Review Journal of Autism and Developmental Disorders (2021) 8:373–388
https://doi.org/10.1007/s40489-020-00228-5

REVIEW PAPER

Self-Stigma of Families of Persons with Autism Spectrum Disorder: a Scoping Review

Naoko Kumada Deguchi[1] · Takashi Asakura[2] · Tomoko Omiya[1]

Received: 4 April 2019 / Accepted: 29 October 2020 / Published online: 4 January 2021

Abstract

This review aimed to understand the dimensions of self-stigma that are unique to the families of persons with autism spectrum disorder (ASD) and the conditions in which self-stigma in families of persons with ASD arises. We reviewed the self-stigma dimensions in families of persons with ASD. Seventeen studies met our inclusion criteria and provided qualitative information on the dimensions of self-stigma. The identified dimensions were social misunderstanding, negative prejudice, social rejection, isolation, emotional reactions, and stigma management. The dimension of social misunderstanding was unique to families of persons with ASD. This review adds insights into self-stigma theory, and, by clarifying the dimensions of self-stigma, suggests areas for future self-stigma research among families of persons with ASD.

Keywords Autism spectrum disorder · Families · Self-stigma · Scoping review · Social misunderstanding

Introduction

Prior to the 1990s, the estimated prevalence of autism spectrum disorder (ASD) was 2–4 per 10,000 people; however, in 2014, data suggested that as many as 13.1–29.3 per 1000 people have ASD (Baio et al. 2018). The prevalence rate of ASD has been sharply increasing, which might be the result of changes in diagnostic criteria, differences in study methodologies, and increased awareness (Wing and Potter 2002). Increased awareness of ASD can create another problem: stigmatization.

The major behavioral characteristics of ASD include persistent deficits in social communication, social interactions, social-emotional reciprocity, and communicative behavior (American Psychiatric Association 2013). These characteristics often present as socially inappropriate or disruptive behaviors in public and this can cause unique stigmatizing aspects against autism (Gray 1993). Therefore, both children with ASD and their parents suffer from the stigma against ASD and have reported significantly higher psychological distress (Wong et al. 2016). Research shows that caregivers of individuals with ASD experience greater stigma than do caregivers of individuals with intellectual or physical disabilities (Werner and Shulman 2015). Parents of children with developmental disorders or mental health problems have also reported higher levels of stigma as compared to parents of nondisabled children after a 10-year period, and their stigma was associated with poor parental health outcomes (Song et al. 2018). Spouses of persons with ASD also reported struggling with loneliness after marriage as well as social misunderstandings by others, leading to social exclusion, with the spouses reporting that “people do not understand me” and feeling they were “being blamed for not living up to the spouse’s role.” These experiences of the loss of spousal identity and connection with others may be categorized as stigmatization (Deguchi and Asakura 2018). Accordingly, stigma against ASD is a critical issue affecting the health (Song et al. 2018) and psychosocial outcomes of family members (e.g., quality of life, self-esteem, and hope; Livingston and Boyd 2010).

Although stigma is an important matter among families of children with developmental disabilities (Ali et al. 2012; Chan and Lam 2017; Mak and Kwok 2010; Wong et al. 2016), to date, there is limited information on the stigma experienced by families of persons with ASD. Although family members of those with ASD experience deleterious outcomes, there is a

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✉ Naoko Kumada Deguchi
naokok-tky@umin.ac.jp

[1] Department of Public Health Nursing, Faculty of Medicine, University of Tsukuba, 1-1-1 Tenno dai, Tsukuba City, Ibaraki, Japan

[2] Laboratory of Health and Social Behavior, Tokyo Gakugei University, Koganei, Japan

lack of research on how the stigma affects their physical and mental health, and a more detailed understanding of how stigma affects this population is needed. In this context, Mazumder and Thompson-Hodgetts (2019) synthesized the existing literature related to the stigmatization of children with ASD and their families and identified several broad, overarching themes. The review divided the existing knowledge about the stigma against children with ASD and their families into four categories using qualitative method such as thematic analysis. Clearly, it is necessary to pursue a more in-depth exploration of how children with ASD and their families experience internalized stigma and which factors influence the process of stigma internalization. Moreover, developing quantitative research to measure the extent of stigma can help identify factors that influence the process of stigma internalization and establish interventions for public stigma reduction. Beyond simply describing lived experiences related to stigma, it is vital to characterize such stigma in order to quantitatively measure more types of stigma experienced by children with ASD and their families and ultimately to combat stigma. Accordingly, conducting a scoping review, we will attempt to identify a few more dimensions (i.e., themes) than the previous review identified and clarify the constructs for the concept of self-stigma in families of persons with ASD and identify characteristics that will guide the development of a scale of dimensions (i.e., degree) of stigma. In this regard, our research advanced a little further than the research by Mazumder and Thompson-Hodgetts. In the following paragraphs, we present the stigma study and study of self-stigma of families, and then describe the originality of our study and how it differs from previous studies.

Stigma Theory

Public stigma and self-stigma have been thoroughly explored through research and are fundamentally different concepts. Public stigma is more common and focuses on the general population's common social attitudes (Pescosolido and Martin 2015) toward persons comprising a particular group (Link et al. 1997). Self-stigma, however, focuses on the internalization of a negative social view (Corrigan and Watson 2002) and refers to the perceptions of internalized acceptance of stigmatization by parties belonging to a particular group and their families (Pescosolido and Martin 2015). Public stigma of mental illness can be distinguished from self-stigma in that the former refers to the negative stereotyping of the general population toward people with mental illness (Corrigan and Watson 2002) and the latter is the internalization of this negative stereotyping by the actual person with mental illness (Corrigan 2000; Corrigan and Watson 2002; Corrigan et al. 2016). Self-stigma can be defined as shame, evaluative thoughts, and fear of the enacted stigma that results from individuals' identification with a stigmatized group and that serves as a barrier to the pursuit of valued life goals. Self-stigma theory includes three components: (1) a stereotype is a negative belief about the self, (2) prejudice is the agreement with others' beliefs about themselves and their negative emotional reactions, and (3) discrimination is the behavioral response to prejudice (Corrigan and Watson 2002). Theoretically, public stigma leads to the development of self-stigma (Corrigan 1998; Vogel et al. 2007, 2013). Public stigma and self-stigma hamper the social lives of persons with mental illness and act as a barrier to recovery (Oexle et al. 2018; Perlick et al. 2001), which can lead to low self-esteem (Lannin et al. 2015; Link et al. 2001) and depression (Corrigan et al. 2019; Pyne et al. 2004). Many studies have addressed the stigma of mental illness. However, these studies have mainly focused on clarifying the dimensions of public stigma, which include social distance, traditional prejudice, exclusionary sentiments, negative affect, treatment carryover, disclosure carryover, and perceptions of danger (Pescosolido and Martin 2015). However, the dimensions of internalized stigma have not yet been fully explored.

