Review Journal of Autism and Developmental Disorders
https://doi.org/10.1007/s40489-023-00361-x

REVIEW PAPER

Understanding the Self-identification of Autism in Adults: a Scoping Review

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Received: 25 April 2022 / Accepted: 17 February 2023

Abstract
Adults are increasingly self-identifying as autistic, and reporting problems being referred for an autism diagnostic assessment. This scoping review aims to ascertain: (1) what research has been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism, and (2) which aspects of the self-identification process could be used to improve the referral and the diagnostic process of an adult autism assessment. The main themes identified were: the diagnostic process from a client´s perspective; the process of self-identifying as autistic from a lifespan perspective; an autistic identity; sexual identity and experiences, and the perception of autism as a difference or a disability. These themes could positively enhance the referral and diagnostic process.

Keywords Autism · Diagnosis · Self-identify · Scoping review · Identity

Introduction

It is now recognised that autism may not be diagnosed until adulthood, in some circumstances (Lai & Baron-Cohen, 2015). In spite of this recognition, many adults report barriers to an autism diagnostic assessment (Jones et al., 2014; Lewis, 2017).

Simultaneously, it has been stated that adults are increasingly self-identifying as autistic (Lewis, 2017). This may be explained by the reported barriers to an autism diagnostic assessment (Lewis, 2016b), for example that General Practitioners (GPs) may fail to recognise the presentation of autism in adults (Crane et al., 2018). Consequently, adults' resort to self-identifying as autistic (Lewis, 2016b).

It is of concern if self-identifying as autistic is becoming a substitute for a formal diagnosis of autism, especially given the documented merit of a formal autism diagnosis (Brownlow & O'Dell, 2006; Moore, 2016). A formal autism diagnosis can help adults to better understand who they are, and/or receive the services and support (e.g., reasonable adjustments at work or in education) they deserve. This diagnosis can also assist adults to reframe their new identity in a positive way (Moore, 2016).

As adults renegotiate their identity, the value of support cannot be underestimated, as the risk of secondary psychological disorders (e.g., anxiety and depression) has been found to increase without appropriate support (Lewis, 2016b). However, it has been reported that adults who are unable to access formal support (or choose not to) find alternative sources of support, such as autism online forums, in which they tend to share their experiences and concerns after the referral and/or the diagnostic process. Yet, with some alternative sources of support, a supportive online environment is not a guarantee. For example, self-identifying as autistic can be a controversial topic in some autism online forums in which some users have been openly sceptical about the validity of it (Sarrett, 2016).

Therefore, in terms of the psychological wellbeing of adults who may be autistic, it is important that the factors underpinning self-identifying as autistic as an adult are understood from a psychosocial perspective. However, little research has been conducted on the self-identification process of autism in adults (Lewis, 2016b), despite the recent

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inclusion of adults that self-identify as autistic in many research studies (e.g., Cooper et al., 2017).

Given the limited research conducted on this topic, a scoping review is appropriate to determine what is known about the factors that seem to be present in adults that self-identify as autistic (Arksey & O'Malley, 2005; Peters et al., 2015). In consideration of the reported barriers to an autism diagnostic assessment, this scoping review had two aims: (1) to ascertain what research has been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism and (2) to ascertain which aspects of the self-identification process could be used to improve the referral and diagnostic process of an adult autism diagnostic assessment.

Method

This scoping review was directed by the research question 'From the existing literature, what is known about the self-identification of autism in adults with or without a formal diagnosis of autism?' and was conducted based on guidance by Arksey and O'Malley (2005) and Peters et al. (2015). The authors of this study went through an iterative process to define, discuss, and finalize the search and review strategy of this scoping review. The aim of this iterative process was to synthesize and critically describe the studies that were selected in this scoping review.

Inclusion Criteria

In order to answer the aims of the scoping review, the following inclusion criteria were set:

(1) Research that involved adults, where the age of the participants was equal to or more than 16 years. In line with the age of transition of individuals from children to adult services in some areas, an adult was defined as an individual of 16 years of age and older.
(2) Adults self-identified as autistic with no formal diagnosis of autism and/or adults initially self-identified as autistic and who subsequently had a formal diagnosis of autism.
(3) Research written in the English language. This was decided on the basis of the time and financial costs of translating articles written in non-English (Arksey & O'Malley, 2005).
(4) Published academic literature. Although scoping reviews can include grey literature (Arksey & O'Malley, 2005; Peters et al., 2015), the decision was made not to. This decision was taken based on the difficulty and time costs of locating grey literature.
(5) Research published from 2000–2021. The year 2000 was chosen to ensure that, as far as possible, all research was identified.

Exclusion Criteria

(1) Research that excluded adults who self-identified as autistic, because the criteria for autism was not met on a screening tool.

Search Procedure

Four online databases (PsycINFO, CINAHL Complete, MEDLINE Complete and APA PsycArticles) were searched using the following eight searches 'self-identification + autism spectrum disorder + adults', 'self-identification* + autism spectrum disorder* + adults*', 'self-identification + autism + adults', 'self-identification + Asperger's + adults', 'self-diagnosis + autism spectrum disorder + adults', 'self-diagnosis* + autism spectrum disorder* + adults*', 'self-diagnosis + autism + adults', 'self-diagnosis + Asperger's + adults'.

The last search was conducted on 24th July 2021.

Study Selection

Following the removal of duplicates, the title and abstract sections of the remaining articles were screened by the first author to remove any articles that did not meet the inclusion criteria. A full text screening of the remaining articles, beginning with the participant section, was subsequently conducted by the first author to check eligibility. A discussion with the second author revealed no discrepancies regarding the articles deemed eligible. The reference lists of all eligible articles were then checked for any additional articles that may meet the inclusion criteria of the scoping review. This process was independently undertaken by the first and second authors, after which a discussion was held to ensure that there was agreement on the final articles included in the scoping review. (See Fig. 1 for the flow chart for the study selection).

Data Extraction

Data extraction was conducted based on the guidance by Peters et al. (2015) and was undertaken by the first author.

The data extracted were: (1) author(s) and title of study, (2) characteristics of study, (3) aims of study, (4) methodology of study, (5) outcome of study, (6) relevant key findings of study. The data extracted from the studies was put into a

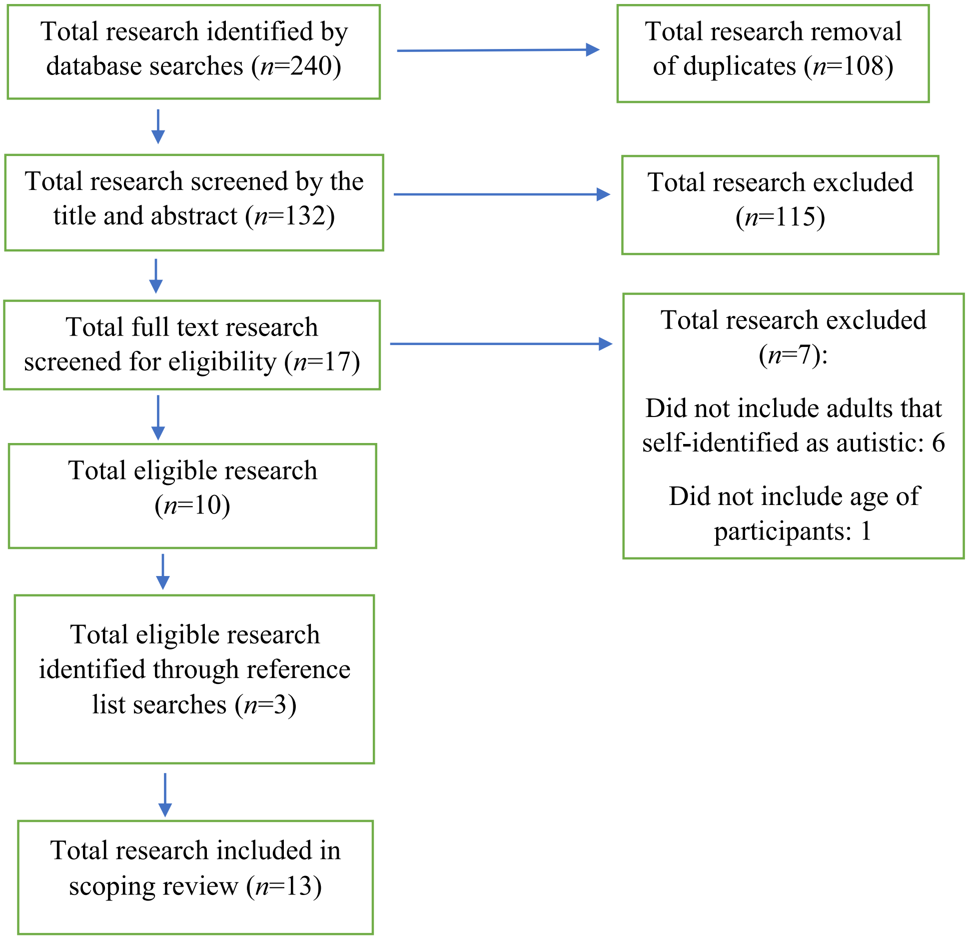


Fig. 1 Flow chart showing the study selection process

table (see Table 1 Appendix), and this was used as a starting point for analysis of the data.

