A systematic review on autistic people's experiences of stigma and coping strategies

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Abstract

Autism can be understood as a concealable stigmatised identity. This is the first systematic review to synthesise the literature on autistic people's experiences of stigma and coping strategies. 2877 studies were screened and 27 were included in this review. The reviewed literature demonstrates that autistic individuals are acutely aware of being stereotyped, judged, and discriminated by others. Autistic people also show signs of internalising stigma, rendering them more vulnerable to low self-worth and poorer mental health. To manage the impact of stigma, the included studies suggest that autistic individuals may use these strategies: concealment and camouflaging, selective disclosure and self-advocacy, as well as positive reframing and reconstructing identity. However, the evidence is limited and mixed in terms of how helpful and effective these strategies are. Future studies should include autistic populations with a wider range of intellectual abilities and explore interventions that can support autistic people in managing stigma to supplement interventions that seek to reduce stigma towards autistic people. The power of language in perpetuating and challenging stigma also has important implications for research and practice, underscoring the need for researchers and practitioners to reflect carefully on the messages they are communicating about autism.

Lay summary

This review has found that autistic people often experience stigma, which refers to negative attitudes and treatment from others. Because of that, some autistic people also have negative beliefs about themselves, which may affect their self-worth and mental health. While research suggests that autistic people use a range of strategies to manage stigma, the evidence is limited and mixed in terms of how helpful these strategies are.

Introduction

Stigma was traditionally defined as "an attribute that is deeply discrediting" and that reduces the stigmatised person "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Subsequent definitions acknowledged the wider social forces that shape stigma, with Link and Phelan (2001) stressing that the production of stigma is dependent on power differences between the stigmatiser and the stigmatised. Link and Phelan conceptualised stigma as a process involving the stigmatiser labelling a human difference, associating the label with negative stereotypes, and separating "us" from "them", resulting in status loss and discrimination for the stigmatised. Current frameworks that integrate various theories of stigma have further delineated stigma mechanisms operating at the levels of the stigmatiser and the stigmatised (Fox et al., 2018). From the perspective of the stigmatiser, stigma can be broken down into the three components of stereotypes, prejudice, and discrimination. From the perspective of the stigmatised, the four most relevant stigma concepts are perceived stigma, experienced stigma, anticipated stigma, and internalised stigma. The key terms used in this paper are defined in Table 1, as adapted from Fox et al. (2018).

Table 1. Key terms and definitions

Terms	Definitions
Stereotypes	Beliefs about the characteristics of a group of individuals
Prejudice	Negative attitudes or feelings towards a group/members of a group
Discrimination	Unfair or unjust behaviours towards a group/members of a group
Perceived stigma	Perceptions of societal stereotypes, prejudice, and discrimination
Anticipated stigma	Expectations and fears of stereotypes, prejudice, and discrimination from others
Experienced stigma	Personal experiences of stereotypes, prejudice, and discrimination from others
Internalised stigma (self-stigma)	Agreement with and application of societal stereotypes, prejudice, and discrimination to the self

In his seminal work, Goffman (1963) made the distinction between stigmatised attributes that are "discredited" (i.e. visible and readily apparent to others), versus those that are "discreditable" (i.e. invisible and can be hidden from others). Visible stigmatised attributes include race, sex, and physical disabilities, while invisible stigmatised attributes include gender identity, sexual orientation, and mental illnesses. Building on this observation, more recent work has developed the concept of concealable stigmatised identities, which refer to identities that are socially devalued and negatively stereotyped but can be concealed (Quinn & Earnshaw, 2013). Living with a concealable stigmatised identity affects psychological wellbeing, with individuals experiencing heightened psychological distress to the extent that they anticipate stigma, internalise stigma, consider their stigmatised identity as central to the self, and frequently think about their stigmatised identity (Quinn et al., 2014; Quinn & Chaudoir, 2009).

Individuals with concealable stigmatised identities have two main coping strategies available to them: 'pass' (conceal their stigmatised identity) or 'reveal' (disclose their stigmatised identity), although there are varying degrees of disclosure in between these (Clair et al., 2005; Goffman, 1963). Social identity theory posits that people's self-esteem is highly influenced by others' views of their social group, hence members of stigmatised groups would seek to protect self-esteem by either concealing their membership and disassociating from the group, or revealing their membership and positively redefining the group (Tajfel & Turner, 2001). A study of adults with a variety of visible and invisible disabilities found that those who strongly endorsed disability as a central aspect of their identity were more likely to support collective strategies aimed at improving the status of the group by reclaiming disability as valuable, expressing community pride, and advocating for social change (Nario-Redmond et al., 2013). Conversely, lower endorsement of disability as central to the self was associated with greater support for individualistic strategies aimed at distancing oneself from the group by concealing, minimising, or trying to overcome disability. Stronger disability identification was found to predict higher self-esteem, but no clear relationships were found between strategy type and self-esteem. While the results showed

that those with less visible disabilities were more likely to use individualistic strategies to 'pass' as non-disabled, no information was given on specific disabilities and it is not clear whether or how this applies to autism.

Autism can be understood, to a certain extent, as a concealable stigmatised identity. As the behavioural characteristics of autism can vary from overt to subtle, it may not be immediately apparent to others that a person is autistic. Gray (1993) reasoned that autism has uniquely stigmatising aspects because of the atypical social behaviours associated with autism, the absence of any physical markers of autism that provide an explanation to others for these behaviours, and the lack of public knowledge of autism. Later studies have consistently found that atypical verbal and nonverbal communication behaviours displayed by autistic individuals are associated with poorer first impressions and reduced intention to pursue social interactions on the part of typically developing individuals across age groups (Sasson et al., 2017; Sasson & Morrison, 2019). Other work has also found that there are societal stereotypes attached to the diagnostic label of Autism Spectrum Disorder (ASD) (Dickter & Burk, 2021; Russell & Norwich, 2012). Thus, stigma towards autistic people could be elicited by both the label of autism and the behaviours of autistic individuals that deviate from social norms, with some research suggesting that autism-related behaviours are more stigmatised than labels (Butler & Gillis, 2011; Gillespie-Lynch et al., 2020).