Self-Stigma of Families

Stigma affects more than just the labeled individuals (Goffman 1963; Mak and Cheung 2008; Mehta and Farina 1988)—it also influences those closely related to them. Past studies have used several terms to refer to such stigma with several terms, including courtesy stigma (Goffman 1963), associative stigma (Mehta and Farina 1988), and affiliate stigma (Mak and Cheung 2008). Courtesy stigma is defined as the negative impact of the association with an individual who has been stigmatized (Goffman 1963). Associative stigma is identified as stigma experienced by people who are merely associated with an afflicted individual rather than being directly marked (Mehta and Farina 1988). Affiliate stigma refers to the self-stigma and corresponding psychological responses of those associated with a stigmatized individual (Mak and Cheung 2008). The study of family self-stigma is challenged by complex definitions and terminology that differ markedly across studies (Pescosolido and Martin 2015). The diversity of these definitions has hampered cross-study comparison and the development of unified measures of family stigma, indicating that more detailed research is required (Pescosolido and Martin 2015).

We defined the self-stigma of families as the experience of an individual who internalizes the stigma that marks their family and its corresponding psychological responses. The current study is unique in that it includes all existing relevant research while restricting its focus to families. By reviewing only research that examines how the family experiences stigma, we can capture family-specific aspects of the types of internalization associated with stigma. A review of previous studies may provide a comprehensive understanding of a family's self-stigma, which has been previously defined in disjointed terms, as well as reveal new aspects of family self-stigma.

Family self-stigma occurs when the families of persons with ASD internalize the stigma, including the agreement with others' negative beliefs, negative emotional reactions, and the behavioral response to prejudice. Such stigma can hamper family members' social lives and has been found to predict subjective well-being among the families of individuals with ASD (Mak and Kwok 2010; Werner and Shulman 2013) and the psychological distress of parents of those with ASD (Wong et al. 2016). Furthermore, courtesy stigma (i.e., self-stigma of families) was found to be a predictor of depression, anxiety, and caregiving burden among parents of those with ASD (Chan and Lam 2017).

Original Findings of this Study Compared to Previous Studies

While researchers have explored the self-stigma of families and its associations with psychological distress and well-being among families of persons with mental illness, little research has explicitly focused on the families of persons with ASD. The study by Mazumder and Thompson-Hodgetts (2019) is one of the few scoping reviews of the existing empirical literature on stigmatization related to ASD. A major difference between the Mazumder and Thompson-Hodgetts (2019) study and ours is the difference in research perspectives. Mazumder and Thompson-Hodgetts (2019) researched the findings on stigma for children with ASD and their families and synthesized them into four themes using thematic analysis and other qualitative methods to describe them. Their study has made a significant contribution to the field and established the need for additional research to increase the understanding of stigma from different perspectives. Our study aims to explore in more detail one of the four themes identified by Mazumder and Thompson-Hodgetts (2019): self-stigma in families of people with ASD. This study will unearth qualitative research to elucidate in detail the lived experience of stigma, identify a number of dimensions, and uncover the components of stigma. We will then attempt to characterize aspects of self-stigma to guide the development of stigma scales. We chose to focus on the self-stigma of families of people with ASD because current quantitative studies using the self-stigma scale have not been developed for families of people with ASD. Self-stigma is also important in elucidating the lived experience of qualitative research. In developing quantitative research in the future, it is necessary to capture the subject's lived experience as unimpaired as possible in a quantitative manner, and for this purpose, it is important to develop a scale tailored to the subject. This study will contribute to the self-stigma theory of families of persons with ASD and provide useful information for the future development of quantitative research on the self-stigma of families of persons with ASD.

We describe four specific differences between this work and the work of Mazumder and Thompson-Hodgetts (2019). First, there is a difference in how the concept of stigma is examined in the two studies. The review by Mazumder and Thompson-Hodgetts (2019) examined both public stigma and self-stigma when selecting articles. While public stigma is defined as public recognition, self-stigma is defined as internalization by persons with ASD and their families. When considering both public stigma and self-stigma, those who encounter either public stigma or self-stigma have different positions and experiences, resulting in notable differences between the two forms of stigma. While public stigma and self-stigma are qualitatively different, it may be difficult to observe their respective phenomena by integrating them. Research has begun to separate public stigma from self-stigma and explore their components in depth. Since Pescosolido and colleagues (Pescosolido and Martin 2015) examined and clarified the dimensions of the public stigma experienced by people with mental illness, we decided to review the dimensions of the self-stigma specific to ASD in order to make the dimensions of self-stigma in ASD family members clearer and more accurate. Second, there are differences in the scope of the studies reviewed. The review by Mazumder and Thompson-Hodgetts (2019) included studies of children of ASD, parents of children with ASD, and typically developing children. Because family stigma depends on the role of the family (Corrigan and Miller 2004; Corrigan et al. 2006), it is inappropriate to consider the stigma of the person diagnosed with ASD and his or her parents' stigma together. We have limited the focus to the family members of persons with ASD. Since stigma may differ depending on a person's role within the family, narrowing the target may further clarify the concept of family stigma. Third, there are differences in the types of disabilities reviewed. The review by Mazumder and Thompson-Hodgetts (2019) included research on intellectual and physical disabilities. As stigma varies by type of disability (Werner and Shulman 2015), it would be inappropriate to include a study of caregivers of children with physical and intellectual disabilities in this study. Therefore, we attempt to articulate the dimensions of self-stigma specifically for families of persons with a diagnosis of ASD and not persons with other intellectual and physical disabilities. Fourth, there are differences in the types of studies reviewed. We believed that a review of existing qualitative research would yield new findings. Current quantitative studies use the self-stigma scale for families of people with ASD that were developed for families of people with intellectual disabilities and mental disorders, and the studies used in the quantitative study by Mazumder and Thompson-Hodgett are similar. Because stigma varies depending on the type of disability (Werner and Shulman

2015), studies that use scales developed for families of people with intellectual disabilities and mental disorders may overlook important dimensions of the stigma of the family of persons with ASD. The field of self-stigma research acknowledges that it is important to elucidate the lived experience included in qualitative research. Reviewing the qualitative study of the families of persons with ASD allows us to identify the specific aspects of the families of persons with ASD and deepen the stigma theory for those with ASD. Furthermore, we have limited our focus on the dimensions of self-stigma by examining the narratives from families with ASD found in qualitative research.

Research Questions, Purpose, and Approach

This study reviews the dimensions of family self-stigma that were experienced by families of those with ASD and was guided by two questions. First, are there any dimensions of self-stigma of families that are unique to the families of persons with ASD? Second, under what conditions does the self-stigma of families experienced by families of persons with ASD occur? We used a scoping review as this approach has been identified as the best "when a body of literature has not yet been comprehensively reviewed, or exhibits a large, complex, or heterogeneous nature not amenable to a more precise systematic review" (Peters et al. 2015, p.141). While the concept of stigmatization, including both public stigma and self-stigma combined together, was thoroughly reviewed by Mazumder and Thompson-Hodgetts (2019), the concept of self-stigma among families of persons with ASD has not been well reviewed, to date, so we first outlined the aspects of family self-stigma in the reviewed research to show the full extent of the concept. The comprehensive nature of scoping reviews allowed for the systematic integration of the existing literature regarding the dimensions of self-stigma among families of individuals with ASD, making it an appropriate method for this study.

Method

This study was designed as a scoping review. The study protocol followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols extension for scoping reviews (PRISMA-ScR; Tricco et al. 2018).