Data Analysis

In line with the guidance by Arksey and O'Malley (2005) and Peters et al. (2015), the data extracted from the studies (see Appendix; characteristics of included studies) was reviewed by the first author to identify key themes that illustrated the research that had been conducted on the self-identification process of autism in adults, who did and did not have a formal diagnosis of autism (the aim of the scoping review). From reviewing the characteristics of the included studies, the authors of this scoping review identified that the studies they reviewed predominantly focused on five themes. The research articles included in this scoping review were categorised thematically into one of the five main areas, according to the focus (aims) of their research. A review of the five key themes identified by the first author was independently undertaken by the fourth author. There was no disagreement on the themes identified, but the names of the themes were refined following a discussion between the first and fourth author. A numerical analysis of the characteristics of the studies (e.g., date of study and methodology used) was then conducted. At this stage the data analysis was reviewed by the second and third authors and a discussion was held between all authors to ensure consensus. The main five themes that were agreed for this scoping review were the following: (1) the diagnostic process from a client´s perspective, (2) the process of self-identifying as autistic from a lifespan perspective, (3) an autistic identity, (4) sexual identity and experiences, and (5) the perception of autism perceived as a difference or as disability.

Results

Study Characteristics

The final thirteen studies comprised five qualitative (Angulo-Jiménez & DeThorne, 2019; Lewis et al., 2021; Lewis, 2016b; Parsloe, 2015; Penwell-Barnett & Maticka-Tyndale, 2015), four quantitative (Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Pohl et al., 2020), three mixed methods (Au-Yeung et al., 2019; Kapp et al., 2013; Lewis, 2017), and one theoretical framework (Wylie et al., 2016). Most of the studies were conducted in the USA ($n = 7$) and the UK ($n = 6$). Studies ranged in date from 2013 to 2021 with the most studies ($n = 3$) published in 2019 (Angulo-Jiménez & DeThorne, 2019; Au-Yeung et al., 2019; Egan et al., 2019) and the overall trend showing an annual increase in studies within the date range (See Fig. 2 for further details). All studies collected data online and the majority ($n = 9$) utilised a survey as a method of data collection (Au-Yeung et al., 2019; Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Kapp et al., 2013; Lewis et al., 2021; Lewis, 2016b, 2017; Pohl et al., 2020). Two studies (Angulo-Jiménez & DeThorne, 2019; Parsloe, 2015) analysed publicly accessible online data (videos and forum posts) with the latter study also conducting interviews. The final study (Penwell-Barnett & Maticka-Tyndale, 2015) conducted interviews.

Ten studies collected data on the diagnostic status of participants (e.g., formally diagnosed with autism, informally diagnosed with autism or self-identified as autistic) and in nine of those studies, the smallest proportion of participants were those that self-identified as autistic (Angulo-Jiménez & DeThorne, 2019; Au-Yeung et al., 2019; Brosnan, 2020; Cooper et al., 2017; Egan et al., 2019; Kapp et al., 2013; Lewis, 2017; Lewis et al., 2021; Pohl et al., 2020). In four of the studies, results from adults who self-identified as autistic were very similar to the results of adults with a formal diagnosis of autism (Au-Yeung et al., 2019; Brosnan, 2020; Kapp et al., 2013; Pohl et al., 2020).

Eight of the studies (Au-Yeung et al., 2019; Brosnan, 2020; Kapp et al., 2013; Lewis, 2017; Lewis et al., 2021; Parsloe, 2015; Penwell-Barnett & Maticka-Tyndale, 2015; Pohl et al., 2020) had a higher proportion of participants that identified as female.

Further details regarding the study characteristics of the final thirteen studies included in this scoping review can be found in Appendix. In line with the scoping review guidance developed by Arksey and O'Malley (2005) no studies were excluded based on their scientific quality.

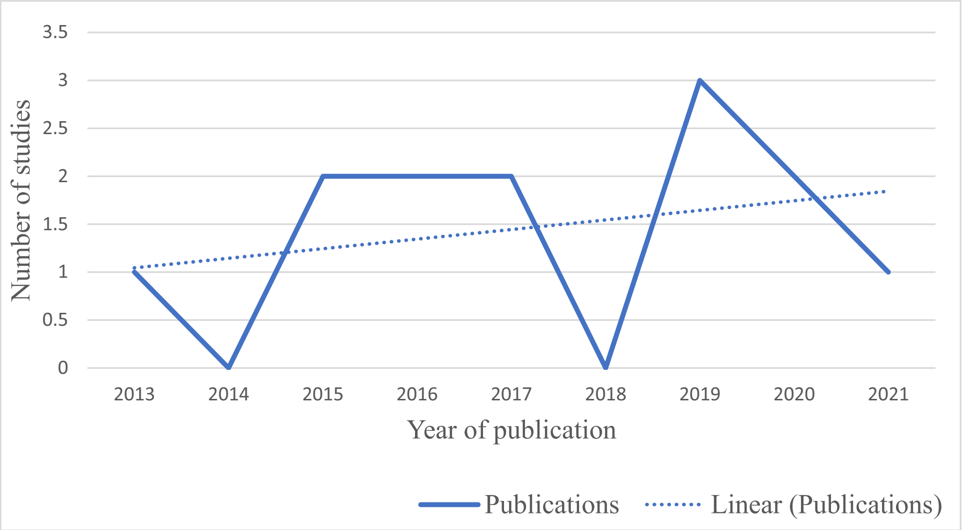
From the thirteen studies analysed, five themes were identified: (1) the diagnostic process from a client´s perspective, (2) the process of self-identifying as autistic from a lifespan perspective, (3) an autistic identity, (4) sexual identity and experiences, and (5) the perception of autism perceived as a difference or as disability.

First Theme: The Diagnostic Process from a Client´s Perspective

Four studies (Au-Yeung et al., 2019; Brosnan, 2020; Egan et al., 2019; Lewis, 2017) related to the diagnostic process. Most of the studies ($n = 3$) were conducted in the UK (Au-Yeung et al., 2019; Brosnan, 2020; Egan et al., 2019), whilst one was conducted in the USA (Lewis, 2017) and collected data from thirty countries which was re-categorised for statistical purposes as five (Australia, Canada, the UK, the USA and Other countries). The studies were split equally ($n = 2$) between mixed methods and quantitative. The two studies (Au-Yeung et al., 2019; Lewis, 2017) that utilised a mixed methods approach investigated the experience and barriers to a formal diagnosis of autism in adulthood, whilst the two studies (Brosnan, 2020; Egan et al., 2019) that utilised a quantitative approach investigated measures of autistic traits in adulthood.

In two studies (Au-Yeung et al., 2019; Lewis, 2017) it was found that the main barrier for not being referred for an adult autism assessment in the USA and the UK was due to the difficulties clients (likely to be autistic) had in verbalizing to healthcare professionals (e.g., physicians or nurses) why they felt they could be autistic. All the adult participants in both studies also reported that in their initial medical appointment with a healthcare

Fig. 2 A line graph showing the number of studies on the self-identification of autism in adults



professional they were not taken seriously. This scepticism from healthcare professionals in those initial medical appointments (with perhaps little knowledge on how the different forms of autism may be present in adults and young people) prevented an important percentage of participants in both studies getting a referral for a formal adult autism diagnostic assessment (Au-Yeung et al., 2019; Lewis, 2017). In Lewis's (2017) study, it was found that an important number of adults that thought that they could be autistic experienced fear of being disbelieved by their healthcare professionals in their initial medical appointments. This fear was identified as another factor that acted as a barrier to getting a referral for a formal autism diagnostic assessment. In Lewis's (2017) study it was also reported that the majority of adults felt that healthcare professionals seemed to have strong stereotypical views of the presentation of autism (more common in non-verbal children that are autistic), and little awareness and understanding of the different forms of autism through the lifespan. This lack of awareness and understanding of autism in healthcare professionals was also found in Au-Yeung et al. (2019) study.

Misdiagnoses were also reported as another barrier to a formal autism diagnosis in adults (Au-Yeung et al., 2019; Lewis, 2017). Adults in both studies reported that throughout their life (from childhood to adulthood), they had been labelled with a broad range of mental health conditions (e.g., anxiety, low mood, challenging behaviour and/or personality disorders, to name a few) which they completely disagreed with because they did not feel that these conditions fully explained who they were, or their personal strengths and difficulties (Au-Yeung et al., 2019; Lewis, 2017).

Adults also reported other barriers to an autism diagnostic assessment, which were country specific (Lewis, 2017). For example, waiting times in Canada and in the UK, and the expensive cost of the assessments in the USA were identified as the most important barriers to being assessed for autism (Lewis, 2017).

With the aim of improving the autism diagnostic pathway for adults, one study conducted by Brosnan (2020) attempted to develop a measure that mirrored the autism diagnostic criteria (A: Social and B: Restricted Repetitive Behaviours -RRB-). Brosnan (2020) study recruited participants with a formal diagnosis of autism and participants that self-identified as autistic. In criteria A (social difficulties) of the measure that Brosnan (2020) aimed to develop, no significant differences were found between those adults with a formal diagnosis of autism and those who self-identified as autistic. In criteria B (restrictive and repetitive behaviours) of Brosnan (2020) measure, it was found that there was a small but significant difference ($p = 0.024$) between adults with a formal diagnosis of autism and adults who self-identified as autistic. Brosnan (2020) suggested that criteria B of his measure could be useful to distinguish between adults who would and would not meet diagnostic criteria for autism and, for this reason, Brosnan (2020) recommended expanding the use of criteria B within the autism diagnostic pathway.

