most used in 12 of 36 studies (33.3%) in this review. However, the studies included had different research methodologies, using a variety of measurements and measuring distinct outcomes. Therefore, it is difficult to compare data across studies and may contribute to a lack of rigor, inaccuracy, and bias. Further, well-designed studies are needed to better understand the stigma status among parents of children with autism by using standard terminology and stigma measurement tools.

In general, health-related stigma can be affected by many factors, including age, gender of parents, severity, and symptoms of the health situation.[30,55] In terms of autism-related stigma toward parents of children with ASD, in studies analyzed in the context of our review, both non-modifiable and modifiable factors were reported, and these closely interacted with each other. However, it was written in two reviews[30,31] that several studies on stigma examined the existing related factors, but none was found to summarize all these variables until this review. Among these factors, behaviors of autism and the severity of symptoms were strongly correlated with stigma among parents of children with ASD.[30] Similar to previous studies, it is recommended from the findings that effective interventions should be implemented focusing on modifiable factors and considering the cultural differences among regions to reduce stigma for children with ASD and especially their caregivers.[30,55]

Limitations

The articles included in the review were all in English. Therefore, potential studies published in other languages were not retrieved. In addition, there is a potential limitation of this review related to the heterogeneity of the study methodologies, the differences in stigma definition, and the wide range of stigma measures used in the included studies may invalidate the conclusions of this review.

Conclusion

This integrative review included 36 articles that provided evidence of the stigma among parents with ASD children and related factors. Despite studies in many countries, stigma was common in all included studies. Parents with ASD children face stigma, including perceived stigma, self-stigma, and enacted stigma. The most commonly used instrument to measure the stigma was the Affiliate Stigma Scale (ASS). Factors relating to stigma among parents of children with ASD, which can be modifiable or non-modifiable, should be considered with the cultural impacts, especially among Eastern and Middle Eastern countries.

Implications for Nursing Practice

Previous studies about stigma among parents of children with ASD were conducted in different countries but mainly in Western countries, and only three studies recruited participants across two countries without comparing the cultural differences between these two countries. Therefore, future studies need to be conducted in low-resource areas to compare stigma related to cultural issues. In addition, longitudinal studies with large sample sizes are also required to evaluate the long-term effects of stigma on parents of children with ASD. Further studies should also focus on assessing stigma in fathers to compare stigma related to gender.

Moreover, further studies should be conducted with rigorous standards to achieve reliable results. The evidence from this review may help other researchers and clinicians design future interventions to address related factors in reducing stigma among parents of children with ASD. The research results also suggest that nurses and nursing students should develop nursing interventions to decrease stigma among parents of children with autism. The factors related to stigma may be contributed to nursing interventions for families who have children with autism.

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Appendix

Table 1. Stigma among parents with ASD children

Author, year, location	Study design	Participant, sample size, sampling methods	Measurements	Findings	Recommendation/ Limitations
Oduyemi et al.[21] 2021 Nigeria	Mixed-method, quantitative cross-sectional study, and qualitative descriptive study	Multistage sampling methodology, 230 parents	Self-design questionnaire	-53% enacted stigma; 83.5% feel stigma -Education level and monthly family income associated with stigma	Internalization of stigma needs further exploration at the community level.
Patra & Kumar Patro[18] 2019 India	Quantitative cross-sectional study	Convenience sampling, 38 parents	ASS scale	The mean total score on the ASS scale was 45.54(± 13.01), range 24-73	Small sample size/ Provide intervention for target group (parents with girl child of autism)
Blanche et al.[45] 2015 Latino- USA	Qualitative descriptive study	Convenience sampling, 15 parents	Interview guide	-Parents experienced stigma as evidence: not telling others about their child's difficulties; covering up their child's atypical behavior; discomfort with having their child's behaviors judged by others	Made no statement on philosophical methodology, No evidence of ethical approval for study
Broady[10] 2017 Australia	Qualitative descriptive study	Convenience sampling, 15 parents	Interview guide	Four domains were determined (i) lack of knowledge, (ii) judgment, (iii) rejection and (iv) lack of support in four main contexts within carers' lives: school, public, family and friends.	Make no clear statement on the methodological approach; no clear statement locating the researcher culturally; the relationship between the researcher and participants has not been adequately considered.
Byrne et al.[52] 2018 Republic of Ireland	Qualitative descriptive study	Convenience sampling, 10 parents	Semi-structured interview guide	Five main themes were identified: (a) blame and stigma; (b) isolation; (c) being vigilant; (d) advocacy; and (e) coping with autism.	Made no statement on philosophical methodology; no clear statement locating researcher culturally; and relationship between researcher and participants not been adequately considered.
Cantwell et al.[22] 2015 Republic of Ireland	Quantitative cross-sectional study	Convenience sampling, 173 parents: 115 parents with disability children and 58 parents in control group (56% parents with ASD children)	Perceived Caregiver Stigma Scale.	-Parents reported depressive symptoms related to stigma. -Stigma and depressive symptoms were mediated by self-esteem. -Caregiver identity and perceived social support associated with stigma	Online survey; small sample size; cross-sectional design; self-selected to take part in the study
Kinnear et al.[8] 2016 USA and Canada	Mixed-method, quantitative cross-sectional study, and qualitative descriptive study	In a multistage sampling methodology, 502 parents	Interview guide	-Parents experienced stigma, including prejudice, denial, and exclusion. -Child behavior related to stigma	Make no statement on philosophical methodology Measures (scales) developed for this study should be tested in other samples.

