



Stigma among parents of children with autism: A literature review

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ABSTRACT

Objective: This literature review aims to summarize current findings from studies examined experiences of stigma among parents of children with autism.

Method: A systematic literature search was carried out to identify relevant studies. Two reviewers independently screened each records based on the selection criteria. Discrepancies were resolved through discussions. Included articles were classified by social-cultural settings.

Result: 25 studies were identified and included in the review, including 15 qualitative, 8 quantitative, and 2 mixed method studies. Parents do in fact experience courtesy stigma which subsequently develop into affiliate stigma. The study of stigma has not received enough attention for parents of children with autism. There lacked large prevalence studies and longitudinal studies examining stigma among parents of children with autism.

Conclusion: Parents of children with autism perceived and experienced stigma and various consequences which were varied with behaviors of autism and the severity of symptoms. Further studies should focus on developing intervention that help to erase stigma among parents of children with autism.

1. Introduction

Autism is a neurological developmental disorder characterized by deficits in social reciprocity, delays in communication skill as well as presences of repetitive behavior that violate social norms (Lord et al., 2000). It affects about 16.8/1,000 (i.e., 1/59), predominantly males (i.e., a prevalence ratio of 4:1). Autistic children often confront stigma for their stereotypes, and misconceptions and discrimination about autism by mainstream society. Stigma not only impacts autistic children, but also extends to individuals who are close to them, particularly their parents. Stigma on parents has been described using the term of courtesy or affiliate stigma (Goffman, 1964), with the former argued that parents perceived stigma as sharing interpersonal links with the marked children (Gray, 1993a, 1993b, 2002a, 2002b) and the later emphasized that parents internalized negative stereotypical perceptions from the public.

2. Objectives

This review aimed to summarize findings from studies examining stigma among parents of children with autism and to evaluate its impacts on parental lives, elaborate current research status, and provide suggestions for future researches. As stigma experiences may vary

across social-cultural background such as politic systems, propriety customs, language grids and value systems (Mak and Kwok, 2010), we proposed to classify included studies by social-cultural settings.

3. Methods

3.1. Search strategy

A systematic literature search was carried out to identify studies published in English concerning stigma among parents of children with autism. Three online databases, PubMed, Embase, and Web of Science were searched by two authors using the searching keywords (stigma OR prejudice OR discrimination OR stereotype) AND (carer OR caregiver OR family OR parent OR father OR mother) AND (autism OR ASD OR Autism Spectrum Disorder).

3.2. Selection criteria

For the records, the following criteria were required for articles to be eligible: published in peer reviewed journals; reported empirical findings rather than theoretical outcomes; involved parents raising at least one child with autism; addressed the issue of stigma among parents. Studies that presented information about parents of children with

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different disabilities were included in case that parents of children with autism constituted over half of the sample size or specially reported on a sub-group. Also, we exclude doctoral dissertations or master's thesis, reviews, editorials and commentaries. There is no restriction on publication date and study methodology.

Before the electronic search, all authors reached a consensus on retrieval strategies. References cited by all eligible citations and two reviews (Papadopoulos et al., 2018; Mazumder and Thompson-Hodgetts, 2019) were manually reviewed for additional relevant studies that might have been omitted. We did not report the methodological qualities of these included studies.

3.3. Data extraction

Two authors independently extracted data from articles, including name of first author, year of publication, country of region, study sample, study method, measurement of stigma as well as main findings.

3.4. Data synthesis

We used descriptive statistics to present study characteristics and study results were qualitatively reviewed.

4. Results

4.1. Overview of the studies included

A total of 129 citations were retrieved from our initial online literature search. After removing 96 duplicates, 33 records was screened. The titles and abstracts were reviewed independently by two authors. As a result, 6 were excluded for not matching the selection criteria. The remaining 27 potentially relevant articles were scrutinized independently by two authors, yielding 25 studies included in this review. Of note, Studies by Chan and Lam in (2017) and in (2018), and studies by Werner and Shulman (2013) and in (2015) were based on identical sample. However, they focused on different aspects and provided useful information. Therefore, 25 articles in total were included in this review.