Considering that Pathological Demand Avoidance (PDA) has been linked with autism, Egan et al. (2019) aimed to examine this relationship by validating a measure that assessed PDA, the Extreme Demand Avoidance Questionnaire – Adult version (EDA-QA). The main purpose of the EDA-QA (Egan et al., 2019) was to use it as a screening tool for PDA in clinical settings. The EDA-QA (Egan et al., 2019) was adapted from the observer-rated EDA Questionnaire (EDA-Q) developed by O'Nions et al. (2014b) and used in children. The EDA-QA (Egan et al., 2019) was found to have good validity and reliability in a sample of 538 adults that identified as autistic, with and without a formal diagnosis of autism, adults with PDA, or that self-identified with PDA (Egan et al., 2019). Egan et al. (2019) concluded that the EDA-QA could be used as a complementary tool in clinical and research settings to determine PDA in adults.

Au-Yeung et al. (2019) and Lewis (2017) indicated that when adults were assessed for autism, they experienced a lot of difficulties in understanding the real meaning of the questions that healthcare professionals were asking during the assessment. Most of these adults also reported difficulties in providing specific examples regarding their personal strengths and difficulties interacting and communicating with others, and how these were part of their own identity (Au-Yeung et al., 2019; Lewis, 2017).

Second Theme: The Process of Self-identifying as Autistic from a Lifespan Perspective

All studies in this scoping review included adults that self-identified as autistic. However, it is important to remark from a neurodiversity-affirming perspective what the study conducted by Lewis (2016b) in the USA found. Lewis (2016b) used a qualitative approach (online survey) to investigate the process of self-identifying as autistic in terms of the experiences and feelings that adults had during that process. The Nine Degrees of Autism developed by Wylie et al. (2016) also described the process of self-identifying as autistic in the fourth degree of autism; self-identification. From a clinical perspective the importance of this process, as an identity facilitator in neurodivergent adults that are likely to be autistic, was highlighted by both authors (Lewis, 2016b; Wylie et al., 2016). Self-identifying as autistic can really help these adults (and their relatives, friends, acquaintances, and mental health professionals) to understand how they think, feel and behave.

In Lewis' (2016b) study, the process of self-identifying as autistic was found to be facilitated by family members, friends, and acquaintances. Participants (adults that self-identified as autistic) in Lewis' (2016b) study reported how different the way they understood certain thoughts, feelings and behaviours was, in comparison to others. Adults that self-identified as autistic in Lewis' (2016b) study also mentioned that from a young age (e.g., late childhood/early adolescence), they had already realized that they had a different way in comparison to their peers and relatives of understanding their personal, social, and physical environment without being aware why. This is in line with the second degree of autism which explains that individuals on the autism spectrum realize that they perceive the world, themselves, and others in a different way, but cannot explain why their approaches are different to other´s ways of understanding the world (Wylie et al., 2016).

Considerations from others and personal self-realizations seemed to be the key factors that were linked to adults starting to consider that being autistic could be a possibility (Lewis, 2016b; Moore, 2016). To validate or rule out this possibility, adults and often their loved ones (such as parents, friends, or partners) tend to do extensive searches on the internet, which may include completing a broad range of (reliable and unreliable) online autism questionnaires. They also read books/articles or watch documentaries about autism in adulthood (Lewis, 2016b; Moore, 2016).

The majority of adults in the studies that were included in this scoping review considered self-identifying as autistic to be beneficial, from a personal perspective, because it had a positive influence on understanding who they really were, after several years wondering why they had different views from the world that they were part of (Lewis, 2016b). The majority of these adults seemed to find a space of safety and personal reassurance in online autism forums or face to face groups with other autistic individuals. The Nine Degrees of Autism´s theory (Wylie et al., 2016) deem self-identifying as autistic to be an essential stage in the process towards the positive acknowledgment of an autistic identity. According to Moore (2016) the self-identification process (the fourth degree of autism), commences with the recognition that being autistic could be a possibility and ends with obtaining a formal diagnosis of autism. This pattern appeared in the narrative of the majority of studies that were included in this scoping review.

For some adults, self-identifying as autistic was satisfactory because it provided the explanation and self-understanding that had been missing throughout their lives. In some cases, the need to pursue a formal diagnosis of autism was not felt necessary. For some of these adults, there was not perceived valuable being formally assessed for autism (Lewis, 2016b). Though, for other adults, a formal diagnosis of autism was pursued for their own validation purposes or with the aim of getting reasonable adjustments in a broad range of settings (e.g., educational and/or at work) (Lewis, 2016b; Wylie et al., 2016).

In the absence of a formal diagnosis of autism, autistic individuals and their significant others are less likely to receive the support and social recognition they deserve. This has been identified as a factor that can influence in a negative way the positive acceptance of their autistic identity (Moore, 2016).

Third Theme: An Autistic Identity

Two studies, one conducted by Cooper et al. (2017) in the UK using a quantitative approach (online survey) and one conducted by Parsloe (2015) in the USA using a qualitative approach (ethnography), studied the role of autistic identity in adults with a formal diagnosis of autism, and in adults that self-identified as autistic without a formal diagnosis of autism.

In Parsloe (2015) study, it was found that adults who self-identified as autistic prior to pursuing a formal diagnosis of autism had a more favourable opinion of autism in comparison to those adults who were given a formal diagnosis of autism. Parsloe (2015) suggested that this positive attitude towards autism could be explained in terms of adults having chosen or identified with an identity in which they felt they fitted, rather than being labelled as autistic, after having completed an autism assessment with a mental health professional. In Parsloe (2015) study, it was also mentioned that the active search of an autism identity by adults that self-identified as autistic, mainly through online platforms could be linked with the need of these individuals of finding an answer that explained who they really were. This seemed to be related with the development of a positive autistic identity, and to the understanding of autism as a condition rather than a disorder like the DSM-5 (American Psychiatric Association, 2013) or the ICD-11 (WHO, 2018) suggests.

In Cooper et al. (2017) study in which 272 adults identified as autistic, 81% reported a formal diagnosis of autism. It was also found that those participants that reported a higher positive autistic identity had a better psychological wellbeing and higher levels of self-esteem.

Fourth Theme: Sexual Identity and Experiences

Two studies conducted in the USA by Lewis et al. (2021) and Penwell-Barnett and Maticka-Tyndale (2015) studied the sexual identity and sexual experiences of adults, who identified as autistic (with or without a formal diagnosis of autism), using a qualitative approach (online survey and online interviews respectively).

In Penwell-Barnett and Maticka-Tyndale´s study (2015), it was found that adults who identified as autistic were less likely to be heterosexual or gender-conforming.

In this study, the need to develop sex education programs (mainly focused on courtship, sensory dysregulation and adequate sex education) that took into account a neurodivergent perspective (identities and experiences of sexuality) was highlighted. The results of the study conducted by Penwell-Barnett and Maticka-Tyndale (2015) are in line with the study that Lewis et al. (2021) conducted with 67 participants who identified as autistic in the USA. Through an online survey, Lewis et al. (2021) identified participants as a “double minority” through the identification in the study of six main themes (1) understanding self-acceptance as a journey; 2) taking into account that autistic traits may complicate self-identification of sexual orientation; 3) how social and sensory stressors may affect sexual expression; 4) how often sexual minority autistic feel misunderstood and isolated; 5) the challenges that often sexual minority autistic have in finding mutually satisfying relationships; and 6) the difficulties that sexual minority autistics have in recognising and communicating sexual needs). Lewis et al. (2021) also concluded that as a consequence of all the challenges reported, numerous adults felt that autism had hindered the recognition of their true sexual identity.

In Lewis et al. (2021) study several participants reported that throughout their lives they had often felt that others were attributing their sexual orientation to being autistic, instead of recognizing the legitimacy of their distinct sexual identity, particularly amongst those who identified as asexual.

Fifth Theme: The Perception of Autism as a Difference or a Disability

Two studies conducted in the USA by Angulo-Jiménez and DeThorne (2019) and Kapp et al. (2013) studied the representation of autism in adults from a qualitative and mixed method approach, respectively. One study conducted in the UK by Pohl et al. (2020) studied the representation of autism within the context of motherhood using a quantitative approach (online survey).