Appendix

Table 1. Stigma among parents with ASD children (Cont.)

Author, year, location	Study design	Participant, sample size, sampling methods	Measurements	Findings	Recommendation/ Limitations
Lovell & Wetherell[25] 2018 UK and USA	Quantitative cross-sectional study	Convenience sampling, n = 212 caregivers	ASS scale	Caregivers' sleep duration and marital status related to stigma	Online survey; did not compare the stigma difference between two cultures.
Ha et al.[44] 2014 Viet Nam	Qualitative ethnographic study	Convenience sampling, 27 parents and 17 managers	Semi-structured interview guide	ASD was culturally and socially constructed as a 'disease or family problem; stigma and discrimination	The relationship between the researcher and participants was adequately considered.
Chan & Lam[16] 2018 Hong Kong	Quantitative cross-sectional study	Convenience sampling, 424 parents	-ASS scale -STARS scale	Life satisfaction depression, caregiving gain, and caregiving burden associated with stigma	Online survey via mail; self-selected to take part in the study
Dababnah & Parish[49] 2013 Israel	Qualitative descriptive study	Convenience sampling, 24 parents	Interview and focus group guides	Discrimination and stigma from extended family members and the larger community intensified parents' feelings of shame and experiences of social isolation.	Made no statement on philosophical orientation; the influence of research on the research was not addressed; no clear statement locating the researcher culturally.
Gill & Liamputtong[24] 2011 Australia	Qualitative descriptive study	Convenience sampling, 15 mothers	Interview guide and solicited diary	-Mothers perceived stigma in school and community environments. -The mothers of children with Asperger's Syndrome perceived more stigmatized than mothers of children with physical disabilities.	No evidence of ethical approval for the study; no clear statement locating the researcher culturally; influence of the researcher on the research not addressed
Gobrial[41] 2018 Egypt	Qualitative grounded theory study	Convenience sampling, 14 mothers	Semi-structured interview guide	Parents experienced stigma as evidence: treated differently by society, felt embarrassed about their child's behavior or ashamed of the condition, hid with their child at home, and felt socially isolated.	No statement on philosophical methodology; no clear statement locating the researcher culturally; influence of the researcher on the research not addressed
Ijalba[26] 2016 Hispanic immigrants, USA	Qualitative phenomenological study	Convenience sampling, 22 mothers	Phenomenological interviews guide	-Stigmatization and social isolation -Lacking awareness about autism, the other families refused to share common areas and referred to her child.	No evidence of ethical approval for study
Mak & Kwok[27] 2010 Hong Kong	Quantitative cross-sectional study	Convenience sampling, 188 parents	- DCFS scale - ASS scale	-The level of self-stigma among parents was severe. -Social support related to self-stigma	Online survey via mail; cross-sectional design; small sample size
Manor-Binyamin & Shoshana[39] 2018 Israel	Qualitative ethnographic study	Convenience sampling, 19 mothers	Semi-structured ethnographic interviews guide	Parents experienced stigma as evidence: exclusion in every aspect of their lives; social isolation even from family; sacrificed most of their personal lives, leading to a sense of isolation	Influence of researcher on study and vice-versa not addressed

Appendix

Table 1. Stigma among parents with ASD children (Cont.)