Since Gray's pioneering study in 1993, public awareness of autism may have improved in parts of the world. This has been suggested by surveys conducted in Australia (S. C. Jones et al., 2021), Denmark (Jensen et al., 2016), France (Durand-Zaleski et al., 2012), Korea (Park et al., 2018), United Kingdom (UK) (Cage et al., 2019), United States (US) and Canada (Mitchell & Locke, 2015) showing that the general population has a basic level of knowledge of autism, such as being able to correctly recognise some autistic traits. However, these survey results also reflected persisting misconceptions about, and reluctance to interact with, autistic people (Jensen et al., 2016; Park et al., 2018). S. C. Jones et al. (2021) highlighted gaps between community reports of people's awareness of autism and the lived experience of autistic people, suggesting that public knowledge may be

superficial and that there is a need to move from mere 'awareness' to deeper understanding and acceptance.

Much of the literature on autism stigma has revolved around the perspectives of the public, such as surveys of the general population above, and the perspectives of parents/caregivers of autistic children. A scoping review has mapped out four main areas of literature relating to the stigma experienced by autistic individuals and their families: public perceptions of autism, social isolation, the impact of stigma on wellbeing and responses to stigma, as well as efforts around stigma reduction (Mazumder & Thompson-Hodgetts, 2019). Several reviews have found that parents/caregivers perceive and experience courtesy stigma by association with their autistic child, which can become internalised and develop into affiliate stigma (Deguchi et al., 2021; Liao et al., 2019; Papadopoulos et al., 2019; Salleh et al., 2020). A systematic review by Papadopoulos et al. (2019) also found consistent evidence of the harmful effects of autism-related stigma on caregiver mental health. Based on the results of this review, a psychosocial stigma protection intervention was subsequently developed to improve the mental health of parents of autistic children (Lodder et al., 2020).

However, as yet, none of the systematic reviews on autism stigma have focused on the perspectives of autistic people themselves. It is important to understand autistic people's lived experiences of stigma to inform the development of interventions to reduce stigma (e.g. autism acceptance training for non-autistic people in D. R. Jones et al. (2021)), as well as interventions to support autistic people in managing stigma (like the aforementioned stigma protection intervention for caregivers in Lodder et al. (2020)). To start addressing this research gap, this review sought to answer the following research questions:

1) What is known about how autistic people perceive, anticipate, and experience stigma?

2) To what extent is there evidence of self-stigma in autistic people?

3) To what extent is there evidence of the impact of stigma on autistic people's mental health?

4) What is known about how autistic people manage stigma?

Method

This systematic review was developed based on PRISMA guidelines (Page et al., 2021) and the review protocol was registered on PROSPERO (CRD42021231810).

Search strategy

The following databases were searched: PsycInfo, MEDLINE, Web of Science, Scopus, ERIC, and ProQuest Dissertations & Theses. A search string was developed based on previous reviews on similar topics (Deguchi et al., 2021; Mazumder & Thompson-Hodgetts, 2019; Salleh et al., 2020). To achieve a comprehensive search strategy, using both free-text terms that increase sensitivity and Medical Subject Headings (MeSH) terms that increase precision is recommended (if available on the database). Thus, each database was searched using a combination of free-text terms "stigma*" and ("Autis*" or "ASD" or "asperger*" or "pervasive developmental disorder" or "PDD") in the title, abstract, and keywords fields. Additionally, on MEDLINE and PsycInfo, relevant MeSH terms were identified and searched (Appendix A). The search strategy was validated by conducting a pilot run on all databases to ensure that it was able to capture a set of ten clearly eligible studies. Searches were restricted to publications in English. No date restrictions were imposed. The search was first conducted in January 2021 and updated in June 2021.

Inclusion and exclusion criteria

Studies that explored stigma from the perspectives of autistic children, adolescents, or adults were included. Studies that examined autism stigma solely from the perspectives of others (e.g. general public, families/caregivers of autistic people) were excluded. Studies that addressed developmental disabilities more broadly were included only if data specific to autism could be isolated and extracted.

Studies that reported data on how autistic people perceive, experience, anticipate, internalise, and/or manage stigma were included, even if the studies were not specifically designed for the purpose of examining stigma. As we envisaged that there would not be many studies explicitly examining autistic people's stigma coping strategies, we also included studies that explored how autistic people navigate concealment and disclosure in relation to stigma or otherwise negotiate their identity in response to stigma. This decision

was made based on our understanding from wider literature (covered in the Introduction) that concealment and disclosure represent two main ways of managing stigma. However, we excluded studies that focused on concealment, disclosure, or identity in autistic individuals without any association to stigma or discussion of closely-related concepts such as lack of understanding and acceptance.
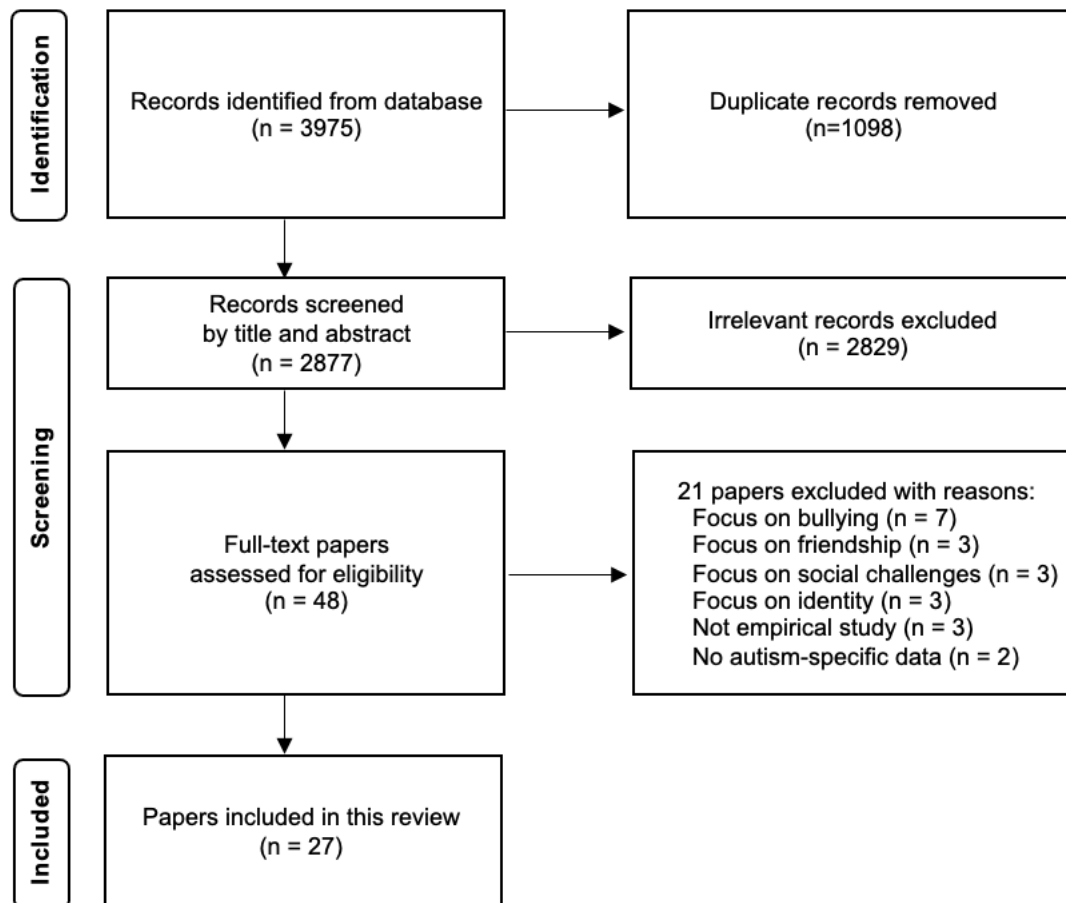
Studies focusing solely on bullying without mention of stigma were excluded, as several other reviews have already analysed the literature on autistic individuals' experiences of bullying as a separate topic (Humphrey & Hebron, 2015; Maïano et al., 2016; Schroeder et al., 2014). Similarly, studies focusing on friendship or general social challenges with little to no mention of stigma were excluded.