Search Strategy

Four electronic databases were searched: Psych INFO, Web of Science, PubMed, and Ichushi Web References. We restricted the search to empirical research written in English and Japanese and searched from the inception of these databases until the end of September 2018.

The search followed the three steps recommended for systematic scoping reviews by Peters et al. in 2015. First, we conducted an initial limited search in PubMed using three keywords: autism spectrum disorder AND stigma AND family. Second, we initially organized keywords into blocks comprising Medical Subject Headings (MeSH) terms using the advanced search feature of PubMed because comprehensive search strategies should consist of both keywords (or free-text words) and index terms. Index terms are used by some major bibliographic databases to describe the content of each published article with a "controlled vocabulary" (Aromataris and Riitano 2014). PubMed lists the medical subject heading (MeSH) terms that represent the controlled vocabulary of MEDLINE. MeSH terms are categorized within 16 main "trees," each of which branches from the broadest to the most specific terms. Thus, using the MeSH terms allowed for an exhaustive keyword search to help identify suitable search terms.

For the other databases, we used shorter search formulas to obtain references related to our topics and technical terms. We consulted librarians about the search formula and methods to refine the search. Finally, we conducted a hand search of the reference lists of all selected articles. We repeated this process until no additional relevant articles were found. Screening the reference lists of studies already selected for inclusion in the review is often a valuable means of identifying other pertinent studies. Similarly, manually searching specific journals is often recommended by systematic review authors to locate studies (Aromataris and Riitano 2014). We used both of these methods to ensure no relevant articles were excluded.

After we developed our search query,[1] the literature search was conducted by one author and an experienced librarian. We used the PRISMA flowchart (Moher et al. 2015) to report the search strategy (see Fig. 1). In writing the scoping review, we adhered to the appropriate protocol with reference to the reporting guidelines.

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[1] The final search strategy for Web of Science and PsycINFO was (Autism Spectrum Disorder* OR ASD OR Autistic Disorder* OR Asperger* syndrome OR Asperger* Disorder* OR Asperger* Disease* OR Child Development* Disorder* OR Pervasive Development* Disorder*) AND Stigma* OR Courtesy Stigma* OR Associative stigma* OR Affiliate stigma* OR Self Stigma* OR Perceived Stigma*) AND (Famil* OR Parent* OR Mother* OR Father* OR Spous* OR Marri* OR Partner* OR Sibling* OR Child*). In Ichushi Web References, we used the same terms in Japanese. In PubMed, we used the same terms, but we used MeSH terms as follows: "autism spectrum disorder"[MeSH Terms], "autistic disorder"[MeSH Terms], "asperger syndrome"[MeSH Terms], Stigma[MeSH Terms], Family[MeSH Terms], Parents[MeSH Terms], Mothers[MeSH Terms], Fathers[MeSH Terms], Spouses[MeSH Terms], Siblings[MeSH Terms], Child[MeSH Terms].

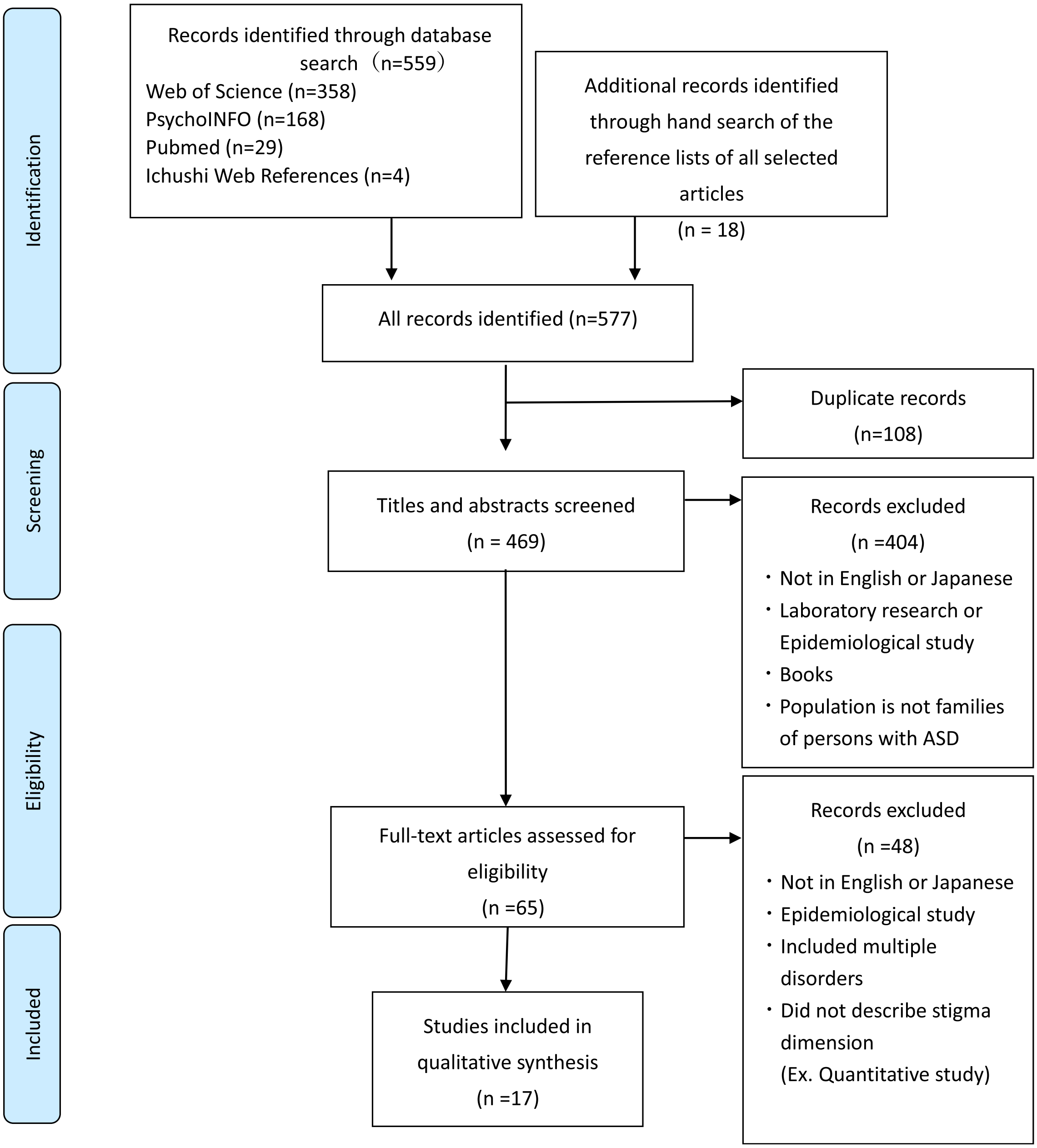

Fig. 1 Flow diagram of articles identified and excluded for self-stigma of families of persons with autism spectrum disorder. Note: The exclusion criteria are duplicated, and the total number of articles excluded from the standard set in this research is shown

Eligibility Criteria

Inclusion Criteria

The following inclusion criteria were used to identify articles for this review: study participants were family members of individuals with ASD, including stigma as the main research theme; in any country; information was published in English or Japanese in original articles and gray literature; and publications were available online or in the library. The reason for not limiting the review to self-stigma and qualitative research at this stage was to avoid missing the necessary articles through such restrictions.

