

The adult experience of being diagnosed with autism spectrum disorder: A qualitative meta-synthesis

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Abstract

There is a dearth of research into the experience of adult diagnosis of autism spectrum disorder, and targeted research is needed to understand the needs of these adults. The aim of this coproduced review was to assess existing qualitative data on the lived experience of receiving an autism spectrum disorder diagnosis, identify recurring themes, and synthesize them into a visual model representing the journey through diagnosis. Using thematic analysis, we analyzed qualitative data from 24 studies of adult experiences of autism spectrum disorder diagnosis from PsycINFO, Embase, MEDLINE, and CINAHL. Thirty-two “descriptive” themes and three superordinate themes were identified. These themes represented how factors relating to identity and relationships are impacted by the diagnosis of autism spectrum disorder and the role of adaptation and assimilation. While the diagnostic process was confusing and disappointing for many, it often led to a sense of relief and clarity regarding past experiences. It created opportunities to connect with other autistic individuals and to access services, though appropriate supports were widely lacking. Recommendations are made that the diagnosis process explicitly considers needs in relation to: the impact of the diagnosis on identity, interactions with other people, choices regarding disclosure, and whether and how to make informed adaptations.

Lay abstract

There is little research looking at the experience of individuals diagnosed with autism spectrum disorder as adults. Adults diagnosed with autism spectrum disorder face different challenges than children, and more research is needed to better understand those challenges. For this review, autistic and non-autistic researchers looked at research on the experience of receiving a diagnosis of autism spectrum disorder as an adult. We looked for themes in people’s experience leading up to diagnosis, going through the diagnostic process, and living their life after diagnosis. We analyzed 24 studies and found three overarching themes that captured thirty-two themes describing the experience of diagnosis. The three overarching themes expressed issues with identity and relationships before and after the diagnosis and identified that the diagnosis of autism spectrum disorder in adulthood impacted people’s adaptation to and assimilation (i.e. the making sense of and internalizing the diagnosis) of autism spectrum disorder. While the diagnostic process itself was confusing and disappointing for many, it often led to a sense of relief and clarity regarding past experiences and had effects on identity and self-esteem. It created opportunities to connect with other autistic individuals and to access services, though appropriate supports were widely lacking. Recommendations are made that the impact of the diagnosis on people’s identity and choices about telling others about their diagnosis, and whether and how people want to make adaptations, should be discussed and thought through in the process of diagnosis.

Keywords

adult, autism, autism spectrum disorder, ASD, diagnosis, mental health, qualitative

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The experiences of individuals diagnosed with ASD as an adult: a qualitative review

The rate of autism spectrum disorder (ASD) diagnosis has risen dramatically over the past several decades¹ (Fombonne, 2020; Huang et al., 2020). Despite a lack of global data, UK rates (Brugha et al., 2011) suggest a corresponding increase in adult diagnosis. An increase in awareness of ASD may have created more opportunities for individuals to recognize themselves or others, contributing to the demand for diagnosis. In spite of this, the body of research into the childhood experience of ASD far outweighs research pertaining to adults (Mukaetova-Ladinska et al., 2012). In addition, adults often have great difficulty accessing clinical services including assessment, diagnosis and intervention (Department of Health [DoH], 2009) and often face poor outcomes in the areas of independence, social functioning, communication, employment, and mental health (Dudley et al., 2019; Farley et al., 2018; Griffith et al., 2012; Hedley et al., 2018; Howlin et al., 2013; Moss et al., 2015).

Receiving an ASD diagnosis often has profound consequences for an individual's identity, wellbeing, and access to support (Huws & Jones, 2008; Lewis, 2016a, 2016b; Powell & Acker, 2016; Punshon et al., 2009). The experience of diagnosis is greatly impacted by how it is communicated and the degree to which individuals feel respected and involved (Sandell et al., 2013). Females are at a higher risk of going unrecognized and undiagnosed, particularly if "high functioning" (Hull & Mandy, 2017); a label rejected by many in the autistic community due to associated problematic connotations downplaying the struggles of autistic individuals in a neurotypically-designed world (Bottema-Beutel et al., 2021; Kenny et al., 2016). While several studies have looked at the qualitative experience of diagnosis for autistic adults, there has yet to be a synthesis of this literature (Crane et al., 2018; Hickey et al., 2018; Powell & Acker, 2016). To provide diagnostic services and post-diagnostic support targeted to help autistic individuals in the most appropriate and beneficial way, it is imperative that we better understand the subtleties of the subjective or lived experience of diagnosis. The aim of this coproduced review was to better understand the experience of adults being diagnosed as autistic by reviewing existing qualitative data on lived experience of receiving a diagnosis, analyzing the themes presented, and synthesizing them into a visual model representing the adult's journey from pre- to post-diagnosis. We included lived experience perspectives in our analysis and validation of the findings, both in terms of the review team and the inclusion of an Advisory Group of experts by experience of adult ASD diagnosis (Glasby & Beresford, 2006). This will inform our understanding of the adult experience and provide a foundation for improving the experience.