All empirical studies (quantitative, qualitative, and mixed method designs) were included, while non-empirical (theoretical) papers were excluded. Doctoral theses were included, while masters theses and conference abstracts were excluded. This was because doctoral theses are typically peer-reviewed and expected to be of publishable standard, while this is not always the case with masters theses.

Study selection

All search results were imported into Endnote for screening. Two reviewers independently screened all the search results by title and abstract for potential eligibility. Full texts of the potentially eligible articles were then retrieved and independently reviewed by the two reviewers for inclusion. There were 12 screening discrepancies at the title and abstract stage and three screening discrepancies at the full text stage, all of which were resolved through discussion. Ambiguities mainly surrounded whether there was sufficient focus on stigma, and decisions were guided by the aim of maximising comprehensiveness of this review (i.e. erring on the side of inclusion rather than exclusion). Details of the studies screened and included at each stage are presented in Figure 1.

Figure 1. PRISMA flowchart

Identification

Records identified from database
(n = 3975)

Duplicate records removed
(n=1098)

Screening

Records screened
by title and abstract
(n = 2877)

Irrelevant records excluded
(n = 2829)

Full-text papers
assessed for eligibility
(n = 48)

21 papers excluded with reasons:
Focus on bullying (n = 7)
Focus on friendship (n = 3)
Focus on social challenges (n = 3)
Focus on identity (n = 3)
Not empirical study (n = 3)
No autism-specific data (n = 2)

Included

Papers included in this review
(n = 27)

Data extraction and quality appraisal

One reviewer extracted data from all included studies using a standardised data extraction form developed in Microsoft Excel. A second reviewer checked the data extracted from all included studies for accuracy and completeness. The following information was extracted from the included studies: authors, publication year, study setting, study design and methods, sample size and characteristics, and key findings relating to stigma. Similarly, one reviewer assessed the quality of all included studies using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). A second reviewer checked decisions on all included studies and discrepancies were resolved through discussion.

Data synthesis

Due to heterogeneity in study designs (qualitative, quantitative, and mixed methods), a meta-analysis was not possible and a textual narrative synthesis was chosen as the best approach (Lucas et al., 2007). Using agreed upon versions of extracted data and quality

assessment, textual summaries of studies were organised according to the four pre-defined research questions. While this was a largely deductive process as our research questions were determined prior to analysis, we also developed new categories and refined these inductively (e.g. the coping strategies identified in response to Research Question 4). This synthesis was conducted by one reviewer with a second reviewer discussing the work as it progressed and agreeing on the final categories. Where possible, similarities and differences among studies were used to draw conclusions across the studies, but where this was not possible, studies were presented individually.

Results

A total of 27 studies were included in this review: 16 qualitative, 6 quantitative and 5 mixed methods. Most studies were conducted in the UK (n=9) and the US (n=8), followed by Canada (n=2), Australia (n=2), and one each in Israel, Germany, and France. Three studies were conducted in an international context, with participants recruited from multiple countries across America, Europe, Asia, and Africa. The included studies involved a total of 2151 autistic adolescents and adults (aged 11 to 73 years), including those who self-identified as autistic, and those who had a formal diagnosis such as ASD, Asperger's Syndrome (AS), and Pervasive Developmental Disorder (PDD). The publication year of the included studies ranged from 2007 to 2021, with an increasing trend of literature on the topic and a notable spike in 2020 during which 7 (26%) of the papers were published.

All the qualitative studies and qualitative components of mixed methods studies met the five quality criteria in the MMAT. In contrast, most of the quantitative studies and quantitative components of mixed methods studies satisfied only three or four out of five criteria in the MMAT. This was largely due to problems with representativeness of samples and appropriateness of measures, which are discussed later. The following sections provide a synthesis of the key findings across studies organised according to the four research questions. Appendix B contains the full characteristics, findings, and quality appraisal of each included study.

Research Question 1: What is known about how autistic people perceive, anticipate, and experience stigma?

Participants across studies were able to describe the stigma they thought to be present against autistic people generally (perceived stigma). Botha et al. (2020) interviewed 20 autistic adults from different countries (14 of whom were British). They conveyed that society considers autism a negative trait, and identified stereotypes of autistic people as male, minimally verbal, infantile, or violent. Treweek et al. (2019) interviewed 12 autistic adults in the UK (11 of whom were diagnosed with AS). They identified that the primary stereotype of autistic people is that they are 'weird', but discussed how each individual may be stereotyped differently due to the heterogeneous nature of the autism spectrum. Participants highlighted that these stereotypes can lead to negative consequences such as exclusion, bullying, and restricting the individuality of autistic people by defining what they should be like and how they should behave. In a qualitative study by Mogensen and Mason (2015), five autistic teenagers in Australia expressed that society attaches connotations of incompetence to autism (e.g. 'stupid', 'anti-social'), typically constructing differences as deficiencies. In another qualitative study by Linton (2014), 76 autistic people participating in online discussion forums from various countries criticised the excessive focus on deficits in ASD diagnostic terminology, which was perceived to have a "trickledown" effect to society and exacerbate public stigma.