Exclusion Criteria

We excluded all articles describing laboratory research, articles on ASD epidemiology, articles exclusively targeting other socially stigmatizing diseases and disabilities, and articles centered on quantitative analyses that did not seek to describe the dimensions of stigma. Exclusion criteria were overlapping; therefore, the number of articles rejected for each criterion could not be determined. Overall, the total number of articles excluded from the standard set in this research was 452. In our review, quality checks were completed on each article that was to be included in the final scoping review. For this process, the Mixed Methods Appraisal Tool version 2018 (MMAT, Department of Family Medicine, McGill University, Montreal, QC, Canada) was used (Hong et al. 2018).

Data Collection and Extraction

The second and third authors are experts in the field of stigma, and the first author is a researcher in the field of ASD; the second author had previously conducted systematic reviews and the first and third authors had previously learned about systematic reviews. The first and second authors reviewed the titles and abstracts of all studies independently and selected articles for full-text review according to the eligibility criteria. In the event of disagreement, the final author served as a tiebreaker, and all three authors reaffirmed that selected articles met the inclusion and exclusion criteria. The reference management software, RefWorks, was used to avoid the duplication of references, perform an initial screening of titles or titles and abstracts, provide a digital backup for archiving, and improve the traceability of the search process of the review. The five steps of reporting scoping reviews were followed: step 1. identifying the research question; step 2. identifying relevant studies; step 3. selecting the studies; step 4. charting the data; step 5. collating, summarizing, and reporting the results (Arksey and O'Malley 2005; Daudt et al. 2013).

To identify our dimensions, we referred to the meta-synthesis method (Sandelowski and Barroso 2006; Thorne et al. 2004). Meta-synthesis was used for examination, including key comparisons and synthesis for published qualitative studies on common topics. This is a validated research process aiming at gaining more knowledge about the phenomenon than what could be achieved from a single independent study (Sandelowski and Barroso 2006; Thorne et al. 2004). It is comprised of five phases: (1) identification of the focus of review; (2) identification of published and relevant articles; (3) quality appraisal of the included articles; (4) data extraction and identification of key concepts; and (5) development and comparison of core themes across the documents and their synthesis into a new conceptual representation. Data were extracted and mapped onto an Excel sheet (Windows, Microsoft Corporation). A narrative synthesis approach was used to compile the data and extract examples from individual studies. Key themes were compared between articles so that findings could be linked between studies and integrated into new concepts (Sandelowski and Barroso 2006). We followed the synthesis of qualitative research approach (Campbell et al. 2003), and the procedure can be seen in Fig. 2. We read the content of each article carefully and extracted the relevant parts related to stigma. This was done for each of the selected articles. The relevant quotations were abstracted from the appraisal sheets for each article and referred back to the original articles to check details and terminology. Key concepts were identified at the bottom of each list. The lists were prepared manually on pieces of paper adjacent to each other. After identifying the main concepts to emerge from each article, the article was systematically searched for the presence or absence of these concepts in all the articles so that they could be synthesized. Through the above procedure, we extracted the key concepts of each article, listed the dimensions existing in the participants of the 17 studies, and confirmed that these key concepts were valid. We categorized the key concepts based on their similarities. Several experts also confirmed the validity of the categorization. Through this process, we decided on the final dimensions. Similar key concepts were extracted from each study, and they were listed and categorized as dimensions of self-stigma of families. Through these steps, we generated dimensions of self-stigma of families specific to those of persons with ASD. Six dimensions were ultimately created.

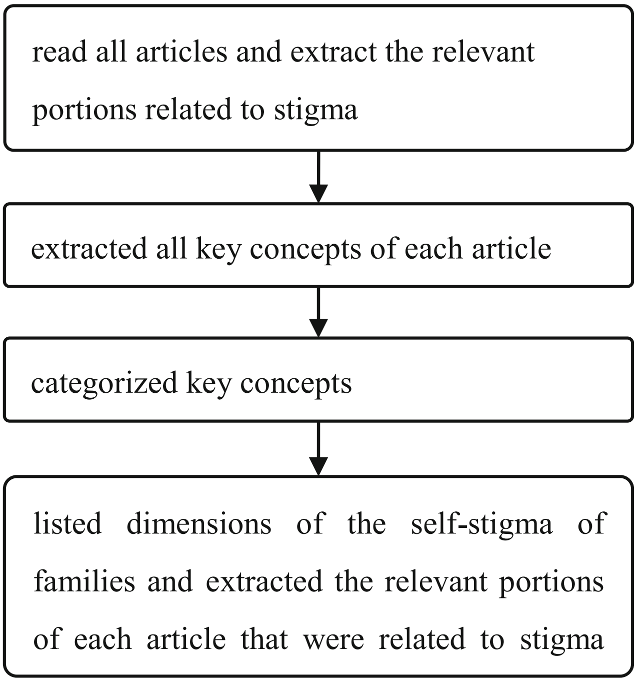

Fig. 2 Processes of data extraction and identification of key concepts

Results

Study Characteristics

Figure 1 provides the details of the search results. A total of 17 studies matched the inclusion criteria (for a full review list and their characteristics, see Table 1; Blanche et al. 2015; Broady

Table 1 Qualitative studies reviewed by study design, and number and characteristics of participants

Authors	Year of publication	Country	Study design	Participants	Number of participants	Age range (years)
Marsack, Christina N. et al.	2018	USA	In-depth, semi-structured interview via phone	Parents of adult children with ASD	51 parents (46 mothers, 5 fathers)	Early 50s to 70s
Selman, Lucy Ellen et al.	2018	UK	Semi-structured interview	Somali parents of children with autism living in Bristol	15 parents (12 mothers, 3 fathers)	28–56 years
Broady, Timothy R. et al.	2017	Australia	Semi-structured interview	Carers of children who are diagnosed with high-functioning autism	15 carers (9 women, 6 men) 12 married participants (including six participants who were married couples), one separated and two divorced participants	Carers: unknown Children: 5–19 years
Krishnan, Raman et al.	2017	India	Focus group discussion	Mothers of children with autism spectrum disorder	24 mothers (6 focus groups)	26–34 years
Ijalba, Elizabeth	2016	USA	In-depth 3-part phenomenological interview	Hispanic immigrant mothers of preschool children with ASD	22 mothers	Mothers: unknown Children: 37–45 months
Loukisas, Theodoros D. et al.	2016	Greece	Content analysis of personal blog	Mothers who have school-aged children on the autistic spectrum	5 mothers	35–45 years
Munroe, Kathryn et al.	2016	UK	Individual semi-structured interview	Mothers of boys diagnosed with ASD	6 mothers	30–45 years
Blanche, Erna Imperatore et al.	2015	USA	In-depth semi-structured Interview	Latino parents with children with ASD	15 parents (12 mothers, 3 fathers)	Parents: unknown Children: 6–18 years
Minhas, Ayesha et al.	2015	Pakistan	In-depth interview	Carers of children with ASD	15 parents (11 mothers, 4 fathers)	Parents: unknown Children: 7–16 years
Russell, Ginny et al.	2012	UK	In-depth semi-structured interview	Parents who were not actively pursuing a diagnosis ($n = 8$); parents of children with an ASD diagnosis ($n = 9$)	17 parents (15 mothers, 2 fathers)	Parents: unknown Children: 5–16 years
Gill, Jessica et al.	2011	Australia	In-depth semi-structured interview and solicited diary methods	Mothers of children who have Asperger's Syndrome	15 mothers	30–55
Morito, Masako et al.	2010	Japan	Semi-structured interview	Mothers of child with developmental disorders	3 mothers	Mean age = 37.3 years
Yamauchi, Akiko et al.	2009	Japan	Semi-structured interview	Mothers who live with their children with autism	8 mothers	Mothers: unknown Children: > 20 years
Farrugia, David	2009	Australia	Semi-structured interview	Parents of children diagnosed with an autism spectrum disorder	16 participants (11 mothers, 5 fathers, 12 semi-structured interviews)	Parents: unknown Children: 5–23 years
Gray, David E.	2002	Australia	In-depth semi-structured interview	Families of children with autism	53 parents (32 mothers, 21 fathers)	Parents: unknown Children: 5–26
Segal, Ruth et al.	2002	None	Semi-structured interview	Parent of children with developmental coordination disorder	8 parents (6 families, both mothers and fathers)	Parents: unknown Children: 9–11
Gray, David E.	1993	Australia	Semi-structured interview	Parents of children with autism	32 parents (23 mothers, 9 fathers)	Unknown