In Kapp et al. (2013) study, it was found in an online survey completed by 657 participants (that included autistic people, relatives and friends of autistic people, and people with no specified relation to autism) that self-identification as autistic and neurodivergent awareness were correlated with viewing autism as a positive part of their identity that does not need any treatment or medical intervention. This suggests a key difference between how the medical model conceptualizes autism (e.g., autism is a mental health disorder that must be treated medically) and the neurodivergent approach (autism is a condition that is characterized by a broad range of strengths and weaknesses). These main outcomes are in line with the study that Angulo-Jiménez and DeThorne (2019) conducted in the USA, in which the representation of autism was analysed through 39 YouTube videos (published from 2007 to 2015) authored by individuals that self-identified as autistic. In Angulo-Jiménez and DeThorne (2019) study, it was found that in most YouTube videos, views of the medical model and the neurodivergent approach were acknowledged. It was also found that the neurodivergent approach appeared mainly in the use of the language in the videos and the description of autistic traits, whereas the medical model appeared mainly in the content areas that appeared in these videos. In both studies, the use of online environments was found to be a common means in which knowledge and awareness of the neurodivergent approach was gained (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013). Autism was represented as a mixture of both disability and difference (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013). Adults with a formal diagnosis of autism or self-identified as autistic were more likely to assign a biological cause to autism (Kapp et al., 2013). Angulo-Jiménez and DeThorne (2019) found that a biological cause provided an explanation for the difficulties faced by autism, with 34 out of 39 bloggers assigning the difficulties encountered to autism. The contribution of societal factors, in the difficulties faced by autism, was also acknowledged in both studies (Angulo-Jiménez & DeThorne, 2019; Kapp et al., 2013).

In the context of motherhood, a study conducted by Pohl et al. (2020) with autistic mothers ($n = 355$) and non-autistic mothers ($n = 132$) from Western countries evaluated the experience of motherhood (including pregnancy, childbirth, the postpartum period, self-perception of parenting strengths and weakness, communication with professionals and the social experience of motherhood). Pohl et al. (2020) study found that the perceived societal representation of autism sometimes prevented mothers revealing an autism diagnosis in parenting contexts or to healthcare professionals. Pohl et al. (2020) study also found that the majority of mothers (75%), who self-identified as autistic never or rarely disclosed this information to other parents or healthcare professionals. As a result, autistic mothers, or mothers who self-identified as autistic seemed to not have the needed support and were likeliest to find motherhood a lonely experience (Pohl et al., 2020).

Discussion

The first aim of this scoping review was to ascertain what research had been conducted on the self-identification process of autism in adults, who do and do not have a formal diagnosis of autism. It was found that research was recent and limited, although steadily increasing. Although this scoping review identified five main themes: 1) the diagnostic process from a client's perspective; 2) the process of self-identifying as autistic from a lifespan perspective; 3) an autistic identity; 4) sexual identity and experiences and 5) the perception of autism as a difference or a disability, there were some factors that overlapped themes (e.g., identity).

Kapp et al. (2013) was the first study in the USA that studied adults who self-identified as autistic. As a recommendation, Kapp et al. (2013) suggested that future research should investigate differences between individuals who do and do not have a formal diagnosis of autism, and the reasonings for not pursuing a formal diagnosis. Since 2013, much research conducted on adults that self-identified as autistic, with or without a formal diagnosis of autism, has focused on the diagnostic process. Research on the diagnostic process mainly found that adults faced difficulties in being referred for an adult autism diagnostic assessment, which in several cases had the consequence that many adults that would have liked to have had an assessment were never assessed (Lewis, 2017). Misdiagnosis was another common factor that appeared in this scoping review (Au-Yeung et al., 2019; Lewis, 2017).

Identity was a factor that was apparent in most of the themes that were identified in this scoping review. Similar to research conducted regarding the impact of an autism diagnosis in adulthood (Lewis, 2016a; Stagg & Belcher, 2019), the process of self-identifying as autistic allowed adults to understand who they really were (Lewis, 2016b). Even so, Moore (2016) advocates that a formal diagnosis of autism can aid the positive acceptance of an autistic identity, which has been associated with better psychological wellbeing (Cooper et al., 2017). Parsloe (2015) suggests that a positive autistic identity could be attained through the process of self-identifying as autistic, but the fact that Pohl et al. (2020) found in their study that three quarters of adults who self-identified as autistic never or rarely revealed this to healthcare professionals, might suggest otherwise or that this process it is context specific. A formal diagnosis of autism is often deemed to be the authenticator of an autistic identity, which may enable self-acceptance (Lewis, 2016a). Self-acceptance can be particularly difficult for adults that identify as autistic and as a sexual minority (Lewis et al., 2021). Therefore, it is concerning that adults face barriers and misdiagnosis in the pursuit of an autism diagnostic assessment and diagnosis (Au-Yeung et al., 2019; Lewis, 2017).

We believe that further studies should investigate what socio-demographic (e.g., ethnicity, education and employment) and psychosocial (e.g., quality of life, subjective wellbeing and self-esteem) factors are associated with the development of a positive autistic identity in adults that self-identity as autistic (with or without a formal diagnosis of autism).

The second aim of this scoping review was to identify which aspects of the self-identification process could be used to improve the referral and diagnostic process of an adult autism diagnostic assessment, for adults who choose this route. Other research suggests that individuals that self-identify with having a mental health condition are more likely to seek help (Evans-Lacko et al., 2019). In several of the studies that were reviewed in this scoping review (Au-Yeung et al., 2019; Brosnan, 2020; Kapp et al., 2013; Pohl et al., 2020), it was found that the results from adults who self-identified as autistic were very similar to the results of adults with a formal diagnosis of autism. This may imply that adults, who may likely be autistic, do have a reasonably accurate understanding of autism as a condition. Interestingly, there was a higher proportion of participants that identified as female (likely to be autistic) in all these studies. However, this understanding of autism was often distrusted or ignored by healthcare professionals (Lewis, 2017).

Certainly, the presentation of autism can differ in adults as autistic traits may not be that obvious to others (including mental health professionals) through the use masking strategies that individuals that are autistic (or identify as autistic) have learnt or copied from others throughout their lives (Fusar-Poli et al., 2020; Lai & Baron-Cohen, 2015). Lai and Baron-Cohen (2015) state that learnt masking strategies may be used more by females, which may contribute to the additional barriers that females encounter in the autism diagnostic process. Research to address the barriers that females encounter is increasing, but it is still a largely under-researched topic (Lockwood Estrin et al., 2021). This is reflected in the findings of this scoping review, in which many of the included studies had a higher number of participants that identified as female.

To ensure the effective screening and diagnosis of autism in adults, Piven and Rabins (2011) previously highlighted the need to develop tools that could take into consideration how autism presents in adults (instead of adapting clinical tools that are mainly used for children and young people). More recently, Lewis (2017) emphasised the need to ensure that these tools also consider the gender-based variations in the presentation of autism amongst adults. Yet, minimal effort has been made to improve the diagnostic pathway for adults in recent years.

In this scoping review, it has been found that little is known regarding how an autistic identity or the fact that an adult has self-identified as autistic has been considered in the referral process of an adult autism diagnostic assessment, or during an adult autism diagnostic assessment. In line with Gallo (2010), we believe that it is important to give adults that self-identify as autistic in clinical settings (e.g., in a GP appointment to get a referral for an autism diagnostic assessment or during an autism assessment), the opportunity to express in their own words the main strengths and difficulties they experience in real life (e.g., at home or at work). We believe this approach should be considered as a complimentary procedure in the current recommendations suggested by the National Institute for Health and Care Excellence (NICE) for adult autism assessments (NICE, 2016).

We have found that only one scale has been developed and validated in the USA recently to assess autism identity in adults in research settings. This scale 'The Autism Spectrum Identity Scale' (ASIS) was developed by McDonald (2016) with a sample of 1139 adults that self-identified as autistic or had a formal diagnosis of autism. The ASIS (McDonald, 2016) has four factors that explain autism identity (changeability; spectrum abilities; context dependent and positive difference). We believe that this questionnaire (or similar ones) could be used as a facilitator tool in diagnostic and therapeutic processes in adults that self-identify as autistic or are autistic.

To date, this scale has not been validated in the UK and has not been used therapeutically or as complimentary measure in the referral or diagnostic process of adults that self-identify as autistic. In line with Leadbitter et al. (2021), we believe that including the ASIS (McDonald, 2016, 2017), or similar neurodivergent-friendly clinical tools, in the referral and diagnostic process of an adult autism diagnostic assessment, would allow healthcare professionals to understand the views of their clients, from a client-centred approach and not only from a medical perspective.

Limitations

This scoping review was limited to the research on the four databases searched. Searching more databases may have found more research that met the inclusion criteria. However, searching four databases is in line with previous scoping reviews (e.g., Huang et al., 2020). Including grey literature may have also resulted in more research. A further limitation was the type and the number of reviewers. We believe that the inclusion of experts by experience and autism activists in the whole process of this scoping review would have enriched the critical analysis of the articles we reviewed.

Future Research

Future research would benefit from the use of other data collection methods, as online surveys were the predominant method of data collection in the studies that were analysed in this scoping review. For example, the use of online focus groups would allow for participants to elaborate their answers more in-depth, and for researchers to clarify them. Focus group discussion can also be advantageous in providing new understandings and perspectives on an emerging area of research (Coolican, 2014; Flick, 2014) such as autism identity in adults.

We also believe future research should address the highlighted difficulties that adults face in obtaining an autism diagnostic assessment. The results of this scoping review indicate that adults who self-identify as autistic seem to have a reasonably accurate recognition of autism/autistic traits in themselves. We think this is something that should be considered in the referral and diagnostic process of an adult autism assessment.

In this scoping review, we also have identified that there are currently no neurodivergent-friendly (complementary) clinical tools in the referral and diagnostic process of an adult autism assessment, that have been developed and validated in the UK (or elsewhere) and consider the views of adults that self-identify as autistic.