Methods

This is a coproduced paper including an author with lived experience of an adult ASD diagnosis. The enhancing transparency in reporting the synthesis of qualitative research (ENTREC) statement aided transparency of reporting throughout the process of the qualitative synthesis (Tong et al., 2012).

Search strategy

We searched PsycINFO, Embase, MEDLINE, and CINAHL from 4 January 1999 to 3 January 2022 using the following search strategy, where ADJ (adjacency) refers to the specified number of spaces away from each other:

("experience* ADJ5 diagno*" or "perspective* ADJ5 diagno*" or "view* ADJ5 diagno*" or "perce* ADJ5 diagno*" or "communicat* ADJ5 diagno*" or "receiv* ADJ5 diagno*" or "deliver* ADJ5 diagno*" or "giv* ADJ5 diagno*" or "process* ADJ5 diagno*" or "news* ADJ5 diagno*" or "inform* ADJ5 diagno*" or "disclos* ADJ5 diagno*" or "tell* ADJ5 diagno*" or "break* ADJ5 news" or "deliver* ADJ5 news") and (ASD or asperger* or autism or autistic, with subject heading terms adapted for each database).

Inclusion criteria

Inclusion criteria included first order data (i.e. quotes from participants) from studies with a formal qualitative component that analyzed adult service-user experiences of the ASD diagnostic process. Articles were included that covered a wider range of ages or experiences if it was possible to identify data points pertaining to the experience of receiving an ASD diagnosis in people aged 18+. To include a broad range of lived experience we used broad inclusion criteria regarding method of diagnosis; studies included participants who did not have a formal diagnosis but identified as autistic (five studies) and those who did not report specific method of diagnosis (two studies). Exclusion criteria included mixed child and adult data that did not specify which data pertained to adult diagnosis. Our inclusion criteria covered relevant book chapters, dissertations, and doctoral theses. Our exclusion criteria included opinion pieces, reviews of books or articles, and articles without available English translations, as well as studies that failed to meet the first two criteria of the CASP scoring system ("Was there a clear statement of the aims of the research?" and "Is a qualitative methodology appropriate?"; Oxford Centre for Triple Value Healthcare, n.d.).

Titles were initially screened for eligibility by authors I.K. and R.P. Potentially eligible studies were then screened by abstract, and eligibility was confirmed by review of full text publication. We also reviewed reference lists of included papers and screened those titles for inclusion. To

establish reliability, the first 50 titles and abstracts were independently screened by C.H., with 94% agreement between authors. Uncertainties or disagreements were resolved by discussion between the authors.

Data extraction

Demographic and methodological information were extracted and tabulated (see Table 1). All articles included were deemed to be of acceptable quality based on review using the first two criteria of the CASP checklist (Oxford Centre for Triple Value Healthcare, n.d.). We used NVivo v.12 software to code first-order data (participant quotations) and second-order data (researcher commentary or interpretations). Second-order data was included for contextual information but was not coded for the thematic synthesis or reflected in the final visual model. While these data were not directly coded and therefore not captured in the descriptive themes, they were used to contextualize the themes during the analysis and for the narrative in the results section. To establish interrater reliability of data extraction, odd numbered excerpts from every fourth article, ordered alphabetically (i.e. articles 4, 8, 12, 16, and 20), were coded by authors I.K. and C.H. or R.P. independently, with 82% agreement. Reviewers were told in advance how many codes each data point received.