Unknown: there is no information regarding this item in the article; *ASD* autism spectrum disorder et al. 2017; Farrugia 2009; Gill and Liamputtong 2011; Gray 1993, 2002; Ijalba 2016; Krishnan et al. 2017; Loukisas and Papoudi 2016; Marsack and Perry 2018; Minhas et al. 2015; Morito and Matsumoto 2010; Munroe et al. 2016; Russell and Norwich 2012; Segal et al. 2002; Selman et al. 2018; Yamauchi et al. 2009). Seven out of the 17 articles (40%) overlapped with those from the article by Mazumder and Thompson-Hodgetts (2019). By using the MMAT (Hong et al. 2018), we revealed that the methodological quality of articles was high, scoring 5/5. The publication years of the included studies ranged from 1993 to 2018. Fourteen of the articles were published within 10 years of each other, and of these, nine articles were published within 5 years of each other. The studies were conducted in seven countries: Australia, Greece, India, Japan, Pakistan, the UK, and the USA. One study did not specify the country. Fourteen studies conducted face-to-face interviews, one study conducted focus group discussions, one study conducted a content analysis of personal blogs, and one study conducted semi-structured phone interviews. Sixteen studies included mothers among the participants, nine studies included fathers, and one study included female and male caregivers. Despite searching for studies involving family members other than parents, such as brothers or wives, there were no studies involving siblings and spouses.

Self-Stigma Among Families with ASD

All 17 studies provided qualitative information on the dimensions of self-stigma among families of persons with ASD (Table 2). The identified dimensions included social misunderstanding, negative prejudice, social rejection, emotional reactions, isolation, and stigma management. Findings in Table 2 indicate the relevant section of each article. Table 3 shows the dimensions of self-stigma explored in each study.

Social Misunderstanding

Social misunderstanding is characterized by intolerance and exclusion due to a lack of understanding regarding ASD. Social misunderstanding indicates that people either do not recognize ASD or, if they do, their understanding of the disorder is insufficient. For example, people may misunderstand the family by assuming that the parents are negligent or that the family has problems. Eight studies focused on the poor understanding of families of people with ASD, and this concept was referred by many names in the articles, including a lack of understanding (Minhas et al. 2015; Selman et al. 2018), a lack of knowledge (Broady et al. 2017), misunderstanding (Marsack and Perry 2018), and poor understanding (Morito and Matsumoto 2010). Participants reported that they felt social misunderstanding from relatives, friends, communities, society, school staff, and medical professionals.

Negative Prejudice

Negative prejudice is characterized as feelings of prejudice from others, including negative judgment toward and blame for ASD in the family. Negative prejudice indicates that the families of persons with ASD feel they are judged negatively by various social relations or during social interaction. Nine articles out of the reviewed studies identified this theme. Negative prejudice was identified as a person being blamed (Munroe et al. 2016), feeling judged (Broady et al. 2017), being treated as if they were bad parents (Farrugia 2009), and receiving rude comments from others (Gray 2002). Again, participants felt that negative prejudice came from others, including relatives, neighbors, friends, social institutions, professionals, and the public.

Social Rejection

Social rejection is characterized as the awareness of social distance and the internalizing of social rejection from others. Social rejection occurs when the families of persons with ASD are aware that they are being deliberately excluded from social relationships or social interactions. Ten articles of the reviewed studies found this theme. Social rejection manifested as exclusion (Broady et al. 2017; Krishnan et al. 2017), discrimination (Selman et al. 2018), and avoidance by others (Gray 2002). Participants felt that social rejection came from friends, family, community members, medical professionals, and others.

Emotional Reactions

Emotional reactions are characterized as internalizing negative prejudice or social rejection and feeling negatively about oneself. Emotional reactions occur when the families of persons with ASD feel the brunt of negative stereotypes. Five of the reviewed studies found this theme. These feelings were reported as emotional reactions (Selman et al. 2018), shying away from others (Russell and Norwich 2012), fatigue (Yamauchi et al. 2009), and embarrassment (Gray 2002; Segal et al. 2002). The participants reported emotional reactions from a variety of sources, including other parents of children attending the same school. The lack of acceptance of their child's problematic behaviors by others led parents of children with ASD to feel negatively about themselves and react emotionally.

Isolation

Isolation starts with the feelings of social misunderstanding, negative prejudice, or social rejection, and the internalization of emotional reactions, which contribute to being socially isolated. Isolation refers to the lack of contact between families of