Conclusion

This scoping review ascertained what research had been conducted on the self-identification of autism in adults, who do and do not have a formal diagnosis of autism. It also identified which aspects of the self-identification process could be used to improve the referral and diagnostic process of an adult autism diagnostic assessment. Results indicate that adults that self-identify as autistic currently face difficulties in being referred and assessed for a formal autism diagnosis. The themes identified in this scoping review acknowledge the importance, from a client-centred perspective, of how vital it is to develop complementary clinical tools in the referral and diagnostic process of adult autism diagnostic assessment that are neurodivergent-friendly. The development and validation of these tools should be conducted considering the views of experts by experience, autism activists and healthcare professionals that conduct autism diagnostic assessments in adults (co-production).

Appendix

Table 1 Characteristics of included studies

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Angulo-Jiménez and De Thorne (2019) *Narratives about autism: An analysis of YouTube videos by individuals who self-identify as autistic*	Study origin = USA Participants, $N = 39$ (perceived male = 26, perceived female = 13. Age range = 13–45, mean = 24, 21 did not state. Perceived as white = 33, perceived Latino/Hispanic = 2, perceived Asian American = 2, perceived African American = 1, not specified = 1. Perceived country of origin: United States = 13, United Kingdom/Great Britain = 5, Canada = 2, Australia = 1, Denmark = 1, Ireland = 1, not specified = 16 24 reported a formal diagnosis of autism and 15 reported self-identifying as autistic 7 reported co-occurring forms of neurodivergence (obsessive compulsive disorder and synaesthesia = 1, anxiety and depression = 2, schizotypal behaviour disorder = 1, sensory-processing disorder = 1, attention-deficit disorder = 1, dermatillomania = 1) No data regarding socio-economic status or levels of education were reported	To answer the research questions: 1) who are the vloggers? and 2) do the videos represent autism as a disorder (medical model), a difference (neurodiversity paradigm), or both?	Qualitative Narrative inquiry approach Publicly accessible Vlog entries where the title was indicative of life with autism and/or an account of autism were found by the research team. Vlog entries were found by online searches conducted by the research team 39 YouTube videos (published between 2007 and 2015) were analysed	The majority of vloggers were adults who were white, male, likely from the USA and reported Asperger's syndrome There were 3 main findings in relation to the representation of autism in the videos; 1) the representation of autism was complex and hybrid. 2) most content areas contained more medical model features, although it was most apparent in relation to the source of challenges that autistic individuals encounter (34 out of 39 assigned the challenges encountered to autism). 3) In relation to the content areas of language and description of autistic traits, neurodiversity characteristics were relatively high in prevalence	ASD was viewed as both a disability and difference Adults tended to prefer language associated with difference (e.g., Aspie) rather than disorder

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Au-Yeung et al. (2019) *Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults*	Study origin = UK Participants, $N = 420$ (male = 103, female = 317. Age range = 18–67.) 208 identified as autistic (reported a formal diagnosis of ASD from a qualified healthcare professional, male = 72, female = 136. Age range = 18–67, mean = 38.6. Age range of diagnosis = 4–59, mean = 34.5), 71 identified as possibly autistic (reported thinking that they may have ASD and were either awaiting an assessment from a qualified healthcare professional or were yet to pursue an assessment, male = 11, female = 60. Age range = 20–57, mean = 40.1). 141 identified as non-autistic (reported no formal diagnosis of ASD and no thoughts of possibly being autistic, male = 20, female = 121. Age range = 20–60, mean = 42.1) No other data on demographic characteristics was recorded	To answer the research questions: 1) are autistic individuals more likely to report receiving mental health diagnosis(es) and if so, what kind of diagnoses were they more likely to receive? 2) are autistic individuals more likely to disagree with these diagnoses? and 3) what were the reasons behind any disagreement?	Mixed methods Participants were recruited through charities, Cambridge Autism Research Database, Cambridge Psychology, MHAutism newsletter, online advertisements and MHAutism webpage Participants were asked a series of closed and open-ended questions regarding mental health diagnoses Participants also completed the Autism Spectrum Quotient (AQ-50) (Baron-Cohen et al., 2001)	Compared to non-autistic adults, autistic and possibly autistic adults reported receiving more mental health diagnoses. Significant differences were found for; depressive disorders, anxiety disorders, obsessive compulsive and related disorders, trauma and stress related disorders, feeding and eating disorders and personality disorders Autistic and possibly autistic adults were also significantly less likely to agree with their mental health diagnoses than non-autistic adults. Two major reasons for their disagreement were 1) ASD characteristics were confused with symptoms of a mental health condition and 2) mental health difficulties perceived to be resultant of ASD. Autistic and possibly autistic individuals spoke about the clinical barriers that hinder accurate diagnosis and support, which include healthcare professionals' lack of awareness and understanding of autism, poor communication between autistic adults and healthcare professionals and treatment not being suited to their needs	Results from autistic and possibly autistic adults were very similar Autistic and possibly autistic adults reported barriers to an accurate diagnosis. Barriers related to experiences and interactions with healthcare professionals

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Brosnan (2020) *An exploratory study of a dimensional assessment of the diagnostic criteria for autism*	Study origin = UK Participants, $N = 1076$ (male = 203, female = 798, non-binary = 72, did not state = 3. Age range = 16–89, mean = 41.0, did not state = 14) 440 reported having a diagnosis of autism, 210 reported self-identifying autism, 425 reported no identification with autism, 1 did not state No other data on demographic characteristics was recorded	To explore the self-reporting of items that directly reflect the diagnostic criteria for autism on a dimensional assessment and compare them to existing dimensional assessments of autistic-like traits	Quantitative Two surveys were included in two different online courses; one that targeted autistic adults and one that targeted the general population Participants completed an online survey, which was comprised of the two diagnostic criteria (RRB and social items). The survey for the general population also included the Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012) at the end of the survey	There were no significant differences between adults who had a formal diagnosis of ASD and adults who self-identified as autistic on the social item There was a significant difference between adults who had a formal diagnosis of ASD and adults who self-identified as autistic on the RRB item In comparison to the non-autistic group, adults with a formal diagnosis of ASD and adults who self-identified as autistic both scored significantly higher on both (social and RRB) items	Results from autistic and self-identified autistic adults were similar
Cooper et al. (2017) *Social identity, self-esteem, and mental health in autism*	Study origin = UK Participants, $N = 539$ 272 were autistic participants, 81% of which reported having a formal diagnosis (female = 47%, average age = 32.7 years, graduates = 52%, heterosexual = 50%, 63% reported having a mental health diagnosis) 267 were not autistic (female = 53%, average age = 34.2 years, graduates = 79%, heterosexual = 82%, 26% reported having a mental health diagnosis) No other data on demographic characteristics was recorded	To investigate the relationship between autism identification, collective self-esteem and psychological wellbeing in autistic people	Quantitative Participants were recruited from online forums (e.g., forums for autistic individuals and forums at the university where the research was undertaken) Participants were asked to complete an online survey All participants were asked to complete a personal self-esteem measure (Rosenberg, 1965), an anxiety measure (Spielberger et al., 1983) and a depression measure (Spielberger et al., 2003). Autistic participants were asked to complete an additional two measures: an autism identification measure (Leach et al., 2008) and an autism collective self-esteem measure (Luhtanen & Crocker, 1992)	Compared to non-autistic individuals, autistic individuals had lower personal self-esteem, and higher depression and anxiety Autism identification was positively related to personal self-esteem to the extent of providing a sense of collective self-esteem	The relationship between autism identification and psychological wellbeing In line with Social Identity Theory (SIT) (Tajfel & Turner, 1979), a positive autistic identity was related to better psychological wellbeing

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Egan et al. (2019) *The measurement of adult pathological demand avoidance traits*	Study origin = UK Study one Participants, $N = 347$ (male = 94, female = 230, other (non-binary/gender fluid) = 19, did not state = 4. Age range = 18–84, mean = 36.9) Mean years of education = 14.7 Reported a prior formal mental health diagnosis = 54.4%. Reported a belief that they had an undiagnosed mental health disorder = 26.6% Reported a formal diagnosis of ASD = 59 Reported self-identifying as autistic with PDA = 29 Reported solely self-identified PDA = 44 Reported self-identified PDA with anxiety or depression = 19 Study two Participants, $N = 191$ (male = 47, female = 14, other (non-binary/gender fluid) = 3, did not state = 127. Age range = 18–76, mean = 29.15) Reported more than 13 years of education = 83.2%, in full or part time study = 39.3%, in full or part time employment = 51.8%, unemployed/retired = 8.9% 26.2% reported a confirmed psychological diagnosis (joint anxiety and depression were most prevalent). 11.5% reported a suspected psychological diagnosis (anxiety and Asperger's syndrome mostly)	Study one To validate the Extreme Demand Avoidance Questionnaire (EDA-QA) (O'Nions et al., 2014a) for use as a self-report measure of traits and behaviours related to PDA in adults without intellectual impairment To use the EDA-Q to examine the relationship between PDA traits, ASD traits and other psychopathology dimensions in a community sample of adults reporting self-identified psychopathology Study two To validate the EDA-Q (O'Nions et al., 2014b) in relation to fuller measures of ASQ, EQ, personality and offending To explore the predictive relationship between the dimensions and offending behaviour	Study one Quantitative Participants were recruited from online platforms that 1) focused on concerns/needs of autistic individuals and 2) incorporated the general population Participants were asked to complete an online survey, which consisted of: the EDA-QA (O'Nions et al., 2014a), the ASQ-SF (Kuenssberg et al., 2014), the ICU (Kimonis et al., 2008) and the PID-5-BF (Krueger et al., 2013) Study two Quantitative Participants were recruited from online platforms that 1) included individuals that self-identified ASD or PDA and 2) incorporated the general population Participants were asked to complete an online survey, which consisted of: the EDA-QA (O'Nions et al., 2014a), the ASQ (Baron-Cohen et al., 2001), the EQ (Baron-Cohen & Wheelwright, 2004), the IPIP-50 (Goldberg, 1999) and the SRED (Moffitt & Silva 1988; Charles & Egan, 2005)	The EDA-QA (O'Nions et al., 2014a) was found to be a reliable and valid measure Self-reported PDA traits were found to partially relate to self-reported ASD traits	N/A