Thematic synthesis

Thematic analysis (Braun & Clarke, 2006) and thematic synthesis (Thomas & Harden, 2008) were used to identify themes recurring in the data. Participant quotes (first-order data) and author interpretations pertaining to the diagnostic process (second-order data) were initially extracted line-by-line and coded (but only first-order data was included in the thematic synthesis), including pre- and post-diagnostic experiences that reflected on the impact of the diagnosis. All relevant data in articles identified from the searches was coded. Thematic synthesis was used to develop and evolve the themes identified from the reviewed papers (Thomas & Harden, 2008). The line-by-line coding was categorized into “descriptive” themes, which were close to, and descriptive of, the data presented in the primary studies (Braun & Clarke, 2006; Thomas & Harden, 2008). The frequency of data points for each theme was tabulated; descriptive themes retained in the final framework were those that were most well-represented by number of data points. As the included articles were deemed to be of acceptable quality based on the relevant CASP criteria, no further quality appraisal was conducted during data coding or synthesis. These descriptive themes were developed into “analytical themes” to represent superordinate or analytical constructs (Thomas & Harden, 2008). This involved engaging with the descriptive themes to understand the impact they were having at

each stage of the diagnostic journey. Three primary analytical themes emerged. This was initially undertaken by one author (C.H.) and reviewed and evolved iteratively by the other authors. Due to the under-researched nature of the female experience of ASD diagnosis, the co-author with lived experience of an adult ASD diagnosis performed a sub-analysis of the female experience (including Chester, 2019; Leedham et al., 2020). All themes were discussed between researchers, and a representative framework was developed from the identified themes, structured along a nonlinear timeline.

Lived and clinical stakeholder input

To improve validity and ensure that the final framework resonated with lived experience, the framework was discussed with an Advisory Group of people with lived experience of ASD diagnosis in adulthood and two clinicians with experience of diagnosing adults with ASD. This feedback was not to generate additional data but refined the language, descriptions and framing of the descriptive themes in line with lived experience.

Results

Characteristics of included studies

The initial database search resulted in 3,675 articles; after screening by title and abstract, 176 full-text articles were assessed for eligibility (see Figure 1). Twenty-four papers were included in the final thematic analysis. Years of publication ranged from 2001 to 2021. Total sample size was 908 (mean 38, *SD* 39, median 12). Eight studies were conducted in the United Kingdom, five in Australia, four in the United States, two in Wales, and one in Sweden. Two studies included multiple countries (Argentina, Australia, Belgium, Canada, Finland, Germany, India, Ireland, the Netherlands, Norway, Russia, Scotland, Singapore, Slovenia, Sweden, Turkey, United Kingdom, and the United States), and two took place online and did not report geographical information. We extracted data from 24 studies regarding the autistic individual's experience. Most studies used semi-structured interviews (14), and four used other types of interviews. Studies also utilized in-person or online questionnaires (five), and two studies analyzed website content.

Thirty-two descriptive themes were identified from the papers; these were identified for pre- and post-diagnosis. In terms of the impact these factors were having, two overarching themes were identified: impact on the self (Identity) and impact on people's relationships (Relationships). A third analytical theme emerged in the interaction between Identity and Relationships, this theme was labeled “Adaptation and Assimilation.” The descriptive and resulting analytical themes were coded across the

Table 1. Demographic, diagnostic, and methodological information.