Given the inconsistency between studies, such as data sources, country settings, and rating scales, meta-analysis was not conducted to quantitatively estimate the stigma among parents of children with autism. Besides, none of the included studies reported statistical outcomes for performing a meta-analysis.

These 25 articles used various research methods, including quantitative ($n = 15$), qualitative ($n = 8$) and mixed ($n = 2$) study designs. All quantitative studies were cross-sectional surveys, except one using longitudinal design (Gray, 1993a, 1993b, 2002a, 2002b), which investigated the same sample population for 10 months and 10 years period. These 25 studies were published between 1993 and 2019, with three published in 1993, 2002 and 2009, and the remaining 22 published after 2010.

These included articles represented findings from 8 different countries and were classified into 4 social-cultural settings. Western cultures ($n = 11$) included: Australia ($n = 5$), the UK ($n = 3$), and the USA ($n = 2$) as well as Ireland ($n = 1$). Asian cultural ($n = 9$) included: China ($n = 7$) and India ($n = 2$). Middle East ($n = 3$) included: Israel ($n = 2$) and Iran ($n = 1$). Cross-cultural ($n = 2$) included: the UK/USA ($n = 1$) and the USA/Canada ($n = 1$).

These eligible articles involved a total of 3178 parents of children with autism, sample sizes ranged from 10 to 502. Specifically, sample sizes of quantitative studies spanned from 12 to 502, that of qualitative studies ranged from 10 to 53. Forty-eight percent ($n = 12$) of these included studies were carried out with 100 or fewer participants. The majority of participants were mothers ($n = 2,339$; 73.6%), whereas fathers only composed a relatively small fraction of the sample size ($n = 332$; 10.4%), also a small number of respondents failed to specify genders ($n = 507$, 16.0%). The vast majority of papers included

participants of both sexes except for 2 that concentrated exclusively on mothers (Kwok et al., 2014; Gill and Liamputtong, 2011). Research participants of the 25 eligible articles contained either a primary focus on parents of children with autism or a specific sub-group analysis of parents of children with autism.

4.2. Definition and measurement of stigma

The work by Goffman (1964) defined stigma as a social identity that is perceived to breach from societal norms and orthodox values. The stigma paradigm from Goffman (1964) laid the dominant theoretical foundation for analyzing stigmatizing conditions in parents who have children diagnosed with autism. The classical proposal in stigma from Goffman (1964) acted as the most basic definition that most authors expanded on in eligible articles. Most studies referred to the broad conception of stigma introduced by Goffman (1964) other than providing an explicit definition for courtesy or affiliate stigma. Seven studies gave a clear definition of affiliate stigma (Lovell and Wetherell, 2018; Werner and Shulman, 2015, 2013; Wong et al., 2016; Dehnavi et al., 2011; Zhou et al., 2018; Patra and Patro, 2019), two articles proposed a specific conception of courtesy stigma (Lodder et al., 2019; Kwok et al., 2014), only one paper suggested the definitions of both (Mak and Kwok, 2010). Two studies differentiated stigma into felt and enacted stigma by referring to Scambler and Hopkins (1986), the former concerned feelings of shame or rejection and the latter described experiences of discrimination or social exclusion (Gray, 2002a, 2002b; Farrugia, 2009). Also one article described stigma by dividing it into self-stigma process and self-stigma content (Chan and Lam, 2018).

The conceptualization of stigma lay a foundation for the development of instruments intended to specifically measure stigma. Most studies applied modified scales to evaluate stigma, but did not validate in the respective cultural contexts. Fifteen studies adopted standardized stigma-related scales to measure stigma in parents of children with autism. Specifically, nine studies adopted the Affiliate Stigma Scale developed by Mak et al. (2007) to explicitly appraise stigma suffered by parents, two studies respectively used the Devaluation of Consumer Families scale and the Perceived Courtesy Stigma Scale examined courtesy stigma among parents, two studies either applied the Perceived Courtesy Stigma Scale or an modified version of Enacted Stigma by Phelan et al. (2011) evaluated different aspects of perceived stigma among parents, also one study developed a self-reported scale to estimate family stigma among parents, only one study developed a parent-perceived stigma scale estimated the self-stigma process among parents. The leaving ten publications, which included eight qualitative studies and two mixed method studies, were not estimated using established instruments of stigma. The results of these ten studies presented as narrative information covering sustain blames, suffer exclusions, lack of understandings, which respectively reflected some aspects of stigma among parents of children with autism.