Table 2 Dimensions of self-stigma of families categorized from studies

Dimensions of self-stigma of families	Authors	Year of publication	Findings	Who stigmatized the participants
Social misunderstanding	Marsack, Christina N. et al.	2018	*Misunderstanding and/or stigma* Many participants recounted the misunderstanding that comes from a lack of knowledge of ASD and variations within the spectrum that contributes to relatives, friends, professionals, and the general public not understanding what behaviors to expect from adults diagnosed with ASD. (p.540)	Relatives Friends Professionals General public
	Selman, Lucy Ellen et al.	2018	Central to being labeled as different, and the associated stereotyping, was a perceived lack of understanding and vocabulary related to autism in the Somali community. (p.786)	Community
	Broady, Timothy R. et al.	2017	*Lack of knowledge* Other people's lack of knowledge about autism was seen as a major contributor to stigmatizing experiences, as suggested by comments such as, "Ignorance is the biggest issue we face" (Allan). Every interviewed carer reported a lack of knowledge of and experience with autism within school communities, as demonstrated by Nicole, who said, "the teacher . . . very limited experience in autism." (p.227)	Other people School Communities
	Ijalba, Elizabeth	2016	*Stigmatization and desire for social acceptance* All mothers in this study described social isolation and feeling stigmatized. In similar accounts across participants, mothers wanted their children to be socially accepted and valued. All mothers described limited understanding and knowledge about autism for themselves, families, and communities. (p.205)	Themselves Families Communities
	Minhas, Ayesha et al.	2015	*Community attitudes* Lack of understanding of ASD in schools. (p.252) *Care outside the home* Lack of understanding of ASD in child health professionals. (p.252)	Schools Child health professionals
	Gill, Jessica et al.	2011	*Where women felt most stigmatized* The general lack of understanding and empathy from school staff and other parents made these mothers feel as though they were different. (p.714)	School staff Other parents
	Morito, Masako et al.	2010	Prejudice from society means that society has not yet recognized the developmental disorder, so it means that the children have not gained an understanding from others, "Those around the children have cold reactions" and "Society is not aware of the developmental disorder" were extracted. The poor understanding of medical professionals about the disability led to a desire for increased professional understanding of children's disabilities. (p.59)	Society Other people Medical professional
	Gray, David E.	1993	Autistic children appear to be physically normal yet suffer from an extremely pervasive disability. It is this combination of a pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children its unique quality. (p.114)	Public
Negative prejudice	Marsack, Christina N. et al.	2018	Stigma can result in an assumption that ASD behaviors are reflections of parenting ability. Mr. Smith from the Midwest says, "Well I think it's a, it's the culprit is a lack of awareness and so the—when a, when a kid is quirky, they kind of blame the parents—it suggests somehow the parenting skills." (p.541)	Relatives Friends Professionals General public
	Broady, Timothy R. et al.	2017	*Judgment* Participants also reflected on experiences where they had personally felt judged by others because of their child (i.e., courtesy stigma). Judgment was an extension of the lack of knowledge regarding the nature of HFA (high-functioning autism) meant that others viewed carers and their children through a lens of what they considered "normal." Again, there is the appearance here of deliberative stigma responses. (p.228)	Others Schools
	Krishnan, Raman et al.	2017	*Abandonment/rejection/stigmatization* Mothers also expressed that relatives and neighbors had avoided them, looked down on them, and commented that they deserved these children. (p.271)	Public Other relatives Social function
	Ijalba, Elizabeth	2016	*Stigmatization and desire for social acceptance* Most mothers described their lack of privacy at home. They often resided in buildings in close proximity to neighbors where listening through walls was easy. When children cried repeatedly or if they made noise at night, neighbors often expressed concern that mothers were neglecting their children. (p.206)	Neighbors
	Munroe, Kathryn et al.	2016	*The pain of stigma and rejection* The implication that the mothers were to blame appeared to be at the root of many judgments and made these particularly difficult to bear, having a negative impact on their identities. Furthermore, parents felt pressured for their children to meet others' expectations. (p.809)	Family Church Community
	Yamauchi, Akiko et al.	2009	*Fatigue due to prejudice against children with autism* Mothers always experience difficulties when they are criticized by others. Mothers have difficulty going to the community dental hospital. (p.24)	Community dental hospital Neighbors

Table 2 (continued)

Dimensions of self-stigma of families	Authors	Year of publication	Findings	Who stigmatized the participants
	Farrugia, David	2009	*Subjectivity, stigma, and resistance* If the medical explanation for their child's behavior is not accepted by others, they are treated as bad parents, a stigmatized position. (p.1019)	Medical establishment Friends
	Gray, David E.	2002	Rude comments by others, however, are much harder to ignore and frequently prompted parents to react. (p.741)	Others
	Gray, David E.	1993	Mothers may perceive more stigma because they are given the primary responsibility for caring for the child. This means that the mother will be the parent to take more responsibility for the daily management of the child and will be the parent most likely to deal with the child in ordinary public activities, such as shopping. (p.119)	Public
Social rejection	Selman, Lucy Ellen et al.	2018	Alongside labeling and stereotyping, participants described the social separation that occurred as a result of their child's autism. This separation, a hallmark of stigma, began with children being labeled sick, mentally ill, different or disabled, and led to their and their families' physical separation from others. (p.787)	Others
	Broady, Timothy R. et al.	2017	*Rejection* Participants reported a direct sense of rejection, in addition to feeling judged by others. These feelings of rejection were directed at carers and their children alike, but carers expressed a sense of personal rejection in either case (i.e., they felt courtesy stigma when their children were rejected). (p.228–229)	Others Schools
	Krishnan, Raman et al.	2017	*Abandonment/rejection/stigmatization* Most mothers agreed that they had avoided social functions (i.e., churches, hotels, theaters, trains, long trips, parks, family gatherings) for fear of facing the public or relatives. (p.271)	Public Other relatives Social functions
	Ijalba, Elizabeth	2016	*Stigmatization and desire for social acceptance* They described often avoiding social situations as a result of their children's disruptive behaviors. Of the mothers participating in this study, 16 stated that they did not know about autism until they were informed that their child had ASD. (p.205)	Social situations
	Loukisas, Theodoros D. et al.	2016	The mothers experienced negative comments and rejection by their social environment due to their children's behavior, especially when outside, in situations involving contact with other people in public places, such as churches, playgrounds, restaurants, or shops. (p.74)	Teachers School Social environment Public
	Munroe, Kathryn et al.	2016	*Pain of stigma and rejection* This super-ordinate theme encompasses painful experiences of being judged and rejected. Sanaa described rejection from her family, Fumni from her church, and Mabinti from the local African community; all mothers, except Nyah, described feeling unwelcome in public places. (p.809)	Family Church Community
	Blanche, Erna Imperatore et al.	2015	*Dealing with stigma and isolation from family and community* Another topic that was brought up repeatedly by the parents was their discomfort and anger with having their child singled out in the community. (6905185010p5)	Community
	Morito, Masako et al.	2010	The reactions by others surrounding the children are cold. (p.59)	Society Other people
	Farrugia, David	2009	*Subjectivity, stigma, and resistance* Enacted stigma was reported by all participants whose children's behavior was regularly socially inappropriate. Parents attributed enacted stigma to a rejection of the medical construction of their children's behavior used by parents in favor of an explanation that focused on parenting. Researcher: "How do you mean that people were unsupportive?" Participant: "You're being a bad mother. He's behaving like that because you do not discipline him. If you did it this way, you would not have problems. That kind of stuff…you know, it does not help." (p.1018)	Medical establishment
	Gray, David E.	2002	Parents less commonly experienced unambiguously enacted stigma, as only about half had actually been the recipient of negative reactions by others. When they did occur, these reactions took three main forms, the most common of which was avoidance. Such reactions were often disturbing to the parents, especially when they affected the social lives of other children in the family. (p.740)	Others
Emotional Reactions	Selman, Lucy Ellen et al.	2018	Examples of enacted stigma demonstrated others' emotional reactions to the child with autism and their parents, and the discrimination directed at them. (p.788)	Others
	Russell, Ginny et al.	2012	Overall, our data reveal that parents may shy away from diagnosis because they view ASD in a negative light as a stigmatizing lifelong condition. (p.234)	People
	Yamauchi, Akiko et al.	2009	There may be fatigue due to prejudice against children with autism. The behavior of ASD is difficult for others to accept. The mother felt negatively about herself, leading to feelings of fatigue. (p.25)	Others
	Gray, David E.	2002		Others

Table 2 (continued)