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Kapp et al. (2013) *Deficit, difference, or both? Autism and neurodiversity*	Study origin = USA Participants, $N = 657$ (male = 26.2%, female = 68.6%, transgender and intersex = 3.5%, did not state = 1.7%. Age range = 8–84, mean = 32.5) Education range = no education – postdoctoral training, mean years of education = 15.5 years Ethnicity, Caucasian = 78.7%, Hispanic = 4.6%, Asian = 2.7%, African decent = 1.8%, Pacific Islander = 3%, mixed ethnicity = 6.1% *Gender or ethnicity were not reported by all participants* 223 reported a formal diagnosis of ASD, 78 reported self-identifying as autistic, 342 reported as non-autistic, 14 reported not knowing if a formal diagnosis had been given (excluded from analysis) No other data on demographic characteristics was recorded	To answer research aims: 1) to characterize awareness of and evaluations of the neurodiversity movement online (where the neurodiversity movement arose and often takes place; e.g., Jordan, 2010), 2) to confirm core distinctions between the medical model and the neurodiversity movement, and 3) to critically examine the perceived opposition between the medical model and the neurodiversity movement	Mixed methods Online survey Participants were recruited from the USA and UK via various online platforms, emails and social networks Participants were asked to complete the AQ-50 (Baron-Cohen et al., 2001) Participants were asked a series of questions about neurodiversity and questions about autism; autism as identity, emotions about autism and attitudes towards parenting	Compared to non-autistic individuals, autistic individuals (individuals with a formal diagnosis and individuals who self-identify as autistic) were more likely to be aware of neurodiversity and to have learned about it online Compared to non-autistic individuals, autistic individuals assigned a lower priority to research on the cause of autism Autistic individuals were more likely to assign a biological cause to autism Being an autistic individual and having an awareness of neurodiversity was associated with a greater likelihood of preferring identity first (e.g., autistic person) language	Results from autistic individuals and individuals who self-identify as autistic were very similar
Lewis (2016a, 2016b) *Exploring the experience of self-diagnosis of autism spectrum disorder in adults*	Study origin = USA Participants, $N = 37$ (male = 20, female = 16, did not state = 1. Age range = 18–52, mean = 29.9) Highest level of education, high school = 5, Vocational/technical/trade = 3, some college education = 13, college graduate = 9, some postgraduate work = 2, postgraduate degree = 4, did not state = 1 Employment, employed = 25, unemployed/disabled = 3, student = 8, did not state = 1 Race/ethnicity, Asian = 1, Black = 2, Hispanic = 1, white = 31, did not state = 2. Country, Argentina = 1, Belgium = 1, Germany = 1, Canada = 4, India = 1, Russia = 1, Norway = 1, Slovenia = 1, Turkey = 1, United Kingdom = 5, United States = 19, did not state = 1 All participants reported self-identifying as autistic	To answer the research question 'What is the experience of being self-diagnosed with ASD?'	Qualitative Participants were recruited through online support groups and public forums for autistic individuals Participants asked to respond to the statement: 'Please describe your experience of coming to a self-diagnosis of autism spectrum disorder. Please share any thoughts, feelings, and specific experiences.'	Five themes ("feeling othered", "managing self-doubt", "sense of belonging", "understanding myself" and "questioning the need for formal diagnosis") were found to be descriptors of the self-diagnosis of ASD journey	Participants felt that a self-diagnosis of ASD was beneficial in terms of understanding themselves Some participants felt that a self-diagnosis of ASD was satisfactory and did not feel the need to pursue a formal diagnosis of ASD Several participants stated barriers to pursing a formal diagnosis of ASD (some relating to physical barriers, e.g., not being able to afford a formal diagnosis of ASD and no availability of adult ASD specialists. Others relating to personal barriers, e.g., the fear of not being believed and extreme anxiety in appointments)

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Lewis (2017) *A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults*	Study origin = USA Study one Participants, $N = 114$ (male = 57, female = 45, agender = 2, gender fluid/gender queer/non-binary gender = 2, did not state = 8. Age range = 18–65, mean = 36.2, did not state = 2) Highest level of education, some high school = 3, high school graduate = 8, vocational/technical/trade training = 7, some college = 35, college graduate = 32, some postgraduate work = 4, postgraduate degree = 15, did not state = 10 Employment, employed = 58, unemployed = 18, homemaker = 3, student = 17, retired = 2, disabled/unable to work = 7, did not state = 9 Ethnicity, white non-Hispanic = 95, Hispanic/Latino = 2, black/African American = 5, native American/American Indian = 2, Pacific Islander/Asian = 4, did not state = 6 77 reported a formal diagnosis or evaluation of ASD and 37 self-identified as autistic) Study two Participants, $N = 665$ (male = 90, female = 363, agender = 90, gender fluid/gender queer/non-binary gender = 69, transgender = 15, unsure/questioning = 7 and did not state = 31 Age range = 18–68, mean = 30.9, did not state = 29) Sexual orientation, heterosexual = 190, gay/lesbian = 57, bisexual = 167, unsure = 41, other = 170, did not state = 40 Marital status, single, never married = 378, married/domestic partnership = 198, widowed = 4, divorced = 47, did not state = 38 Highest level of education, some high school = 25, high school graduate = 51, vocational/technical/trade training = 29, some college = 258, college graduate = 135, some postgraduate work = 43, postgraduate degree = 85, did not state = 39 Employment, employed = 261, unemployed = 77, homemaker = 27, student = 143, retired = 6, disabled/unable to work = 113, did not state = 38 Health insurance, primary source from government = 179, primary source from employer = 87, primary source through member of family = 211, primary source self-funded = 41, no insurance = 105, did not state = 42 216 reported a formal diagnosis or evaluation of ASD, 135 reported an informal evaluation of ASD, 280 reported self-identifying as autistic and 34 did not state	To answer the research questions: 1) (qualitative) 'what barriers do adults with ASD face in reaching a formal diagnosis?' and 2) (quantitative) 'what is the incidence and severity of each of these barriers?'	Mixed methods Study one Qualitative Secondary data analysis of two phenomenological studies: 1) being formally diagnosed with ASD as an adult (Lewis, 2016a) and 2) being self-diagnosed with ASD as an adult (Lewis, 2016b) Study two Quantitative From the secondary data analysis in study one, a list of potential barriers to a formal diagnosis of ASD was devised Participants were recruited through online forums and message boards for autistic individuals Participants were asked to read each of the listed barriers and rate the severity of the barrier on a 4-point Likert-type scale (1 = Not a barrier/no influence, 2 = Somewhat of a barrier, 3 = Moderate barrier and 4 = Extreme barrier) to obtaining a formal diagnosis of ASD Participants were also asked to complete the AQ (Baron-Cohen et al., 2001)	Nine themes ("Anxiety", "Cost", "Access to ASD adult specialists", "Fear of not being believed", "Inability to describe symptoms", "Mistrust of healthcare professionals", "Stigma", "Complexity of healthcare system" and "Lack of perceived value of formal diagnosis") were found to potential barriers to a formal diagnosis of ASD The most frequently reported barriers were: concerns about not being believed (94.4%), followed by not being listened to (92.3%) and being told that they were 'making up' symptoms (92%). These barriers were also reported to be the most severe, with each barrier reported as extreme barriers for at least 50% of participants. The mean score for not being believed was 3.28, for not being listened to was 3.21 and for being told that they were 'making up' symptoms was 3.19	Participants reported personal barriers to obtaining a formal diagnosis, most frequently and as most severe The personal barriers related to the interactions with healthcare professionals