4.3. Stigma among parents of children with autism in western cultures

The electronic search yield eleven studies reporting on stigma among parents who have children with autism beyond the western culture contexts. These articles were originated in Australia ($n = 5$), the UK ($n = 3$), the USA ($n = 2$) and Ireland ($n = 1$).

Broadly et al. (2017) qualitatively investigated the process of internalized stigmatization in the suffering of caregivers who have children diagnosed with high functioning autism. The result drawn a framework constituted four distinct domains in which provided a detailed account of stigma experienced by these primary caregivers through associations with their marked children. The stigmatizing experience of caregivers can be explained by multiple aspects such as insufficient autistic knowledge, interpersonal exclusions, stereotyped comments, and inadequate social supports. Gray (2002a,b) shed lights on stigma experienced by parents of children with high functioning autism by

differentiating felt and enacted stigma. Data from in-depth interviews indicated that parents, especially mothers, experienced both types of stigma from public circumstances. This was particularly truthful with regard to enacted stigma, where most mothers rather than fathers confronted social rejections, discreditable gazes and negative judgments, since they typically assume the responsibilities as primary caregivers. The study by Gray (1993a,b) drew attentions to perceived stigma among parents of children with autism, findings from qualitative data indicated that most parents experienced stigma through affiliation with the autistic children, with mothers particularly affected in comparison with fathers. To understand stigmatization in parents of children with autism, Farrugia (2009) noted that parents faced considerable enacted stigma simply because of being associated with the marked children, but they resisted it by strategically deploying discourses drawn from medicine. Gill and Liamputtong (2011) offered insights into exploring stigma of being mothers of children with autism. The result concluded that mothers endorsed evident courtesy stigma emerging from various public environments, specifically in school environments and community settings. Lodder et al. (2019) examined impacts of psycho-social interventions on parents of children with autism in a randomized controlled study. The 8-week stigma support program improved mental health of parents by increasing their resistance to stigma. Mitter et al. (2018) sought to determine variables that predict stigma among families living with autistic children. The result showed that most family members met with stigma due to the maladaptive behaviors exhibited by the autistic children. Furthermore, both perceived stigma and caregiving burden may aggravate affiliate stigma, whereas subjective well-being functioned conversely. A qualitative study by Russell and Norwich (2012) elaborated how the ASD diagnosis functioned on parental lives. The result showed that parents experienced prominent stigma stemmed from public stereotypes and actively adopted coping strategies in struggle against stigma. A study on parents of children with autism by Zuckerman et al. (2018) identified variations that influenced autism stigma experienced by parents. Stigma evidently associated with unmet care needs rather than therapy hours or therapy types. Stigma was mainly determined by social-demographic variables, with traditionally marginalized families particularly affected. Findings from Neely-Barnes et al., 2011 pointed out that although some parents viewed experiences of raising autistic children in positive ways, the children's disrupted behaviors still inevitably exposed parents to stigma. The study of Gary et al. (2018) characterized life experiences in parents who have children diagnosed with autism via semi-structured interviews. The result showed that parents were subjected to stigma for their marked children. The issue of stigma was one of the five themes emerged from thematic analysis (Table 1)

4.4. Stigma among parents of children with autism in Asian cultures

Stigma may be particularly prominent among Asian societies due to the concept of "face" and shame-socialized. This review article identified nine studies conducted in Asian cultures, including China (n = 7) and India (n = 2).