| Paper | Country | Sample size | Sample gender | Formal diagnosis/Self-diagnosed | Data collection method | Data analysis method | Temporal codes | No. of codes | Age at participation | Age of diagnosis (only data pertaining to 18+ included in synthesis) |
|----------------------------|---|--|--|--|---|--|---|--------------|---|--|
| Alverson et al. (2019) | United States | 5 | All male | Formal diagnosis | Semi-Structured Interviews | Multistage Analysis Process | Pre-diagnosis: 0 Diagnosis: 0 Post-diagnosis: 4 | 4 | 19–22 years old | Three diagnosed at 17, 18, and 19. Two diagnosed as children. |
| Atherton et al. (2021) | United Kingdom | 8 | Four female, four male | Formal diagnosis | Semi-Structured Interview | Interpretive Phenomenological Analysis (Smith & Shinebourne, 2012) | Pre-diagnosis: 4 Diagnosis: 1 Post-diagnosis: 6 | 11 | Unreported | 24–61 years old |
| Baldwin & Costley (2016) | Australia | 282 | 82 female, 200 male | Formal diagnosis | Questionnaire | Mix of descriptive, statistical and thematic analysis | Pre-diagnosis: 9 Diagnosis: 2 Post-diagnosis: 5 | 16 | Female Range: 18–64 Mean: 32.7 Male Range: 18–70 Mean: 33.2 | Female Range: 2–63 (58% 18+) Mean: 25 Male Range: 2–66 (56% 18+) Mean: 25.5 Mean: 21.3 |
| Bargiela et al. (2016) | United Kingdom | 14 | All female | Formal diagnosis | Semi-Structured Interviews | Framework Analysis | Pre-diagnosis: 7 Diagnosis: 1 Post-diagnosis: 2 | 10 | Range: between 18 and 35 Mean: 26.7 | Not reported |
| Clarke & Van Amerom (2008) | Unspecified | 30 blogs | Self-identified autistic: Male: 9 Female: 14 Parent/caregiver: Male: 4 Female: 16 | Participants identify as autistic | Online blogs | Qualitative Content Analysis | Pre-diagnosis: 1 Diagnosis: 0 Post-diagnosis: 1 | 2 | Not all specified, F:M ratios 1–10 years: 1:0 11–20 years: 3:3 21–30 years: 3:1 >30 years: 2:2 | Not reported |
| Crane et al. (2018) | United Kingdom | 30 (10 autistic adults, 10 parents of autistic children and 10 professionals involved in autism spectrum disorder (ASD) diagnosis) | Autistic adults: 6 Female 4 Male | Formal diagnosis | Telephone Semi-Structure Interviews | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 6 Diagnosis: 6 Post-diagnosis: 8 | 20 | Autistic adults: Mean: 42.89 Range: 29–59 years old (all but one diagnosed in adulthood) Over the age of 18 | Autistic adults: Mean: 38.90 Range: 10–57 years old |
| Lewis (2016a) | 11 different countries | 36 | Female: 16 Male: 20 | Self-Diagnosed | Survey | Thematic Analysis (Colaizzi's, 1978) | Pre-diagnosis: 29 Diagnosis: 0 Post-diagnosis: 51 | 82 | Mean: 29.9 Range 18–52 | Range between 18 and 60 years old |
| Lewis (2016b) | Australia, Belgium, Canada, Finland, Ireland, The Netherlands, Norway, Scotland, Singapore, Sweden, United Kingdom, and the United States | 77 | Female: 32 Male: 40 | Self-reported either formal diagnosis or evaluated as meeting diagnostic criteria by healthcare professional | Open-Ended Online Survey | Thematic Analysis (Colaizzi's, 1978) | Pre-diagnosis: 10 Diagnosis: 0 Post-diagnosis: 20 | 30 | Mean: 30 Range: 18–65 | Range between 18 and 60 years old |
| Griffith et al. (2012) | Wales | 11 | 4 female 7 male | Formal diagnosis (9) or self-diagnosis (seeking diagnosis, 2) | Semi-Structured Interviews | Interpretive Phenomenological Analysis (IPA; Smith et al., 1999) | Pre-diagnosis: 1 Diagnosis: 1 Post-diagnosis: 10 | 12 | Range: 37–57 years | Range: 19–50 years |
| Haertl et al. (2013) | United States | 24 | Not reported | Unclear, described as “diagnosed” | Phenomenological Interview-Based Design | Deductive and inductive (thematic) analysis | Pre-diagnosis: 6 Diagnosis: 0 Post-diagnosis: 5 | 11 | Not reported | Not reported |
| Hickey et al. (2018) | United Kingdom | 13 | 3 female 10 male | Formal diagnosis | Semi-Structured Interviews | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 2 Diagnosis: 0 Post-diagnosis: 24 | 26 | Range: 51–71 years | Range: 47–62 years old |

(Continued)

Table 1. (Continued)