Dimensions of self-stigma of families	Authors	Year of publication	Findings	Who stigmatized the participants
			Another manifestation of enacted stigma was overtly hostile staring by others. This usually took place in the context of a public encounter where the child had behaved in a socially inappropriate manner. In these cases, the parents were already in a situation where they were embarrassed, and the negative reactions of others were particularly hurtful. (p.741)	
	Segal, Ruth et al.	2002	The stigma situation was related to a school activity in which the child did not have the leeway to exercise a stigma management technique. Embarrassment to the child and his family were the consequence of this stigma situation. (p.425)	School
Isolation	Selman, Lucy Ellen et al.	2018	Many parents had become socially isolated from the wider community. (p.787)	Community
	Broady, Timothy R. et al.	2017	At a more practical level, carers reported a lack of support as characterizing their stigmatizing experiences. This was a common perception among carers whose children were attending mainstream schools. Carers felt that schools did not support their attempts to improve their children's educational experiences. While this domain did not reflect any malicious intent, a lack of support in caring for a child with additional needs was generally felt as stigma. (p.229)	Others Schools
	Ijalba, Elizabeth	2016	*Stigmatization and desire for social acceptance* All mothers reported social isolation, their desire for acceptance, and feelings of stigmatization. A lack of awareness about autism within their social circles contributed to the mothers' social isolation. Stigmatization was associated with their children's disruptive social behaviors, such as crying. A lack of privacy at home weighed heavily on how mothers described their own social-emotional well-being and that of their children. (p.207)	Family Community Neighbors
	Loukisas, Theodoros D. et al.	2016	Some mothers reported loneliness and isolation as a consequence of rejection by the social environment, an actual experience of social exclusion, and some reported loss of friends and social life. (p.74)	Social environment Friends Social life
	Blanche, Erna Imperatore et al.	2015	*Dealing with stigma and isolation from family and community* Discomfort with having their child's behaviors judged by others led parents to the most prevalent strategy: social isolation. These quotes illustrate how dealing with stigma in some cases led to changes in social practices with friends and family, resulting in isolation. (p. 6905185010p5)	Others Friends
	Gray, David E.	1993	As a consequence, many parents tend to isolate themselves and their families from social contact with the outside world. To a certain extent this isolation, especially for mothers, is a direct effect of the limitations placed on their activities outside the home because of their child's autism. (p.109)	Public
Stigma management	Blanche, Erna Imperatore et al.	2015	*Dealing with stigma and isolation from family and community* The mothers often referred to the coping strategies they developed to avoid what they referred to as *chisme* or gossip. One strategy involved a mother not telling others about her child's difficulties because of fear that stories about the problem would leak back to her village of origin in Central America. Another strategy described by a mother was to cover up her child's atypical behavior by, for example, tickling her child when he laughed without a reason so it would appear as though his laughing was due to her tickling. (p. 6905185010p5)	Others
	Segal, Ruth et al.	2002	In this case, the child, Johnny, found a way to be part of the group without participating in the physical aspect of the game and making his motor difficulties interfere with the group activity. The success of this stigma management strategy may be attributed to both Johnny and his peers. Stigma is a situational attribute, that is, persons are stigmatized when their discrediting attribute is visible or known about and group members reject them. Johnny's peer group was different from those of other children in this study. In the following quote, Mary described that Johnny's peers made sure that he could play tag again and that Nick, a peer, used his own strength and wishes to construct a playful experience. (p.425)	Peers

Findings: italicized headings identify the themes listed by the article's author. The quotations partially summarize the content or supplement the language. At the end of the cited section, the page numbers described in the paper should be noted: (page)

Who stigmatized the participants: this refers to by whom/under what circumstances participants felt stigmatized

persons with ASD and society. Six studies examined the social separation that manifested as isolation (Blanche et al. 2015; Loukisas and Papoudi 2016; Selman et al. 2018) and lack of support (Broady et al. 2017). Participants reported that they felt isolation through the actions of friends, family, the community, and the public.

Table 3 Types of self-stigma of families for each study

Authors	Year of publication	Dimensions of self-stigma of families					
		Social misunderstanding	Negative prejudice	Social rejection	Emotional reactions	Isolation	Stigma management
Marsack, Christina N. et al.	2018	●	●				
Selman, Lucy Ellen et al.	2018	●		●	●	●	
Broady, Timothy R. et al.	2017	●	●	●		●	
Krishnan, Raman et al.	2017		●	●			
Ijalba, Elizabeth	2016	●	●	●		●	
Loukisas, Theodoros D. et al.	2016			●		●	
Munroe, Kathryn et al.	2016		●	●			
Blanche, Erna Imperatore et al.	2015			●		●	●
Minhas, Ayesha et al.	2015	●					
Russell, Ginny et al.	2012				●		
Gill, Jessica et al.	2011	●					
Morito, Masako et al.	2010	●		●			
Yamauchi, Akiko et al.	2009		●		●		
Farrugia, David	2009		●	●			
Gray, David E.	2002		●	●	●		
Segal, Ruth et al.	2002				●		●
Gray, David E.	1993	●	●			●	

Stigma Management

Stigma management is characterized by coping with stigma from the surrounding environment to avoid internalizing stigma. Stigma management occurs when the families of persons with ASD avoid certain situations or develop coping strategies. Two of the reviewed studies found this theme. This has been referred to in studies of families of persons with ASD as stigma management (Segal et al. 2002) and coping strategies (Blanche et al. 2015). Participants reported that they felt that stigma management was prompted by peers and others. The nature of stigma is highly situational, that is, persons are stigmatized when others know about their discrediting attribute and the group members reject them. The person then uses stigma management to cope with the stigma and its associated rejection.

Discussion

Through this scoping review, we attempt to identify several more dimensions than the previous review, clarify the constructs for the concept of self-stigma in families of persons with ASD, and identify characteristics that will guide the development of a scale of dimensions for self-stigma. The results revealed six dimensions of self-stigma—social misunderstanding, negative prejudice, social rejection, emotional reactions, isolation, and stigma management—in families of persons with ASD. Previous research has identified dimensions of public stigma, which primarily refer to people's perceptions of those with mental illness in society. Additionally, the previous review combined the concepts of self-stigma of persons with ASD and their families with public stigma. However, public stigma and self-stigma of individuals and family members are inherently different concepts. No previous review has focused on the self-stigma of family members of persons with ASD to reveal its dimensions in detail, and the research results on the feelings of family members of persons with ASD have not been integrated into previous research. This study is significant in that it contributes to a basic understanding for the development of future quantitative studies to measure the extent of self-stigma and the factors that influence the process of self-stigma. The six dimensions identified in this study reinforce the self-stigma theory of families of persons with ASD and suggest directions for future research.

Our review initially compares the overlapping literature with previous reviews that are based on the results of the 17 studies referenced. There was relatively little overlap in the studies examined in this review compared to previous reviews. Only 2 out of the 17 (12%) studies overlap with those in the review by Pescosolido et al. (Pescosolido and Martin 2015), which identified the dimensions of public stigma, and 8 out of the 17 (47%) studies overlap with those in the review by Mazumder and Thompson-Hodgetts (2019), who overviewed the stigma of persons with ASD, the stigma experienced by families of persons with ASD, and public stigma.