Author, year, location	Study design	Participant, sample size, sampling methods	Measurements	Findings	Recommendation/ Limitations
Neely-Barnes et al.[53] 2011 USA	Qualitative descriptive study	Convenience sampling, 11 parents	Focus group interview guide	Parents experienced blame for their children's autism-related behavior from public and extended family.	No clear statement of philosophical or theoretical basis of study; researchers' cultural and theoretical orientation not declared clearly
Zuckerman et al.[5] 2018 USA	Quantitative cross-sectional study	Random sample, 489 parents	PPAS scale	Unmet ASD care needs, child public insurance, parent nativity, number of children with ASD in the household, parent-reported ASD severity, and family structure related to stigma	Cross-sectional design
Čolić et al.[17] 2021 Serbian	Quantitative cross-sectional study	Convenience sampling, 82 parents	-PPPAS scale - ASS scale	-46.3% reported low (scores = 1.1-2.5), 36.6% moderate (scores = 2.51-3.5), and 16.0% high (scores = 3.51-5.0) degrees of perceived stigma. -Child's age, intervention year, number of children in family correlated with stigma	The small sample size and the limited geographic location, cross-sectional design
Minhas et al.[19] 2015 India and Pakistan	Qualitative narrative review	Convenience sampling, 15 parents	Semi-structured interview guide	Stigma and discrimination against families were identified, such as keeping the child at home; social isolation; and embarrassment because of the child's behavior	The study did not clearly state methodological approach.
Tekola et al.[23] 2020 Ethiopia	Qualitative descriptive study	Convenience sampling, 18 parents	Semi-structured interview guide	-Parents received support and understanding from their families, neighbors, schoolteachers and general public. -People with better awareness had positive reactions and understood parents' situation	Made no clear statement of philosophical perspective of study; influence of researchers on study not addressed
Carmen et al.[46] 2020 China	Quantitative cross-sectional study	Convenience sampling, 63 parents	ASS scale	- Level of affiliate stigma was moderate and did not relate to how often parents went out with children. - The engagement of children in two particular activities: children's hygiene and physical activities in the community, correlated significantly with the parents' affiliate stigma.	Small sample size; sampling method
Gray[20] 2002 Australia	Qualitative descriptive study	Convenience sampling, 53 parents	Semi-structured interviews guide	Most parents experienced both felt stigma and enacted stigma, but mothers were stigmatized more than fathers.	Made no statement on ethical approval process; no statement that clarified the researcher's cultural and theoretical orientation.
Farrugia[43] 2009 Australia	Qualitative descriptive study	Convenience sampling, 16 parents	Semi-structured interviews guide	Parents experienced stigma because of child's normal appearance but abnormal behavior.	Ethical approval not declared; no statement clarifying researcher's cultural and theoretical orientation

Appendix

Table 1. Stigma among parents with ASD children (Cont.)