Based on their understanding of prevailing social beliefs about autism, participants were also able to describe the stigma they expected to receive (anticipated stigma). Both autistic adolescents and adults expressed fears that having an ASD label meant that others would make prejudgments about them and treat them differently, even if they had not yet experienced such stigma directly (Huws & Jones, 2008; Johnson & Joshi, 2016; Schneid & Raz, 2020). In a mixed methods study in the US, autistic adolescents also predicted how autism-related stigma would negatively affect them in the future, such as making it harder for them to get married or employed: "I don't know if I'll be able to marry anyone, because who wants to marry a guy who has Asperger's?" (Berkovits et al., 2020, p. 836).

Finally, autistic individuals in various studies described personal encounters of stigma (experienced stigma). They recounted stigmatising interactions in the community, in school, in the workplace, and sometimes within their own families; characterised by a lack of understanding that led to prejudicial attitudes and discriminatory behaviours (Botha et al., 2020; Cage et al., 2018; Lee et al., 2021). Many participants reported being misunderstood, teased, insulted, bullied, excluded or rejected by peers, at different levels of severity and regularity (Berkovits et al., 2020; Cameron, 2014; Humphrey & Lewis, 2008; Punshon et al., 2009). Some recalled instances where teachers made false assumptions about their abilities and needs based on their diagnostic label, causing them to receive unwanted help, feel patronised and be singled out as 'different' (Brownlow et al., 2021; Cameron, 2014). Others reported that employers and co-workers made false assumptions about their abilities and needs based on their physical appearance, thus failing to acknowledge and accommodate for the challenges they may experience (Teindl et al., 2018). Regardless of the type of misconceptions, autistic people expressed a common desire for more effective communication, fair treatment, and to be accepted the way they are, "without being under-estimated or over-glorified" (Lee et al., 2021, p. 8).

Two mixed methods studies compared autistic people's perceptions and experiences of different sources of stigma. Drummond (2013) found that autistic adolescents in Canada perceived lower parent and teacher stigmatisation than those with Attention Deficit Hyperactivity Disorder (ADHD). However, they perceived equal peer stigmatisation to adolescents with ADHD and higher peer stigmatisation than typically developing adolescents. Similarly, Cameron (2014) found that autistic adolescents in the UK reported more experiences of being made fun of by other pupils compared to adolescents with intellectual disability. However, they reported fewer experiences of being made fun of by teachers, the public, and family members.

Research Question 2: To what extent is there evidence of self-stigma in autistic people?

Only two studies sought to quantitatively measure internalised stigma in autistic populations (Bachmann et al., 2019; Dubreucq et al., 2020). Both used the Internalised Stigma of Mental Illness Inventory (ISMI) (Ritsher et al., 2003), with Bachmann et al. (2019) using a brief version of the scale and replacing all references to mental illness with 'ASD' (Boyd et al., 2014). Both versions of the scale contain the same five dimensions of internalised stigma: alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. Scores range from 1 to 4: 1.00-2.50 indicates no stigma to mild internalised stigma; 2.51-4.00 indicates moderate to severe internalised stigma.

In Bachmann et al. (2019), 149 autistic adults in Germany had a mean score of 1.93 (SD=0.57), with 15.4% of participants reporting moderate to severe internalised stigma. Being 35 years or older and having a low educational status were associated with higher internalised stigma, while IQ, sex and ASD diagnostic subtype were not associated with stigma severity. The authors concluded that compared to individuals with a range of mental disorders, the level of internalised stigma in autistic adults (without intellectual disability) appears to be lower. However, it is important to note that these participants may not be representative of the general autistic population, as they had high IQ, high educational levels, and were recruited from highly-specialised outpatient clinics at university hospitals providing high-quality and supportive therapeutic environments.

Dubreucq et al. (2020) evaluated self-stigma in 738 participants in France, comprising 45 autistic participants and the rest with serious mental illnesses (SMI) such as schizophrenia, bipolar disorder, major depressive disorder, anxiety disorders, and borderline personality disorder (BPD). The authors reported that the highest prevalence of moderate to severe self-stigma was found in the BPD group (43.8%) and the lowest prevalence was found in the autistic group (22.2%). Nonetheless, mean self-stigma scores on the ISMI did not differ significantly between the autistic (2.13, SD=0.48) and BPD (2.36, SD=0.47) groups. Again, these participants may not be representative of all autistic individuals as they were enrolled in psychiatric rehabilitation, although some sample characteristics (e.g. sex ratio, co-occurring conditions) were comparable to the general SMI and autistic population.

Although none of the qualitative studies focused on self-stigma in autistic individuals, the narratives of many participants suggested that experiences of stigma affected their self-concept. They applied negative stereotypes to themselves, describing themselves as "weird" or a "misfit" (Botha et al., 2020, p. 10), "not normal", a "freak" or having a "bad brain" (Humphrey & Lewis, 2008, p. 31), "wrong", "broken" or "defective" (Leedham et al., 2020, p. 139), a "wimp", "bad" or "disgusting" (Drummond, 2013, p. 109). The process by which an autistic individual may internalise stigma is illustrated in the following two quotes: "I have been called lazy. I believe I am lazy . . . I probably really am." (Punshon et al., 2009, p. 276); "All these years I have been judging myself because I was judged by others" (Schneid & Raz, 2020, p. 3). For some, this led to feelings of shame and embarrassment about their diagnosis and/or autistic traits, as well as feelings of isolation and alienation from humanity (Drummond, 2013; Leedham et al., 2020; Leven, 2020).