However, the results of our review differed from the conclusions of the previous reviews. The review by Pescosolido and Martin (2015) revealed seven dimensions of public stigma, which were inherently different from the dimensions of self-stigma experienced by the family members of a person with ASD. Additionally, there were four points of originality in the current study. The first point was that the current study considered specific aspects of the self-stigma of ASD. Although self-stigma theory includes stereotype, which is a negative belief about the self (Corrigan and Watson 2002), previous research by Mazumder and Thompson-Hodgetts (2019) combined the concepts of public stigma and self-stigma, so the stereotypes perceived by family members of people with ASD themselves were not present in the results. Our study identified the stereotypes of the dimensions of self-stigma among family member of a person with ASD as social misunderstanding, negative prejudice, and social rejection. In particular, social misunderstanding was considered to be specific to families of individuals with ASD. The second point was the concept of emotional reactions, which was newly identified in this study. Although self-stigma theory includes the concept of prejudice, an agreement with belief and negative emotional reaction, the Mazumder and Thompson-Hodgetts review (2019) did not identify the concept of family emotions in persons with ASD. The third point was the concept of stigma management, which refers to the perception that families of individuals with ASD have of themselves. This was a new concept reviewed in this study and was not present in past self-stigma theories; it was considered to be a unique aspect of the family of a person with ASD. Mazumder and Thompson-Hodgetts (2019) described the concept of stigma reduction with regard to education programs and anti-stigma programs to increase understanding among people in society. While Mazumder and Thompson-Hodgetts provide an important perspective, their review identified a public stigma perspective and therefore was different from the self-stigma, which focuses on the lived experiences of the family members of the person with ASD. For the fourth point, the study revealed the sources of the stigmatization of family members of persons with ASD because the perceived sources of stigmatization may be useful for future educational programs designed to reduce the stigma. These results were also specific to this study. Another similar concept was identified in this review and that of Mazumder and Thompson-Hodgetts (2019), who identified the concept of social isolation, which represents part of the self-stigma of some individuals with ASD and their families and is similar to the concept of isolation identified in this study.

The literature reviewed in this study showed that parents suffered social misunderstanding from the people around them. The major behavioral characteristics of ASD include persistent deficits in social communication, social interactions, social-emotional reciprocity, and communicative behavior (American Psychiatric Association 2013). These features can overlap with normal development and it is sometimes difficult to see that certain behaviors are the result of ASD. Given this, the family of individuals with ASD internalized social misunderstanding. Family members of persons with ASD faced problems relating to the characteristics of the disability and how society reacted to those characteristics, as well as challenges experiencing typical social relationships with their family members who have ASD. The self-stigma of families of those with ASD arose from these problems. Previous studies show that autism has uniquely stigmatizing aspects (Gray 1993) and that the families of persons with ASD have experienced social exclusion (Deguchi and Asakura 2018). Furthermore, families of children with ASD often feel that it is difficult for society to accept the behavioral characteristics of ASD. Family members also feel that they have violated social norms by raising a child with ASD, as the parents of a child with ASD may be regarded as not being dedicated enough to childrearing, causing others to blame or consider them to be bad parents (Ijalba 2016; Krishnan et al. 2017; Marsack and Perry 2018). Thus, internalized family stigma begins with social misunderstanding.

In addition to social misunderstanding, individuals experience negative prejudice, social rejection, emotional reactions, isolation, and stigma management. Negative prejudice and social rejection correspond to the self-stigma theory (Corrigan and Watson 2002) and its construct of stereotypes (i.e., the negative belief about the self), emotional reactions correspond to the construct of prejudice in the self-stigma theory (i.e., the agreement with belief and negative emotional reactions), and isolation corresponds to discrimination (i.e., behavioral responses to prejudice). Although stigma management is a behavioral response to prejudice, it has not been previously identified in self-stigma theory (Corrigan and Watson 2002). We identified two studies that examined stigma management (Blanche et al. 2015; Segal et al. 2002) and reported that successful stigma management might reduce the negative influences of the self-stigma of families.

This review adds new insights to self-stigma theory. Previous studies have primarily examined public stigma (Pescosolido and Martin 2015), whereas we explored the dimensions of family stigma, particularly in the families of persons with ASD, who have been overlooked in previous research. Many studies found that stigma is a predictor of psychological problems (Livingston and Boyd 2010). By expanding what is known about the dimensions of family stigma, we can identify future research directions that focus on family-internalized stigma and its related psychological problems, which could provide practical suggestions to effectively manage the self-stigma of families. Stigma definitions and measures have varied widely across prior studies, so we propose that utilizing our stigma dimensions when developing a stigma scale for families of persons with ASD would be practical for both research and clinical practice. As a practical application, this research revealed that family members of those with ASD felt that they were stigmatized by teachers, medical professionals, and the broader community. Since social misunderstanding could result in stigma for families of persons with ASD, providing education regarding the experiences and challenges of these families in schools, hospitals, and community settings may reduce experiences of self-stigma.

Five directions for future research can be recommended based on our findings. First, future research should focus on the internalization process and the mechanism of self-stigma in the families of those with ASD. This is because there is little research focusing on the mechanism of self-stigma in the families of those with ASD. Second, future research needs to compare the differences between the internalization of self-stigma in a person with ASD and their family members. While family stigma changes depending on a person's role in the family (Corrigan and Miller 2004; Corrigan et al. 2006), self-stigma in a person with ASD and their family members may also differ. Third, it would be beneficial for future research to investigate the factors affecting the internalization of self-stigma in families with persons with ASD. This is because revealing the factors leads to practical suggestions to support the families of persons with ASD. Fourth, although there are studies in which either mothers or both parents of persons with ASD are analyzed, no study has focused exclusively on fathers, spouses, or siblings, so future research should include a wide range of family members. Finally, future research needs to investigate the self-stigma in families of adults with ASD, as most research has focused on the family of children with ASD.

Our review has some limitations partly because of this lack of research. First, although we searched for the "family" of persons with ASD, most studies targeted parents, particularly mothers. This made it difficult to explore gender differences in the experience of self-stigma in this analysis; therefore, it is necessary to accumulate research on fathers, siblings, spouses, and children of persons with ASD. Second, the review excluded studies that were not in English or Japanese. Nevertheless, our findings expand the body of knowledge on self-stigma theory and the experiences of families of those with ASD.

Conclusions

This review revealed dimensions of self-stigma that were experienced by family members of persons with ASD, including social misunderstanding, negative prejudice, social rejection, emotional reactions, isolation, and stigma management. One dimension, social misunderstanding by others, was specific to the families of persons with ASD. The families of persons with ASD recognized self-stigma from such sources as social connections, the community, health professionals, school, neighbors, friends, relatives, family, and so on. It is hoped that this review will identify more dimensions than previous reviews, identify components of the concept of self-stigma in families of individuals with ASD, add new insights to self-stigma theory, and encourage further practical applications and future studies.

Acknowledgments The authors are grateful to representatives of The Japan Science Society of Public Interest Incorporated Foundation.

Funding This work was supported by the Sasakawa Scientific Research Grant from The Japan Science Society (grant number 2018-1015).

Compliance with Ethical Standards This article does not contain any studies with human participants or animals performed by any of the authors.

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