Author, year, location	Study design	Participant, sample size, sampling methods	Measurements	Findings	Recommendation/ Limitations
Alshaigi et al.[11] 2020 Saudi Arabia	Mixed method, quantitative cross-sectional and qualitative descriptive study	Convenience sampling, 163 parents	Self-design questionnaire	-33.7% felt stigma (50.3% were fathers); 41.75% feeling of self-stigma (more among mothers); 25.8% enacted stigma (mother more affected). -Gender, lack of knowledge and understanding associated with stigma.	Lack of local literature review in different regions; related factors were not in wide range (lack of social factors).
Dehnavi et al.[40] 2011 Iran	Quantitative cross-sectional study	Convenience sampling, 95 mothers	ASS scale	Affiliate stigma predicted 25% of mental health problems.	Small sample size and the limited geographic location
Werner & Shulman[28] 2013 Israel	Quantitative cross-sectional study	Convenience sampling, 170 parents	Modified ASS scale	-General health scores below average, especially for parents of children with ASD -Self-stigma is one predictor of subjective well-being. -Affiliate stigma higher in parents with ASD children	Small sample size and limited geographic location lack of psychiatric diagnosis
Werner & Shulman[47] 2015 Israel	Quantitative cross-sectional study	Convenience sampling, 170 parents	Modified ASS scale	-Higher levels of affiliate stigma reported by caregivers of children with ASD -Higher levels of affiliate stigma related to feeling sad, burdened, emotionally hurt and feeling embarrassed by child's behavior.	Diagnosis based on caregivers' reports rather than representing an objective diagnosis.
Wong et al.[48] 2016 Hong kong	Quantitative cross-sectional study	Convenience sampling, 180 parents	Modified ASS scale	Significant association between affiliate stigma and psychological distress found among caregivers with low levels of self-compassion.	The small sample size and cross-sectional design
Ting et al.[13] 2018 China	Quantitative cross-sectional study	Convenience sampling, 263 caregivers (212 parents)	Modified ASS scale	-Severe affiliate stigma among parents -Rural area; caregivers' low self-esteem; high proneness to shame; family functioning (family cohesion and family adaptability) related to stigma.	Lack of discussion of important factors: behavior problems and severity of symptoms
Mitter et al.[12] 2018 UK	Quantitative cross-sectional study	Convenience sampling, 407 caregivers (215 ASD careers)	FAMSI scale	Challenging behavior burden and subjective well-being were predictive of total affiliate stigma.	Online survey
Russell & Norwich[29] 2012 Australia	Qualitative grounded theory study	Convenience sampling, 17 parents.	Semi-structured interview guide	Parents felt blamed for their child's behaviors and bad parenting.	Influence of researcher on study was not declared; relationship between researcher and study participants not addressed.

Appendix

Table 1. Stigma among parents with ASD children (Cont.)

Author, year, location	**Study design**	**Participant, sample size, sampling methods**	**Measurements**	**Findings**	**Recommendation/ Limitations**
Tait et al.[54] 2014 Hong Kong	Mixed method, quantitative cross-sectional and qualitative descriptive study	Convenience sampling, 100 parents	Semi-structured interviews guide	Lack of understanding by others; lack of free educational options; attitudes to inclusion was poor among HK teachers.	Small sample size, limited geographic location, and online survey
Chan & Lam[14] 2017 Hong Kong	Quantitative cross-sectional study	Convenience sampling, 424 parents	-PSS scale -DCFS scale	-Depression, anxiety, and caregiving burden correlated with stigma.	Lack of causal relationship
Lodder et al.[15] 2019 UK	RCT	Convenience sampling, 24 parents	-Modified DCFS scale -Modified ASS scale	The intervention improved the mental health of parents by increasing resistance to stigma.	Need larger RCT
Gray[42] 1993 Australia	Qualitative descriptive study	Convenience sampling, 32 parents	Semi-structured interview guide	-Parents perceived themselves as stigmatized: Isolated, difficulty coping with a child's behavior in social environment. -Gender of parents, age and the severity of child associated with stigma	Made no statement on ethical approval; locating the researcher culturally or theoretically not declared; influence of the researcher on study and vice-versa not addressed