Zhou and Wang (2018) quantitatively described affiliate stigma and depression in Chinese caregivers who have children with autism. Findings from interview information suggested that caregivers of children with autism were characterized by an evident degree of affiliate stigma. The study by Mak and Kwok (2010) focused on explaining stigma among parents of children with autism via investigating 188 participants in China. The result demonstrated that parents endured some form of stigma in broad social environments. Findings from attribution model displayed that parents accepted associative stigma through pathways of controllability, responsibility as well as self-blame. The study conducted by Kwok et al. (2014) provided an sophisticated understanding of stigma experiences in mothers of children with mental disorder including autism. The results confirmed an adverse association between perceived stigma and marital satisfaction of mothers, burden

served as a mediator in this negative relationship. The study by Wong et al. (2016) shed lights on the protective function of self-compassion on stigma among Chinese parents of children with autism. Results suggested a significant positive correlation between affiliate stigma and psychological distress, self-compassion buffered this relationship. The study by Chan and Lam (2018) appraised stigma among parents of children with autism by subdividing stigma into content versus process. They noted that process and content of stigma can produce differences in psychological outcomes respectively. Moreover, stigma was positively correlated with psychological depressions and negatively related with life satisfactions. Another study by Chan and Lam (2017) focused on psychological impacts of stigma on parents who have children diagnosed with autism. Findings indicated a positive relationship between stigma and psychological distress among parents, trait mindfulness relieved this association. The study by Tait et al. (2014) provided valuable insights into the stigmatizing aspects among Chinese parents of children with autism. They emphasized that community discrimination was the main issue raised from parental interviews. Cantwell et al. (2015) pointed out that parents who have children with autism had to battle with stigma from public environments. There was a positive association between stigma and depressive, which was mediated by self-esteem varies across emotional support. There is no association between stigma and the children's disrupted behaviors and the lack of association may be explained by the fact that the selected measures fails to identify children's problem behaviors. Patra and Patro (2019) reported affiliate stigma perception among parents of children with autism by investigating thirty-eight parents in a cross-sectional study. The result showed that a large proportion of parents reported higher scores in attitude domain whereas a comparatively lower proportion experienced stigma in behavioral domains of Affiliate Stigma Scale.

4.5. Stigma among parents of children with autism in middle eastern cultures

The present review identified only three studies pertaining to stigma among parents of children with autism in middle eastern cultures (two in Israel and one in Iran).

The study by Werner and Shulman (2015) provided insights in understanding affiliate stigma regarding Israel caregivers who have children with developmental retardation. The experience of stigma among caregivers varied across diagnosis of their children. Caregivers of children with autism sustained higher affiliate stigma in comparison with those who have children with mental retardation or physical disability. In attempts to explore the association between affiliate stigma and subjective well-being, Werner and Shulman (2013) studied stigma on caregivers of children with different mental disorders including autism. Findings indicated the important role of positive psycho-social resources in the experiences. The negative association between affiliate stigma and quality of life among caregivers was regulated by self-esteem, social supports and positive views. Dehnavi et al. (2011) put emphasis on multilevel functions of societal stigma on mental health of mothers who have children on the autism spectrum. They noted that mothers of children with autism struggled to affiliate stigma in various spheres of living. Twenty-five percent of the variations in maternal mental health can be predicted by the degree of internalized stigma.

4.6. Stigma among parents of children with autism in cross-cultural studies

Although it is necessary to conduct multicultural studies to examine stigma as perceptions about autism differs from cultures, only two studies (one in the UK/USA and one in the USA/Canada) concerning stigma among parents who have children with autism from a cross-cultural perspective were yielded in our literature search.

With respect to explore effects of personal variables and family factors on affiliate stigma, Lovell and Wetherell (2018) investigated a

Table 1
The main findings of included studies.