Participants in Linton (2014) explained how the impairment-focused descriptions of autism in DSM-5 (American Psychiatric Association, 2013) not only shape how society perceives autistic people, but also how autistic people perceive themselves, potentially causing self-stigma. The strong influence of the medical model on the autistic community was supported by other studies. In a case study by Bagatell (2007), a 21-year-old autistic male recounted how his psychiatrist, teachers, and parents persistently reminded him of his marginalised position and encouraged him to 'fit in' and 'act normal'. As a result, he increasingly felt that there was something 'wrong' with him and started to adopt what he called a 'cure mentality'. This desire to find a 'cure' for autism and 'become normal' was also expressed by interviewees in Humphrey and Lewis (2008) and Punshon et al. (2009).

Research Question 3: To what extent is there evidence of the impact of stigma on autistic people's mental health?

Four quantitative studies explored the impact of stigma on the mental health or wellbeing of autistic populations. Shtayermman (2009) assessed the relationship between perceived stigma and mental health diagnoses among ten adolescents and young adults diagnosed with AS in the US. When asked five questions about whether they think they are

treated differently by others because of their AS, participants answered "yes" to three out of five questions on average. Twenty per cent of the participants met the criteria for a diagnosis of major depressive disorder and 30% met criteria for generalized anxiety disorder. However, due to the small sample size, the study was not able to establish correlation between levels of stigma and levels of depressive symptoms, anxiety or suicidal ideation.

Botha and Frost (2020) used the minority stress model (Meyer, 2003) to examine the extent to which stigma-related stress is associated with mental health outcomes in a sample of 111 autistic individuals without intellectual disabilities in the UK. Using an online survey, the researchers found that minority stressors such as victimisation, everyday discrimination, expectation of rejection, and internalised stigma consistently predicted lower levels of wellbeing and higher levels of psychological distress. These associations persisted even after controlling for general life stress and demographic factors, suggesting that stigma-related stress has an additional adverse effect on mental health that is not attributable to general stress exposure alone. Similarly, a subsequent survey of 223 autistic adults in the UK found that higher perceived stigma was associated with poorer wellbeing (Perry et al., 2021), and another survey of 1139 autistic adults in the US reported that higher perceived stigma was associated with lower self-esteem and quality of life (McDonald, 2016).

A mixed methods survey by Cage et al. (2018) investigated how perceptions and experiences of autism acceptance affect the mental health of another 111 autistic adults in the UK. Quantitative data showed that depression was significantly predicted by personal acceptance and external acceptance from society, family and friends. Stress was only significantly predicted by external acceptance, and there was no significant correlation found between anxiety and autism acceptance. The experience of mental health difficulties as a consequence of non-acceptance was also documented in the qualitative data.

While Botha and Frost (2020), Cage et al. (2018), McDonald (2016) and Perry et al. (2021) found a strong relationship between stigma and mental health or wellbeing, it is important to note that they were cross-sectional studies and thus cannot provide conclusive evidence of the causal direction of this relationship. Moreover, these studies lacked

representative samples as they had disproportionate numbers of participants who were female and highly educated.

None of the qualitative studies specifically examined the impact of stigma on the mental health of autistic individuals. However, three studies did present evidence of participants' mental health struggles, including depression, anxiety, and self-harm, which appeared to be entwined with the internalisation of stigma and a consequently devalued sense of self (Bagatell, 2007; Leedham et al., 2020; Punshon et al., 2009).

Research Question 4: What is known about how autistic people manage stigma?

To manage stigma and its negative consequences, the literature suggests that autistic individuals may adopt a few main strategies: concealment and camouflaging, selective disclosure and self-advocacy, as well as positive reframing and reconstructing identity.

Concealment and camouflaging

Concealment referred to withholding one's autistic status to avoid stigma associated with the label of autism, while camouflaging referred to masking one's autistic traits to avoid stigma associated with such behaviours. These two strategies were often used together, with autistic individuals describing efforts to hide their diagnosis and purposefully minimise outward differences with neurotypical individuals in order to 'pass as normal' (Bagatell, 2007; Botha et al., 2020; Drummond, 2013; Humphrey & Lewis, 2008; Leedham et al., 2020; Leven, 2020; Mogensen & Mason, 2015; Punshon et al., 2009; Schneid & Raz, 2020). For some participants, camouflaging involved controlling their behaviour, mirroring neurotypical behaviour, putting on different personas in different social situations, or even using alcohol to help them become more sociable. Participants described how they developed these habits over the years, sometimes deliberately and sometimes less consciously, in response to intense and continuous pressure to assimilate in their social environments.

Some autistic individuals found camouflaging a successful strategy, albeit requiring substantial time and energy. These individuals felt that camouflaging helped them to adapt to various social situations and be perceived by others as 'normal' (Leven, 2020; Mogensen

& Mason, 2015). However, other participants described camouflaging as an ineffective coping strategy, leading to greater unhappiness, exhaustion, stress, anxiety around being discovered, and having a negative impact on their self-esteem (Bagatell, 2007; Leedham et al., 2020; Leven, 2020; Punshon et al., 2009). Furthermore, several participants felt that camouflaging reaffirmed the stigma of being autistic as it implied that something had to be hidden because it was 'flawed' or 'faulty' (Schneid & Raz, 2020).

A mixed methods survey in the UK by Cage et al. (2018) reported camouflaging as a consequence of non-acceptance and showed a potential relationship between camouflaging and poor mental health in autistic adults. Qualitative data reflected the negative impact of camouflaging on psychological wellbeing, and quantitative data suggested a link between camouflaging and higher rates of depression. A quantitative survey in the UK by Botha and Frost (2020) also reported that higher levels of concealment of autism were associated with higher levels of internalised stigma and lower levels of social wellbeing in autistic adults. Meanwhile, another quantitative survey in the UK by Perry et al. (2021) found that camouflaging did not mediate the relationship between stigma and poorer mental wellbeing among autistic adults. However, they did find that higher perceived stigma predicted higher levels of self-reported camouflaging, supporting the position that camouflaging represents a response to stigma.

Many autistic individuals expressed a desire to show their true selves and recognised some benefits of disclosing, but feared that disclosure would attract more stigma, causing others to associate them with negative stereotypes and treat them differently (Botha et al., 2020; Johnson & Joshi, 2016; Leedham et al., 2020; Mogensen & Mason, 2015; Schneid & Raz, 2020). In Botha et al. (2020), interviewees reported being caught in a "double bind", recognising that both concealment and disclosure had negative consequences: "I'm damned if I do and damned if I don't if you know what I mean…I can tell people [I'm autistic] and they think I'm weird and if I don't tell people, they think I'm weird…" (p. 12-13).