Table 2. Quality of included studies

Criteria	1	2	3	4	5	6	7	8	9	10	Total
Qualitative studies											
Blanche et al.[45] (2015)	0	1	1	1	1	1	1	1	0	1	8
Broady[10] (2017)	0	1	1	1	1	0	0	1	1	1	7
Byrne et al.[52] (2018)	0	1	1	1	1	0	1	1	1	0	7
Ha et al.[44] (2014)	1	1	1	1	1	1	0	1	1	1	9
Dababnah & Parish[49] (2013)	0	1	1	1	1	0	0	1	1	1	7
Gill & Liamputtong[24] (2011)	1	1	1	1	1	0	0	1	0	1	8
Gobrial[41] (2018)	0	1	1	1	1	0	0	1	1	1	7
Ijalba[26] (2016)	1	1	1	1	1	1	1	1	0	1	9
Manor-Binyamin & Shoshana[39] (2018)	1	1	1	1	1	1	0	1	1	1	9
Neely-Barnes et al.[53] (2011)	0	1	1	1	1	0	1	1	1	1	8
Minhas et al.[19] (2015)	0	1	1	1	1	1	1	1	1	1	9
Tekola et al.[23] (2020)	0	1	1	1	1	1	0	1	1	1	8
Gray[20] (2002)	1	1	1	1	1	0	0	1	0	1	7
Farrugia[43] (2009)	1	1	1	1	1	1	0	1	0	1	8
Russell & Norwich[29] (2012)	1	1	1	1	1	0	0	1	1	1	8
Gray[42] (1993)	1	1	1	1	1	0	0	1	0	1	7
Mixed-method studies											
Oduyemi et al.[21] (2021)	0	1	1	1	1	0	0	1	0	1	6
Kinnear et al.[8] (2016)	0	1	1	1	1	0	0	1	1	1	7
Alshaigi et al.[11] (2020)	0	1	1	1	1	0	0	1	1	1	7
Tait et al.[54] (2014)	0	1	1	1	1	0	0	1	0	1	6
Criteria	1	2	3	4	5	6	7	8	Total score		
Quantitative studies											
Patra & Kumar Patro[18] (2019)	1	1	1	1	0	0	1	1	6		
Cantwell et al.[22] (2015)	1	1	1	1	1	1	1	1	8		
Lovell & Wetherell[25] (2018)	1	0	1	1	1	1	1	1	7		
Chan & Lam[16] (2018)	0	1	1	1	0	0	1	1	5		
Mak and Kwok[27] (2010)	0	1	1	1	0	0	1	1	5		
Zuckerman et al.[5] (2018)	1	1	1	1	0	0	1	1	6		
Čolić et al.[17] (2021)	0	1	1	1	0	0	1	1	5		
Carmen et al.[46] (2020)	1	1	1	1	1	1	1	1	8		
Dehnavi et al.[40] (2011)	0	1	1	1	0	0	1	1	5		
Werner & Shulman[28] (2013)	0	1	1	1	0	0	1	1	5		
Werner & Shulman[47] (2015)	0	1	1	1	0	0	1	1	5		
Wong et al.[48] (2016)	0	1	1	1	0	0	1	1	5		
Ting et al.[13] (2018)	1	1	1	1	1	1	1	1	8		

Table 2. Quality of included studies (Cont.)

Criteria	1	2	3	4	5	6	7	8	9	10	Total			
Mitter et al.[12] (2018)	0	1	1	1	1	1	1	1	7					
Chan & Lam[14] (2017)	0	1	1	1	0	0	1	1	5					
Mix method study														
Oduyemi et al.[21] (2021)	0	1	1	0	0	0	1	1	4					
Kinnear et al.[8] (2016)	0	1	1	1	1	1	1	1	7					
Alshaigi et al.[11] (2020)	1	1	1	1	0	0	1	1	6					
Tait et al.[54] (2014)	1	1	1	1	0	0	1	1	6					
Criteria	1	2	3	4	5	6	7	8	9	10	11	12	13	Total score
RCT														
Lodder et al.[15] (2019)	1	1	1	1	0	0	1	1	1	1	1	1	1	11

Keynotes for quality criteria[34,35,36]

Quantitative research: "1- Were the criteria for inclusion in the sample clearly defined? 2- Were the study subjects and the setting described in detail? 3- Was the exposure measured in a valid and reliable way? 4- Were objective, standard criteria used for measurement of the condition? 5- Were confounding factors identified? 6- Were strategies to deal with confounding factors stated? 7- Were the outcomes measured in a valid and reliable way? 8- Was appropriate statistical analysis used?"[34]

Qualitative research: "1- Is there congruity between the stated philosophical perspective and the research methodology? 2- Is there congruity between the research methodology and the research question or objectives? 3- Is there congruity between the research methodology and the methods used to collect data? 4- Is there congruity between the research methodology and the representation and analysis of data?, 5- Is there congruity between the research methodology and the interpretation of results?, 6- Is there a statement locating the researcher culturally or theoretically?, 7- Is the influence of the researcher on the research, and vice-versa, addressed?, 8- Are participants, and their voices, adequately represented?, 9- Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?, 10- Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?"[35]

RCT: "1- Was true randomization used for assignment of participants to treatment groups? 2- Was allocation to treatment groups concealed?, 3- Were treatment groups similar at the baseline?, 4- Were participants blind to treatment assignment?, 5- Were those delivering treatment blind to treatment assignment?, 6- Were outcomes assessors blind to treatment assignment?, 7- Were treatment groups treated identically other than the intervention of interest?, 8- Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?, 9- Were participants analyzed in the groups to which they were randomized?, 10- Were outcomes measured in the same way for treatment groups?, 11- Were outcomes measured in a reliable way?, 12- Was appropriate statistical analysis used?, 13- Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?"[36]