First Author	Publish Year	Country	Sample Sizes	Methods	Measure of Stigma	Main Findings
Zhou T, et al.	2018	China	263caregivers 61males 188females 14 unclear 15 mothers	Quantitative	Shame: The Shame Scale Affiliate stigma: The Affiliate Stigma Scale	(1)The results suggested that affiliate stigma in caregivers of children with autism was prevalent and severe. (2)Low self-esteem, high shame proneness and poor family adaptability were associated with experience of affiliate stigma. Mothers perceived themselves to be stigmatized specifically in the school and community environments
Gill J, et al.	2011	Australia	192caregivers 186 females 17parents 2 fathers 15 mothers	Qualitative	Self-reported stigmatized experience	Non-partnered caregivers were more likely to report affiliate stigma, as were caregivers with shorter sleep duration. Parents view ASD as a stigmatizing lifelong condition
Lovell B, et al.	2018	UK/US	170caregivers 134females	Quantitative	Affiliate stigma: The 22 item Affiliate Stigma Scale	
Russell G, et al.	2012	UK	53parents 32mothers 21fathers 16participants 11mothers 5 fathers	Qualitative	Parents-reported stigmatized experience	
Werner s, et al.	2015	Israel	188 parents 158mothers	Quantitative	Affiliate stigma: The Affiliate Stigma Scale	Caregivers of individuals with ASD endorsed higher affiliate stigma than caregivers of individuals with ID or PD.
Gray D	2002	Australia		Qualitative	Felt and enacted stigma	The results indicate that a majority of the parents experienced both felt and enacted stigma, but that mothers were more likely to do so than fathers.
Farrugia D	2009	Australia		Qualitative	Parents-reported enacted stigma	Parents experienced considerable enacted stigma, but successfully resisted felt stigma by deploying medical knowledge to articulate unspoiled subject positions.
Mak WWS, et al.	2010	China		Quantitative	Courtesy stigma: The 7-item Devaluation of Consumer Families Scale Affiliate stigma: The 22-item Affiliate Stigma Scale	(1)It suggested three paths of internalizing courtesy stigma, including the direct path to affiliate stigma, through perceived controllability, or through perceived responsibility and self-blame. (2)The internalization of stigma among parents of ASD children was severe. (3)Support from family, friends, or professionals was found to be related to affiliate stigma.
Kwok S Y C L, et al.	2014	China	160mothers	Quantitative	Courtesy stigma: The Devaluation of Consumer Families scale	(1)Perceived stigma and perceived burden were significant predictors of mothers' marital satisfaction. (2)Perceived burden were found to be significant mediators between perceived stigma and marital satisfaction.
Gary B, et al.	2018	Irish	10 participants	Qualitative	Parents-reported stigma experience	Five main themes were identified (1)blame and stigma; (2) isolation; (3) being vigilant; (4)advocacy; (5) coping with autism.
Zuckerman K E, et al.	2018	USA	351 participants 316mothers	Quantitative	Parent-Perceived ASD Stigma:11 items addressed parents' perceptions of ASD stigma	(1)Stigma evidently associated with unmet care needs rather than therapy hours or therapy types. (2)Stigma was mainly determined by social-demographic variables, with traditionally marginalized families particularly affected. Parents experienced blame from the public and extended family
Neeley-Barnes S. L, et al.	2011	America	11parents 9mothers 2 fathers	Qualitative	Parents-reported stigmatized experience	Parents perceived themselves to be stigmatized
Gray D	1993	Australia	32parents 23mothers 9fathers 100parents	Qualitative	Parents-reported stigmatized experience	(1)Lack of understanding (2)Discrimination from the community (3)Became proactive to reduce stigma
Tait K, et al.	2014	China		Mixed	Affiliate stigma: The 22 item Affiliate Stigma Scale	(1)Affiliate stigma was significantly associated with psychological distress. (2)Self-compassion as a moderator in the association between affiliate stigma and psychological distress
Wong C C Y, et al.	2016	China	180 parents 149 females 28males 3 unclear	Quantitative		

(continued on next page)

Table 1 (continued)