Selective disclosure and self-advocacy

As an alternative strategy to concealment and camouflaging, some autistic individuals pursued disclosure and self-advocacy. In Botha et al. (2020), some autistic adults from different countries described disclosing to directly challenge stigmatising comments made by others: "I will sometimes just say, 'I was diagnosed with Asperger's when I was younger, and I don't think you should be saying something like that'" (p. 14-15). Similarly, several autistic adults from Israel (Schneid & Raz, 2020) and the US (Lee et al., 2021) chose to fight stigma and advocate for themselves by telling neurotypical individuals to respect the way they communicate: "If, until now, I said to people that I am a person who enjoys being alone and they called me a loner, now I just say, no, I'm an autist and I enjoy this very autistic communication" (Schneid & Raz, 2020, p. 5).

For most participants, disclosure was practised selectively and strategically in different circumstances and to different people. Saunders (2017) observed that five autistic university students in the UK demonstrated the ability to discern appropriate times and places to disclose their autism diagnosis. For example, one interviewee described how he avoided disclosing in school to protect himself from stigma, but planned to disclose when he goes into the job market to take advantage of federal mandates to hire employees with disabilities as part of diversity and inclusion initiatives. Similarly, in the qualitative study by Leven (2020), autistic adults across the globe described assessing social situations where they could be their authentic selves, and other situations where they had to try to fit into societal norms, even if it was temporarily exhausting. In the mixed methods study by Johnson and Joshi (2016), autistic adults in the US adopted a complex interplay of stigma expression and stigma suppression strategies in the workplace. They discussed the potentially stigmatising effects of disclosing and tended to only disclose to individuals whom they thought were trustworthy. In the qualitative study by Teindl et al. (2018), autistic adults in Canada identified factors that facilitated disclosure in the workplace, including having an accepting and understanding employer, having an employment support worker to disclose on their behalf, and using a strengths-based approach when disclosing to reduce negative misconceptions and ensure that employers understood their abilities.

Among autistic individuals who disclosed, some experienced positive relationship changes and improved understanding and acceptance, while others experienced unhelpful, dismissive, and patronising reactions (Humphrey & Lewis, 2008; Leedham et al., 2020; Leven, 2020). Leven (2020) reported that positive experiences of disclosure helped to build confidence and comfort with the autistic identity, while negative experiences reinforced the stigmatised identity. In Botha et al. (2020), many interviewees described an unequal power dynamic between themselves and neurotypical individuals when they disclosed, including being told "you are not really autistic" (p. 13) or "everyone's a bit like that" (p. 14). Participants expressed concern that such responses detract from their identity, erase their experience, and remove their need for support. Furthermore, in the quantitative survey by Botha and Frost (2020), a higher degree of disclosure was in fact associated with poorer mental health among autistic adults.

Positive reframing and reconstructing identity

Throughout the literature, disclosure and self-advocacy were often intertwined with the "process of reconstructing… personal identity and embracing autism as a valid, positive social identity" (Bagatell, 2007, p. 422). Those who reframed autism as a positive part of their *personal* identity (i.e. a personal characteristic that defined them as a distinct individual) often attributed their positive qualities and unique strengths to autism (Drummond, 2013; J. L. Jones et al., 2015; Leven, 2020; Mogensen & Mason, 2015). Those who reframed autism as a positive part of their *social* identity (i.e. a social group they belonged to) emphasised how the autistic community provided them with a sense of belonging to help them negotiate feelings of alienation and isolation from society (Drummond, 2013; J. L. Jones et al., 2015; Leedham et al., 2020; Punshon et al., 2009; Schneid & Raz, 2020).

In Botha et al. (2020), all 20 autistic adults from different parts of the world described autism as a central and integral part of their identity. They used identity-first language ('autistic person') rather than person-first language ('person with autism') to reclaim the stigmatised label of autism and de-stigmatise it by reinforcing that autism cannot and does not need to be separated from the individual. In another international study by Leven (2020),

eight out of ten autistic adults had positive views of autism and integrated autism into both their personal and social identities. Young autistic adults in Australia (Brownlow et al., 2021) and the US (Lee et al., 2021) also reported gaining self-acceptance and positively claiming their autistic identity as they engaged in self-advocacy and transitioned into adulthood.

However, the literature suggests that there may be some age-related differences in autistic identity development. In Mogensen and Mason (2015), only one out of five autistic teenagers in Australia described both autism and being 'different' as positive and fundamental parts of their identity. Similarly, in Drummond (2013), only one of 13 adolescents in Canada expressed a sense of self-acceptance and pride in being autistic. While the rest were able to identify some strengths associated with their diagnosis, their descriptions of autism were still largely dominated by negative appraisals, similar to data from autistic adolescents in the US (Berkovits et al., 2020) and the UK (Humphrey & Lewis, 2008). In Jones et al. (2015), autistic adolescents in the US also wrestled with reconciling the positive and negative aspects of their diagnosis. They described the paradoxical nature of the autism label, wanting to reject parts of their diagnosis that they perceived as socially unacceptable while maintaining aspects that made them unique or talented.

For some autistic individuals, making downward social comparisons was part of how they constructed their identity in positive terms. Punshon et al. (2009, p. 278) reported that a minority of their participants framed their AS as an advantage, describing themselves as being "one rung up on the evolutionary ladder" and having a "superiority complex". Similarly, in Saunders (2017, p. 106), a university student with AS used the rhetoric of intellectual functioning to position himself as better than both his neurotypical peers and other autistic peers, carving out a narrow space for himself as an "exceptional autistic". In Jones et al. (2015), several interviewees also specifically identified with the label of 'Asperger's' or 'high functioning autism', dissociating themselves from the label of 'disability' and differentiating themselves from people with more significant impairments.

In a mixed methods study in the UK by Cameron (2014), positive social comparisons were associated with higher self-esteem among a sample of autistic adolescents. These

participants had positive self-esteem despite experiencing stigma, though it could not be concluded that making social comparisons helped them to manage the impact of stigma. In a quantitative survey in the US, McDonald (2016) also found that attitudes characterising the autism spectrum as a positive difference and as a changeable attribute may provide resilience and mediate the impact of stigma on the wellbeing of autistic adults, but causality could not be determined due to the cross-sectional nature of the study.