ตราบาปในบิดามารดาของเด็กที่มีภาวะออทิซึม: การทบทวนวรรณกรรมเชิงบูรณาการ

Thi Loan Khanh, Thi Lan Anh Mai, Phương Anh Hoang*

บทคัดย่อ: จำนวนเด็กที่ได้รับการวินิจฉัยว่าเป็นออทิซึมเพิ่มขึ้นทั่วโลก บทบาทของบิดามารดามีส่วนสำคัญในการดูแลเด็กที่มีภาวะออทิซึม แต่เรื่องตราบาปเป็นประเด็นที่ท้าทายและพบเห็นอย่างแพร่หลายซึ่งครอบครัวต้องเผชิญในการเลี้ยงดูและดูแลเด็กที่มีภาวะนี้ การทบทวนวรรณกรรมเชิงบูรณาการนี้ดำเนินการโดยนักวิจัยพยาบาลในปี พ.ศ. 2565 ที่สังเคราะห์ความรู้ที่มีอยู่จากงานวิจัยในปัจจุบันเกี่ยวกับสถานะของตราบาปและปัจจัยที่เกี่ยวข้องกับตราบาปในบิดามารดาของเด็กที่อยู่ในกลุ่มอาการออทิซึมหรือออทิสติก ฐานข้อมูลอิเล็กทรอนิกส์ที่ค้นหาครั้งนี้ ได้แก่ PubMed, CINAHL (EBSCO), EMBASE, และ Scopus โดยใช้คำสำคัญ “stigmatization,” “parents,” และ “autism”

การทบทวนวรรณกรรมนี้ประกอบด้วยงานวิจัย 36 เรื่องโดยไม่จำกัดเวลา เป็นการศึกษาเชิงคุณภาพ 16 เรื่อง เชิงปริมาณ 15 เรื่อง เชิงผสานวิธี 4 เรื่อง และการศึกษาเชิงทดลองในการดูแล 1 เรื่อง ผลการวิจัยพบว่าตราบาปเป็นประเด็นที่พบในบิดามารดาของเด็กที่มีภาวะออทิซึมในทุกงานวิจัย อย่างไรก็ตามพบว่ามีความแตกต่างกันเกี่ยวกับตราบาปในเชิงวัฒนธรรมของบิดามารดาของเด็กที่มีภาวะออทิซึมในประเทศแถบตะวันตก เอเชีย และตะวันออกกลาง ทั้งปัจจัยที่ปรับเปลี่ยนได้และปัจจัยที่ปรับเปลี่ยนไม่ได้ที่เกี่ยวข้องกับตราบาป เช่น อายุของบิดามารดา สถานภาพการสมรส พฤติกรรมของเด็ก และการสนับสนุนทางสังคม ข้อเสนอแนะ คือควรมีการศึกษาระยะยาวเพิ่มเติมเกี่ยวกับตราบาปในกลุ่มที่ขาดแคลนทรัพยากร และกลุ่มผู้ดูแลที่มีความแตกต่างกัน ในกลุ่มตัวอย่างที่มีขนาดใหญ่ เพื่อระบุความชุกของตราบาปและการเปลี่ยนแปลงตราบาปในบิดามารดาของเด็กที่มีภาวะออทิซึม ผลการทบทวนวรรณกรรมครั้งนี้นำเสนอข้อมูลหลักฐานสำหรับพัฒนาการศึกษาเชิงทดลองที่มีโปรแกรมการดูแลที่ระบุปัจจัยที่เกี่ยวข้องกับการลดตราบาปในบิดามารดาของเด็กที่มีภาวะออทิซึมต่อไป นอกจากนี้ บุคลากรด้านการดูแลสุขภาพซึ่งรวมถึงพยาบาลที่ทำงานกับครอบครัวของเด็กที่มีภาวะนี้ ควรประเมินระดับตราบาปในกลุ่มบิดามารดาเพื่อให้การช่วยเหลือสนับสนุนอย่างทันท่วงที

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