First Author	Publish Year	Country	Sample Sizes	Methods	Measure of Stigma	Main Findings
Chan K S, et al.	2018	China	424 parents 365mothers	Quantitative	Self-stigma process : The 8-item STARS Self-stigma content: The 22-item Affiliate Stigma Scale	(1)Process and content of stigma can produce differences in psychological outcomes respectively. (2)Stigma was positively correlated with psychological depressions and negatively related with life satisfactions.
Mitter N, et al.	2018	UK	407 caregivers (216ASD)	Quantitative	Family stigma: The new Family Stigma Instrument	Perceived family stigma, caregiver burden and subjective wellbeing were the strongest predictors of family stigma.
Lodder A, et al.	2019	UK	12cases 12control	Randomized controlled trial	Courtesy stigma: The Perceived Courtesy Stigma Scale	Stigma of Living as an Autism Carer (SOLACE) could potentially improve the psychological well-being of parents/family carers of autistic children through increased resistance to stigma.
Werner S, et al.	2013	Israel	170caregivers (56ASD)	Quantitative	Affiliate stigma: The 22 item Affiliate Stigma Scale	Among caregivers of individuals with ASD, greater levels of stigma were associated with lower ratings of subjective well-being, whereas such an association was not found among caregivers of individuals with ID or PD.
Cantwell J et al.	2015	India	115 parents (64 ASD)	Quantitative	Perceived stigma: Two items from Phelan et al. (2011) Enacted stigma	(1)Parents reported more depressive symptomology, which was related to stigma. (2)The association between stigma and depressive symptomology was mediated by self-esteem.
Dehnavi SR et al.	2011	Iran	93mothers	Quantitative	Affiliate stigma: The Affiliate stigma Scale	Internalized stigma predict 25 percent of variation in mental health and autism quotient had no significant relationship with mental health.
Chan K K S et al.	2017	China	424 parents 365mothers	Quantitative	Perceived public stigma: The Perceived Public Stigma Scale Perceived courtesy stigma: The Perceived Courtesy Stigma Scale (PCSS) Self-reported stigmatized experience	Hierarchical regressions revealed significant interactions between public stigma and trait mindfulness and between courtesy stigma and trait mindfulness in predicting depression, anxiety, and caregiving burden.
Broadly T R et al.	2017	Australia	15caregivers	Qualitative		Four domains of stigmatizing (1)Lack of knowledge (2)Judgment (3)Rejection (4)Lack of support
Kinnear SH, et al.	2016	US/Canadian	502 parents 476mothers	Mixed	Parents-reported stigmatized experience	Parents experienced stigma processes of stereotyping, rejection, and exclusion.
Patra S et al	2019	India	38 parents 24 mothers 14fathers	Qualitative	Affiliate Stigma: The Affiliate Stigma Scale	A large proportion of parents reported higher scores in attitude domain whereas a comparatively lower proportion experienced stigma in behavioral domains of Affiliate Stigma Scale.

convenience sample of 212 caregivers of children with autism from the UK and the USA. Of the variables tested in the study, characteristics of caregivers, particularly relationship status and sleep hours, which emerged as key contributory factors on affiliate stigma. Caregivers without partners or with shorter sleep duration may be more likely to experience affiliate stigma. According to [Kinnear et al., 2016](#), most parents in the sample suffered from associative impacts of stigma against their children which resulted in the difficulty of rearing autistic children. Both the behaviors of autism and the severity of symptoms were significant predicted stigma components of stereotype, rejection, and isolation. Despite the uses of cross-national samples, this two studies failed to yield comparable results about cross-cultural differences in stigma, which were not within the scopes of the two studies.

5. Discussions

This systematic review was performed based on current research findings to evaluate stigma among parents who have children with autism. Existing body of research about the stigma experienced by parents of children with autism was organized according to social-cultural settings. Results consistently indicated that parents of children with autism perceived and experienced stigma which varied with both the behaviors of autism and the severity of symptoms, especially for mothers. Moreover, most parents declared to be particularly susceptible to stigma in school environments and community settings.

Most studies were carried out in countries (mainly in western countries) with substantial autism resources and only two reports based on cross-cultural settings were identified. Therefore, it is imperative to pay more attentions to support studies in resource-poor regions. Studies were mainly published after 2010, suggesting that stigma among parents of children with autism has been increasingly highlighted by researchers in the past decade. Studies either employed quantitative methods to collect data from relatively large groups or adopted qualitative analysis to collect information from semi-structured interviews.