Discussion

Traditionally, it has been thought that autistic individuals struggle with theory of mind, meaning that they may find it difficult to perceive the thoughts, beliefs, intentions of others, as well as predict and interpret their behaviour (Baron-Cohen et al., 1985; Bowler, 1992; Happé, 1994). This systematic review has found that autistic individuals (without accompanying intellectual or cognitive disabilities) appear acutely aware of how they are being stigmatised by others. They are able to identify societal stereotypes of autistic people that parallel literature from the perspectives of non-autistic people, such as common myths that autistic people are unempathetic, socially disinterested and potentially dangerous (Durand-Zaleski et al., 2012; John et al., 2018; S. C. Jones et al., 2021; Wood & Freeth, 2016). They are also able to anticipate how they may be judged, excluded or treated differently by others in ways that align with research showing that neurotypical individuals make unfavourable judgements of autistic individuals and are less likely to interact with them (Jensen et al., 2016; Park et al., 2018; Sasson et al., 2017; Sasson & Morrison, 2019).

As a result of their experiences of stigma, the reviewed literature suggests that some autistic people may develop internalised stigma. Two quantitative studies suggested that levels of self-stigma among autistic adults are lower than that of adults with various mental disorders, but it is important to note that both studies used the Internalised Stigma of Mental Illness Inventory (ISMI) (Bachmann et al., 2019; Dubreucq et al., 2020). While ISMI is an established and widely used instrument, it was designed for mental illness-related stigma and not autism specifically. In particular, as Dubreucq et al (2020) did not explicitly state whether they had replaced references to mental illness with autism, it is questionable

whether autistic participants would have applied questions about mental illness to themselves, potentially underestimating the extent of self-stigma in this population. The qualitative studies provided more evidence of internalised stigma, as the narratives of many autistic individuals suggested that they incorporated the opinions of others into their self-concept and applied negative stereotypes to themselves, thereby harming their sense of self-worth (Botha et al., 2020; Drummond, 2013; Humphrey & Lewis, 2008; Leedham et al., 2020; Punshon et al., 2009).

There was some limited evidence showing that both perceived or experienced stigma and internalised stigma have a negative impact on the mental health of autistic individuals, but the direction of this relationship was not conclusive due to the cross-sectional design of respective studies (Botha & Frost, 2020; Cage et al., 2018; Perry et al., 2021). A longitudinal study (as part of a doctoral thesis that was not captured by the database searches in our review) further elucidates the relationship between stigma-related stress and mental health in the autistic population (Botha, 2020). Higher exposure to minority stressors (such as everyday discrimination, expectation of rejection and internalised stigma) was significantly associated with poorer mental health nine months later, supporting the findings of the aforementioned cross-sectional studies. However, although both disclosure and concealment were associated with poorer mental health in previous cross-sectional analysis (Botha & Frost, 2020), this study found that higher levels of disclosure predicted better mental health nine months later, while concealment had no significant relationship with mental health over time (Botha, 2020).

Indeed, while the reviewed literature suggests that autistic people may use concealment and camouflaging, selective disclosure and self-advocacy, as well as positive reframing and reconstructing identity to manage stigma, the evidence was mixed on how effective and helpful these strategies are. Concealment and camouflaging were seen as potentially helpful to protect oneself from stigma, but exhausting to maintain, not being true to oneself, and leaving stigma unchallenged. Conversely, disclosure and self-advocacy could promote authentic self-expression and reduce stigma but could also expose oneself to

more stigma. Clair et al. (2005) contended that individuals with concealable stigmatised identities consciously weigh the risks and benefits of revealing their identity, and their decision is driven not only by the external threat of stigmatisation but also the internal concern for authenticity and legitimacy. In line with this wider literature on concealable stigmatised identities, deciding whether to conceal or disclose their diagnosis was a salient issue for many autistic individuals in the included studies. A recent scoping review by Thompson-Hodgetts et al. (2020) has also revealed discrepancies between the perspectives of autistic people and non-autistic people regarding the outcomes of diagnostic disclosure, whereby research from the perspectives of non-autistic people suggests that disclosure generally reduces stigma, but research from the perspectives of autistic people reveals experiences with and/or fears of stigma following disclosure. Thus, Thompson-Hodgetts et al. (2020) rightly warned against the assumption that autistic people should always be encouraged to disclose their diagnosis. Rather, these conflicting results suggest that autistic people may need support and guidance in discerning when, to whom, and how to disclose.

However, before making decisions surrounding disclosure, autistic individuals may also first need time and support to make sense of what autism means to them. Those who have internalised negative messages about autism and themselves may also need help to reframe autism and their self-concept in more positive ways. It is notable that many autistic adults who participated in the included studies described autism as a positive part of their identity, while many autistic adolescents did not. This may be due to the fact that adolescence is the stage at which individuals are just starting to explore their identity and may face more pressure to fit into their peer groups (Drummond, 2013), while the transition to adulthood is a time when autistic individuals may be more likely to develop self-acceptance and self-advocacy skills (Lee et al., 2021). Studies outside of this review have also found that stronger affiliation with autistic identity is linked to higher collective self-esteem and improved mental health among autistic adults (K. Cooper et al., 2017; R. Cooper et al., 2021). Meanwhile, stronger alignment with non-autistic culture has been linked to more positive self-perceptions among autistic adolescents (Cresswell & Cage, 2019),

although this study's findings need to be interpreted with caution given the lack of overall significant effects and small sample size. In any case, this does not mean that autistic adults do not need support with creating and maintaining a positive identity, as there is also evidence of them struggling to do so (Bagatell, 2007; Leedham et al., 2020; Punshon et al., 2009).