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Lewis et al. (2021) *"Straight Sex is Complicated Enough!": The Lived Experiences of Autistics Who are Gay, Lesbian, Bisexual, Asexual, or Other Sexual Orientations*	Study origin = USA Participants, $N = 67$ (male = 22, female = 28, agender = 4, gender fluid/gender queer/non-binary = 9, transgender = 1 did not state = 3. Age range = 18–57, mean = 27.6) Sexual orientation, gay/lesbian = 15, bisexual = 10, asexual, 19, pansexual = 11, demisexual = 3, omnisexual = 1, queer = 3, no label = 2, did not state = 3 Relationship status, single = 38, in a relationship = 15, married = 8, divorced = 2, did not state = 4 Highest level of education, some high school = 2, high school graduate = 8, vocational/technical/trade training = 2, some college = 19, college graduate = 21, some postgraduate work = 7, postgraduate degree = 4, did not state = 4 Employment, full time employment = 19, part time employment = 8, unemployed = 13, student = 18, disabled/unable to work = 6, did not state = 3 Ethnicity, white, non-Hispanic = 55, Hispanic/Latino = 1, black/African American = 2, Native American/American Indian = 1, Asian/Pacific Islander = 1, multi-racial = 4, did not state = 3 42 reported a formal diagnosis of ASD, 17 reported having been informally identified as autistic by a healthcare professional, 5 reported self-identifying as autistic and 3 did not state	To answer the research question 'What is the lived experience of being an autistic who identifies as gay, lesbian, bisexual, asexual, or other sexual minority orientation?'	Qualitative Participants were recruited through online platforms for autistic individuals Participants asked to initially provide a written response to four open-ended questions; 1) What has been your experience as an individual with ASD and identifying with a sexual minority identity? Please share any thoughts, feelings, and specific experiences in as much detail as possible. 2) Please describe any challenges and/or aspects of pride. 3) How would you describe your sexual orientation? 4) Please describe your comfort level with your self-identity. How has this changed over time? Based on participant response to the four open-ended questions, individualised follow-up questions were asked. Examples given were; '1) In your previous response, you said that you are "less willing to seek companionship out of fear of hurting other people by neither satisfying their emotional nor physical needs." Can you tell us more about this? 2) In your previous response, you said that you "don't have any sexual drive to form a romantic relationship." To clarify, do you desire a romantic relationship that does not involve a sexual relationship? For example, would you be interested in having an asexual romantic relationship with a partner?'	Six themes ("self-acceptance is a multi-layered journey", "autism complicates understanding of sexual identity", "anxiety, sensory overload, and social stressors affect sexual expression", "feeling misunderstood and misunderstanding others", "concerns about the ability to find mutually satisfying relationships and "inability to effectively identify and communicate intimate desires".) were found to be indicative of the lived experience of sexual minority autistic individuals	ASD affected sexual identity and sexual relationships

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Moore (2016) *The fourth degree of autism: Self-identification*	Theoretical framework Not a research study	Theoretical framework Not a research study	Theoretical framework Not a research study	Theoretical framework. Not a research study	Self-identifying as autistic is recognised as a key sequential step in positively accepting an autistic identity The value of a formal diagnosis of ASD is highlighted. A formal diagnosis helps adults to understand themselves
Parsloe (2015) *Discourses of disability, narratives of community: Reclaiming an autistic identity online*	Study origin = USA Participants, $N = 10$ (male = 4, female = 6. Age range = 18–56, average age = 35) Ethnicity, Caucasian = 10 6 reported a formal diagnosis of autism, 2 reported an informal diagnosis of autism and 2 reported a self-diagnosis of autism No other data on demographic characteristics was recorded	To answer the research question: how do those with high functioning autism and Asperger's syndrome communicatively construct an Aspie identity on the Internet?	Qualitative Netnographic approach. Public sections of the online community Aspies Central (AC) was used for data collection 10 interviews (telephone = 1, Skype with video feature = 1, Skype without video or sound = 4, Facebook chat = 1, email = 3) were also conducted Participants were recruited through online platforms for autistic individuals Participants were asked to describe differences and similarities between Neurotypical and Aspie communities, to discuss the difficulties faced by Aspies and to describe disclosure and passing strategies	Four themes ("naming versus labelling", "narrative identity construction", "coalition building" and "othering/ selfing") were found to be conclusions about the process of identity construction online	A more positive view of Aspieness tended to be expressed by self-diagnosed participants and participants that self-diagnosed ASD before pursuing a formal diagnosis

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Penwell-Barnett and Maticka-Tyndale (2015) *Qualitative exploration of sexual experiences among adults on the autism spectrum: Implications for sex education*	Study origin = USA Participants, $N = 24$ (6 reported a masculine identity, 13 reported a feminine identity and five reported a genderqueer or androgynous identity Age range = 18–61, mean = 37) Identifying as Caucasian or white = 22 Reported the completion of some post-secondary or professional education = 21 Relationship status, married = 9, single = 8, domestic partnership = 2, cohabiting = 3, in a serious, not cohabiting, relationship = 2 Many (number not reported) participants lived independently. Other (number not reported) participants received supplemental income, health insurance or had a personal assistant All participants reported a self-identification as a person on the autism spectrum	The aim of the research was 1) to begin to develop an understanding of how autistic individuals describe their own sexuality and sexual experiences, and 2) to examine the implications of those descriptions for the delivery of sex education	Qualitative Participants were recruited through website announcements and Listservs for the autistic community Participants participated in online semi-structured interviews of their choice (email = 18, chat = 2, and in streaming (e.g., Skype) = 4)	Compared to the general population, individuals who self-identified as autistic were less likely to be gender conforming or heterosexual The most common reported concerns were courtship difficulties and sensory dysregulation in the context of partnered sexuality	ASD affected sexual identity and sexual relationships

Table 1 (continued)

Study	Characteristics of Study	Aims of Study	Methodology of Study	Outcome of Study	Relevant Key Findings of Study
Pohl et al. (2020) *A comparative study of autistic and non-autistic women's experience of motherhood*	Study origin = UK Participants, $N = 487$ 355 reported being an autistic mother: 235 reported a formal diagnosis of ASD and 120 reported self-identifying as autistic (male = 2, female = 339, other = 2. Age, mean = 42.7) Education, high school/some secondary = 20, completion of high school/secondary = 55, completion of some of an undergraduate degree = 71, completion of an undergraduate degree = 102, completion of a postgraduate/graduate degree = 107 Marital status, single = 36, married = 202, civil partnership = 9, divorced = 44, widowed = 4, separated = 28, long-term partner = 29, other = 3 Living with current partner, yes = 240, no = 3 Single parenthood, currently a single parent = 98, been a single parent in the past = 79, never been a single parent = 178 Country (top 5), UK = 173, USA = 80, Australia = 45, France = 11, Canada = 12 132 reported being a non-autistic mother (male = 3, female = 129. Age, mean = 44.6) Education, high school/some secondary = 9, completion of high school/secondary = 25, completion of some of an undergraduate degree = 10, completion of an undergraduate degree = 35, completion of a postgraduate/graduate degree = 53 Marital status, single = 12, married = 88, civil partnership = 1, divorced = 3, widowed = 2, separated = 9, long-term partner = 16, other = 1 Living with current partner, yes = 103, no = 2 Single parenthood, currently a single parent = 23, been a single parent in the past = 20, never been a single parent = 89 Country (top 5), UK = 75, USA = 23, Australia = 23, France = 4, Canada = 2	The aim of the research was to explore autistic mothers' experience of the perinatal period and parenthood	Quantitative Community-based participatory research model Participants were recruited through online platforms (social media and specific support groups for autistic individuals) An online survey was created and was completed by autistic and non-autistic mothers Participants were also asked to complete the Autism Spectrum Quotient 10 (AQ-10) (Allison et al., 2012) Chi-squared analysis was used to compare responses	Compared to non-autistic mothers, autistic mothers find aspects of parenthood more difficult. Aspects included communication difficulties with professionals, negative perceptions of their mothering and high rates of postpartum depression	40% of mothers with a diagnosis of ASD reported that they rarely or never disclosed their diagnosis. For adults who self-identified as autistic, 75% reported rarely or never disclosing Compared to 41% of non-autistic mothers, over 70% of autistic mothers reported an additional psychiatric condition Self-identified adults scored significantly higher than non-autistic mothers on the AQ-10 (Allison et al., 2012)

Author Contributions This scoping review was suggested by the second author (FMS). The first author (GLO) searched the literature and conducted the data analysis, both of which were reviewed by the second author (FMS). At this stage, input was also received from the third (RM) and fourth (PC) authors. The article was written by the first and second authors and critically reviewed by the third and fourth authors.

Funding This scoping review forms part of the PhD research of the first author. No funds, grants, or other support was received.

Declarations

Competing Interests The authors have no competing interests to declare that are relevant to the content of this article.

References

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "red flags" for autismscreening: The short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(2), 202–212. https://doi.org/10.1016/j.jaac.2011.11.003

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.

Angulo-Jiménez, H., & DeThorne, L. (2019). Narratives about autism: an analysis of YouTube videos by individuals who self-identify as autistic. *American Journal of Speech-Language Pathology, 28*, 569–590. https://doi.org/10.1044/2018_AJSLP-18-0045

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism, 23*(6), 1508–1518. https://doi.org/10.1177/1362361318818167

Baron-Cohen, S., & Wheelwright, S. (2004). The empathy quotient: An investigation of adults with Asperger syndrome or high functioning autism, and normal sex differences. *Journal of Autism and Developmental Disorders, 34*, 163–175. https://doi.org/10.1023/B:JADD.0000022607.19833.00

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autismspectrum quotient (AQ): Evidence from asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*, 5–17. https://doi.org/10.1023/A:1005653411471

Brosnan, M. (2020). An exploratory study of a dimensional assessment of the diagnostic criteria for autism. *Journal of Autism and Developmental Disorders, 50*, 4158–4164. https://doi.org/10.1007/s10803-020-04474-8

Brownlow, C., & O'Dell, L. (2006). Constructing an autistic identity: AS voices online. *Mental Retardation, 44*(5), 315–321. https://doi.org/10.1352/0047-6765(2006)44[315:CAAIAV]2.0.CO;2

Charles, K. E., & Egan, V. (2005). Mating effort correlates with self-reported delinquency in a normal adolescent sample. *Personality and Individual Differences, 38*(5), 1035–1045. https://doi.org/10.1016/j.paid.2004.06.021

Coolican, H. (2014). *Research methods and statistics in psychology* (6th ed.). Psychology Press.

Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology, 47*(7), 844–854. https://doi.org/10.1002/ejsp.2297

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders, 48*(11), 3761–3772. https://doi.org/10.1007/s10803-018-3639-1

Egan, V., Linenberg, O., & O'Nions, E. (2019). The measurement of adult pathological demand avoidance traits. *Journal of Autism and Developmental Disorders, 49*, 481–494. https://doi.org/10.1007/s10803-018-3722-7

Evans-Lacko, S., Stolzenburg, S., Gronholm, P. C., Ribeiro, W., York-Smith, M., & Schomerus, G. (2019). Psychometric validation of the self-identification of having a mental illness (SELF-I) scale and the relationship with stigma and help-seeking among young people. *Social Psychiatry and Psychiatric Epidemiology, 54*(1), 59–67. https://doi.org/10.1007/s00127-018-1602-2

Flick, U. (2014). *An introduction to qualitative research* (5th ed.). SAGE.

Fusar-Poli, L., Brondino, N., Politi, P., & Aguglia, E. (2020). Missed diagnoses and misdiagnoses of adults with autism spectrum disorder. *European Archives of Psychiatry and Clinical Neuroscience*, 1–12. https://doi.org/10.1007/s00406-020-01189-w

Gallo, D. P. (2010). *Diagnosing autism spectrum disorders*. Wiley-Blackwell.

Goldberg, L. R. (1999). A broad-bandwidth, public-domain, personality inventory measuring the lower-level facets of several five-factor models. In I. Mervielde, I. Deary, F. De Fruyt, & F. Ostendorf (Eds.), *Personality psychology in Europe* (Vol. 7, pp. 7–28). Tilburg: Tilburg University Press.

Huang, Y., Arnold, S. R., Foley, K. R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: a scoping review. *Autism, 24*(6), 1311–1327. https://doi.org/10.1177/1362361320903128

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: a survey of adults in the United Kingdom. *Journal of Autism and Developmental Disorders, 44*(12), 3033–3044. https://doi.org/10.1007/s10803-014-2161-3

Jordan, C. J. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities, 48*, 220–227. https://doi.org/10.1352/1934-9556-48.3.220

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? *Autism and Neurodiversity. Developmental Psychology, 49*(1), 59–71. https://doi.org/10.1037/a0028353

Kimonis, E. R., Frick, P. J., Skeem, J. L., Marsee, M. A., Munoz, L. C., Aucoin, K. J., & Morris, A. S. (2008). Assessing callous-unemotional traits in adolescent offenders: validation of the inventory of callous-unemotional traits. *International Journal of Law and Psychiatry, 31*(3), 241–252. https://doi.org/10.1016/j.ijlp.2008.04.002

Krueger, R. F., Derringer, J., Markon, K. E., Watson, D., & Skodol, A. E. (2013). The Personality Inventory for DSM-5 Brief Form

(PID-5-BF). http://www.psychiatry.org/file%20library/practice/dsm/dsm-5/thepersonalityinventoryfordsm5briefformchildage11to17.pdf

Kuenssberg, R., Murray, A. L., Booth, T., & McKenzie, K. (2014). Structural validation of the abridged Autism Spectrum Quotient-Short Form in a clinical sample of people withautism spectrum disorders. *Autism, 18*(2), 69–75. https://doi.org/10.1177/1362361312467708

Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry, 2*, 1013–1027. https://doi.org/10.1016/S2215-0366(15)00277-1

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology, 12*, 1–7. https://doi.org/10.3389/fpsyg.2021.635690

Leach, C. W., van Zomeren, M., Zebel, S., Vliek, M. L. W., Pennekamp, S. F., Doosje, B., Ouwerkerk, J. W., & Spears, R. (2008). Group-level self-definition and self-investment: A hierarchical (multicomponent) model of in-group identification. *Journal of Personality and Social Psychology, 95*(1), 144–165. https://doi.org/10.1037/0022-3514.95.1.144

Lewis, L. F. (2016a). Realizing a diagnosis of autism spectrum disorder as an adult. *International Journal of Mental Health Nursing, 25*(4), 346–354. https://doi.org/10.1111/inm.12200

Lewis, L. F. (2016b). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing, 30*, 575–580. https://doi.org/10.1016/j.apnu.2016.03.009

Lewis, L. F. (2017). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of Autism and Developmental Disorders, 47*, 2410–2424. https://doi.org/10.1007/s10803-017-3168-3

Lewis, L. F., Ward, C., Jarvis, N., & Cawley, E. (2021). "Straight sex is complicated enough!": the lived experiences of autistics who are gay, lesbian, bisexual, asexual, or other sexual orientations. *Journal of Autism and Developmental Disorders, 51*, 2324–2337. https://doi.org/10.1007/s10803-020-04696-w

Lockwood Estrin, G., Milner, V., Spain, D., Happé, F., & Colvert, E. (2021). Barriers to autism spectrum disorder diagnosis for young women and girls: a systematic review. *Review Journal of Autism and Developmental Disorders, 8*(4), 454–470. https://doi.org/10.1007/s40489-020-00225-8

Luhtanen, R., & Crocker, J. (1992). A collective self-esteem scale: Self-evaluation of one's social identity. *Personality and Social Psychology Bulletin, 18*(3), 302–318. https://doi.org/10.1177/0146167292183006

McDonald, T. M. (2016). *Identity as a mediator between stigma and stereotype threat on postsecondary outcomes for adults on the autism spectrum*. (Doctoral dissertation, The University of Wisconsin-Madison). ProQuest Dissertations and Theses (Number: 10096823).

McDonald, T. A. M. (2017). Discriminative and criterion validity of the autism spectrum identity scale (ASIS). *Journal of Autism and Developmental Disorders, 47*(10), 3018–3028. https://doi.org/10.1007/s10803-017-3221-2

Moffitt, T. E., & Silva, P. A. (1988). Self-reported delinquency: Results from an instrument for New Zealand. *Australian & New Zealand Journal of Criminology, 21*(4), 227–240.

Moore, D. (2016). The fourth degree of autism: Self-identification. In P. Wylie, W. B. Lawson, & L. Beardon (Eds.), *The nine degrees of autism: a developmental model* (pp. 85–108). Routledge.

NICE. (2016). *Autism spectrum disorder in adults: diagnosis and management*. Retrieved from https://www.nice.org.uk/guidance/CG142.

O'Nions, E., Christie, P., Gould, J., Viding, E., & Happé, F. (2014a). Development of the 'extreme demand avoidance questionnaire'(EDA-Q): preliminary observations on a trait measure for pathological demand avoidance. *Journal of Child Psychology and Psychiatry, 55*(7), 758–768. https://doi.org/10.1111/j.cpp.12149

O'Nions, E., Viding, E., Greven, C. U., Ronald, A., & Happé, F. (2014b). Pathological demand avoidance: Exploring the behavioural profile. *Autism, 18*(5), 538–544. https://doi.org/10.1177/1362361313481861

Parsloe, S. M. (2015). Discourses of disability, narratives of community: reclaiming an autistic identity online. *Journal of Applied Communication Research, 43*(3), 336–356. https://doi.org/10.1080/00909882.2015.1052829

Penwell-Barnett, J., & Maticka-Tyndale, E. (2015). Qualitative exploration of sexual experiences among adults on the autism spectrum: implications for sex education. *Perspectives on Sexual and Reproductive Health, 47*(4), 171–179. https://doi.org/10.1363/47e5715

Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation, 13*(3), 141–146. https://doi.org/10.1097/XEB0000000000000050

Piven, J., & Rabins, P. (2011). Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society, 59*(11), 2151–2155. https://doi.org/10.1111/j.1532-5415.2011.03632.x

Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism, 11*(3), 1–12. https://doi.org/10.1186/s13229-019-0304-2

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Sarrett, J. C. (2016). Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics, 9*, 23–36. https://doi.org/10.1007/s12152-016-9247-x

Spielberger, C. D., Brunner, T. M., Ritterband, L. M., & Reheiser, E. C. (2003). The nature and measurement of depression. *International Journal of Clinical and Health Psychology, 3*(2), 209–234.

Spielberger, C.D., Gorsuch, R.L., Lushene, R.E. and Vagg, P.R. (1983). State-Trait Anxiety Inventory (STAI). BiB, 2010, 180.

Stagg, S. D., & Belcher, H. (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine, 7*(1), 348–361. https://doi.org/10.1080/21642850.2019.1684920

Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In W. G. Austin & S. Worchel (Eds.), *The social psychology of intergroup relations* (pp. 33–47). Brooks/Cole: Monterey, CA.

World Health Organisation. (2018). *International classification of diseases* (11th ed.). World Health Organisation.

Wylie, P., Lawson, W. B., & Beardon, L. (2016). *The nine degrees of autism: a developmental model*. Routledge.