Most papers included participants of both fathers and mothers except for two that focused exclusively on mothers. Mothers accounted for a majority proportion of the sample size, whereas fathers only constituted of a relatively small percentage. The skewed gender distribution across samples of parents makes it difficult to perform an evaluation on stigma among parents by genders. Despite the broad geographic distribution in sample, diversity in terms of parental ethnicity, education and social status was still limited. Most of the respondents received secondary or tertiary education, enjoyed middle to high socioeconomic status and have higher-than-average incomes, therefore, low income families or the disadvantaged minority were not represented. Most participants were recruited from single settings, mainly health care centers or special education institutions, which might cause limited generalizations to individuals who were not enrolled in these organizations. Also, no study examined stigma among parents of autistic children in different periods of autism. All the included studies adopted cross-sectional methods rather than reported longitudinal designs. Almost all articles used naturalistic designs, except one study focused on the functions of psycho-social interventions addressing stigma among caregivers of children with autism.

The stigma paradigm from [Goffman \(1964\)](#) has remained the initial conceptual framework for elaborating stigma experiences in parents who have children with autism. Seven studies provided a clear definition of affiliate stigma, two articles proposed a specific conception of courtesy stigma, only one paper provided definitions of both. Two studies differentiated stigma into felt and enacted stigma, and one study described stigma by dividing it into self-stigma process and self-stigma content. Variations in study methods, such as sample sources and outcome measures led to challenges for comparing data between studies. Measures for assessing stigma among parents of children with autism were also inconsistent. Specifically, fifty studies adopted standardized stigma-related scales, and the most frequently used stigma measure was

the Affiliate Stigma Scale ([Mak et al., 2007](#)), which was used in thirty-six percent ($n = 9$) of the included studies.

6. Limitation

The cross-sectional study design in most studies made it difficult to appraise stigma changes over time. To date, there is a marked lack of empirical researches regarding interventions for stigma in parents of children with autism. Since the present review focused exclusively on articles written in English, relevant findings published in other languages were not retrieved. Relevant works might also have been excluded through our inclusion criteria of only of peer-reviewed papers. Besides, existing literatures focuses mainly on parents, experiences of other family members may have been overlooked.

7. Conclusion

In conclusion, all the 25 included publications provided evidences of stigma among parents of children with autism. Stigma experiences and perceptions are common problem for parents of children with autism, despite heterogeneity between studies. Parents from different cultures (western to eastern) all are struggled to deal with stigma for their autistic children.

There is a marked need for comparable study settings such as measure instruments and evaluation indicators to allow a direct comparison between studies of different research groups. It is imperative to implement specific interventions involving interpersonal, educational, and biomedical collaborations to reduce stigma among parents of children with autism. Another important issue is that cultural tailoring should be taken into accounts, researchers performing cross-cultural studies should consider cultural factors including language, social customs, religious beliefs. Further, longitudinal studies are warranted to investigate long-term effects of stigma on parents of children with autism. More efforts should be devoted into considering stigma in fathers to estimate gender-based differences exist in the experience. Future studies also would benefit from analyzing the complex interaction between stigma and contextual variables, individual characteristics and psychological outcomes. A fertile area for ongoing researches is to develop theory-based models as existing studies reported predominantly descriptive information. Future researches should be improved in terms of research objects shifted the attention from parents to broader family members and close acquaintances. There is much room for improvements, and hopefully, the advancements of future studies will shift their attentions from simply investigations towards exploring interventions regarding stigma-reduction strategies among parents of children with autism.

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Authors' contributions

Yamin Li contributed to conception, acquisition, analysis, critically revised the manuscript. Gave final approval, agrees to be accountable for all aspects of work ensuring integrity and accuracy.

Xiaoli Liao contributed to acquisition, analysis, interpretation, drafted the manuscript. Critically revised the manuscript, gave final

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Xianyang Lei contributed to acquisition, analysis, interpretation the manuscript. Gave final approval, agrees to be accountable for all aspects of work ensuring integrity and accuracy.

Ethical statement

Not applicable.

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Declaration of Competing Interest

All authors of this paper declare that there is no conflict of interest related to the content of this manuscript.

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