Notwithstanding the importance of building a positive autistic identity, concerns have been raised that a sense of pride can occasionally shade into a sense of superiority (Brownlow & O'Dell, 2006; Parsloe, 2015). Literature within and outside of this review suggests that some autistic people may strive to preserve a positive identity by making downward comparisons (Huws & Jones, 2015; Punshon et al., 2009; Saunders, 2017). Some also prefer the label of 'Asperger's' or 'high functioning autism' and distance themselves from the label of 'ASD' or 'disability' (Chambers et al., 2020; J. L. Jones et al., 2015; Smith & Jones, 2020). In addition to being a coping strategy, this could also be a sign of internalised stigma as these individuals (consciously or unconsciously) agree with the stereotypes attached to respective labels. Other autistic scholars and research participants have critiqued the rhetoric of functioning for redirecting stigma, rather than reducing it (Bottema-Beutel et al., 2020; Kenny et al., 2016). While such rhetoric may help some members of the autistic community to mitigate stigma, it may come at the expense of marginalising others. Furthermore, while making downward social comparisons may help to boost self-esteem in the short-term, it could also lead to unrealistically high self-expectations that are harmful in the long run (Huws & Jones, 2015). Alternatively, using the narrative of neurodiversity, which recognises all neurological differences as natural and valuable parts of human diversity, may be more constructive to facilitate acceptance of the full variation of cognitive functioning and abilities (Kapp et al., 2013; Singer, 1999).

Limitations

While qualitative research does not aim to achieve a representative sample, a common and major limitation across both the quantitative and qualitative studies is that they have largely focused on the perspectives of autistic individuals with average to above-

average intellectual and verbal communication abilities. Only one of the more recent quantitative studies included participants with a wide range of cognitive functioning, with 35% of the sample having below-average cognitive abilities (Berkovits et al., 2020). Thus, the existing literature on the topic, and consequently the perspectives and experiences presented in this review, are not representative of the whole autistic population.

Furthermore, as there has been little explicit exploration of stigma management among autistic people, the coping strategies identified in this review are suggestive rather than definitive, and certainly not exhaustive. While evidence suggests that the processes of concealment, camouflaging, disclosure, self-advocacy, positive reframing and reconstructing identity are related to stigma, they may not always be used in direct response to stigma or motivated solely by stigma. Similarly, as all the quantitative studies in this review employed cross-sectional designs, the relationships established between stigma, various coping strategies, and mental health or wellbeing, are purely correlational rather than causal.

Another limitation of this review is that only articles published in English were included, and most of the studies were conducted in the UK and US. This introduces the possibility of language and location bias as experiences of stigma and responses to stigma may vary with context and culture.

Recommendations for research and practice

Based on the limitations above, there is a need for more autism-related stigma research involving autistic individuals across a wider range of intellectual and verbal communication abilities, and from outside of Europe and North America. An analysis of published memoirs of three minimally speaking autistic youths revealed their over-arching concern that the way they were perceived from the outside (e.g. uncomprehending, child-like) did not match who they were on the inside (e.g. intelligent, insightful, socially interested) (Welch et al., 2019). More research giving insight into the perspectives and experiences of non-speaking and/or minimally verbal autistic individuals should be pursued. Future research may also wish to explore how autistic individuals with accompanying intellectual disabilities (and/or other stigmatised attributes) experience and manage multiple stigmatised identities.

Moving forward, there is also a need for more longitudinal research examining causal relationships between variables as well as experimental studies exploring interventions that can help autistic people to manage stigma. Drawing on the findings of this review and research on self-stigma interventions from the mental health field (Yanos et al., 2015), possible types or components of interventions could include empowering autistic people to challenge negative stereotypes, assisting them to construct a positive autistic identity, equipping them with self-advocacy skills, as well as evaluating the pros and cons of disclosure to arrive at an informed decision. Any interventions should be developed in collaboration with the autistic community, and ideally led by autistic people themselves, in order to redress the power imbalances that underpin stigma production.

In addition to interventions for autistic individuals, interventions targeting the non-autistic population are equally crucial. An emerging body of literature has shown that interventions combining education and contact can improve the knowledge and attitudes of non-autistic individuals towards autistic individuals, but findings are inconsistent regarding their effectiveness in changing behavioural intentions (Dachez & Ndobo, 2018; Morris et al., 2020; Ranson & Byrne, 2014; Staniland & Byrne, 2013). Online training programmes have also shown potential to increase understanding and acceptance of autistic people, although recent studies have reported conflicting results on whether such training is more effective at reducing explicit biases or implicit biases (D. R. Jones et al., 2021; Gillespie-Lynch et al., 2021). Continued efforts in evaluating and improving such interventions are encouraged so that onus is not placed solely on the autistic community to advocate for themselves, although it is crucial that these interventions also involve the input of autistic voices.

The power of narratives in producing and resisting stigma also has important implications for research and practice. Bottema-Beutel (2020) have compiled guidance to help researchers make language choices that reduce stigmatisation of autistic people. For example, deficit-based terms such as "high-functioning" and "low-functioning" should be replaced with descriptions of specific strengths and needs, "symptoms" replaced with "characteristics" or "traits", and "treatment" replaced with "supports" or "services". Instead of

ableist discourses that promote a cure rhetoric or prioritise "passing" as non-autistic, autistic people should be at the centre of decision making, prioritising their mental health and wellbeing (which can include embracing autistic identities). Professionals also need to reflect carefully on the messages they are communicating to the autistic individuals, their caregivers, and the general public. The discourses that autistic people are exposed to, especially during diagnosis and post-diagnosis, will affect whether and how they integrate autism into their own identity (Bagatell, 2007; Leedham et al., 2020; Mogensen & Mason, 2015; Punshon et al., 2009). Instead of focusing solely on impairment, professionals should learn to support autistic individuals in exploring positive aspects of their diagnosis and building on their strengths in addition to addressing their challenges (Brown et al., 2021).

Conclusion

Contrary to the belief that autistic people struggle to perceive others' thoughts and interpret others' actions, this systematic review has found that autistic individuals are acutely aware of how they are being stigmatised by others. Existing research also provides some evidence that autistic people internalise stigma and apply negative stereotypes to themselves, thereby harming their sense of self-worth and mental health. Some autistic individuals may seek to protect themselves from stigma by concealing and camouflaging, while others may choose to challenge stigma by disclosing and self-advocating, which is also often tied to reframing autism and reconstructing a positive autistic identity. The tensions that autistic people experience between concealment and disclosure, between societal perceptions and self-perceptions, as well as between positive and negative aspects of their diagnosis, suggest that support may needed in these areas. The power of discourse in both perpetuating and challenging stigma also have important implications for research and practice. This review calls on everyone, including researchers, clinicians, and the general public, to continue reflecting on the language we use to talk about autism and disability, in order to promote acceptance of the full diversity of human cognition.

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