| Paper | Country | Sample size | Sample gender | Formal diagnosis/Self-diagnosed | Data collection method | Data analysis method | Temporal codes | No. of codes | Age at participation | Age of diagnosis (only data pertaining to 18+ included in synthesis) |
|-------------------------|----------------|--|--|--|--|---|---|--------------|---|---|
| Huang et al. (2021) | Australia | 190 | Diagnosed: 86 female 34 male 14 other 3 missing Undiagnosed: 43 female 5 male 4 other 3 missing | Formal diagnosis (137) and self-diagnosis (53) | Online Survey | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 5 Diagnosis: 7 Post-diagnosis: 6 | 18 | Diagnosed: Average: 41.90 20-34: 42 35-49: 57 50-64: 33 65+: 5 Undiagnosed: Average: 40.77 20-34: 18 35-49: 23 50-64: 9 65+: 5 | Average: 38.85 |
| Huws & Jones (2008) | Wales | 9 | 3 female 6 male | Formal diagnosis | Semi-Structured Interviews | Interpretative Phenomenological Analysis (IPA) | Pre-diagnosis: 2 Diagnosis: 0 Post-diagnosis: 4 | 8 | Aged 16-21 | Not reported for all participants (some were children) |
| Johnson & Joshi (2016) | United States | 23 (7 diagnosed as teenagers not included) | Not reported | Formal diagnosis | Semi-Structured Interviews (30 ppts) and An online survey (193 ppts) | Inductive Thematic Analysis | Pre-diagnosis: 2 Diagnosis: 0 Post-diagnosis: 19 | 21 | Range: Aged 24-58 Average: 31 years | Seven diagnosed as teens or children (not included) Average: 15 in 20 s or 30 s 8 in 40 s |
| Jones et al. (2001) | Unspecified | 5 | Not reported | Unclear, described as "diagnosed" | Thematic Analysis of web pages containing first-hand accounts | Thematic Analytic Approach | Pre-diagnosis: 2 Diagnosis: 0 Post-diagnosis: 1 | 3 | Not reported | Not reported (mention some participants diagnosed in adulthood) |
| Kanfisz et al. (2017) | United Kingdom | 7 | All female | Formal diagnosis | Semi-Structured Interviews | Multi-Stage Narrative Analysis | Pre-diagnosis: 7 Diagnosis: 0 Post-diagnosis: 8 | 15 | Over the age of 18 | Over the age of 18 |
| Leedham et al. (2020) | United Kingdom | 11 | All female | Formal diagnosis | Semi-Structured Interviews | Interpretative Phenomenological Analysis (Smith et al., 1999) | Pre-diagnosis: 5 Diagnosis: 0 Post-diagnosis: 21 | 26 | Range: 40-62 | Range: 43-64 |
| Lilley et al. (2021) | Australia | 26 | 14 female 10 male 1 non-binary 1 unknown 59% male | Formal diagnosis | Oral History Methodology | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 51 Diagnosis: 0 Post-diagnosis: 32 | 83 | Range: 46.9-70.2 | Range: 42-68 |
| Powell & Acker (2016) | United States | 74 | 3 female 7 male | Either formally diagnosed (54) or fell into the subclinical threshold (20) | Interview | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 2 Diagnosis: 2 Post-diagnosis: 55 | 59 | Average age: 36.08 | Over the age of 18 otherwise not reported |
| Pushon et al. (2009) | United Kingdom | 10 | 3 female 7 male | Formal diagnosis | Semi-Structured Interviews | Interpretative Phenomenological Analysis (Smith et al., 1999) | Pre-diagnosis: 30 Diagnosis: 0 Post-diagnosis: 30 | 60 | Range: 21-44 Median: 31 | Range: 21-44 Median: 35 |
| Sandell et al. (2013) | Sweden | 15 | 4 female 11 male | Formal diagnosis | Semi-Structured Interviews | Qualitative Content Analysis | Pre-diagnosis: 1 Diagnosis: 4 Post-diagnosis: 5 | 11 | Range: 28-53 Mean: 39 | 18 years old or over |
| Seers and Hogg (2021) | Australia | 8 | All female | Formal diagnosis | Semi-Structured Interview | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 5 Diagnosis: 6 Post-diagnosis: 16 | 27 | Range: 24-54 | Range: 23-53 |
| Seagg & Belcher (2019) | United Kingdom | 9 | 5 female 4 male | Formal diagnosis | Free-Associative Narrative Interview | Thematic Analysis (Braun & Clarke, 2006) | Pre-diagnosis: 13 Diagnosis: 0 Post-diagnosis: 9 | 22 | Range: 52-54 | Participants over the age of 50 who were recently diagnosed |
| Webster & Garvis (2017) | Australia | 10 | All female | Formal diagnosis | Semi-Structured Interviews | Narrative-themed Analysis | Pre-diagnosis: 0 Diagnosis: 0 Post-diagnosis: 1 | 1 | Range: 28-55 | After the age of 18 |

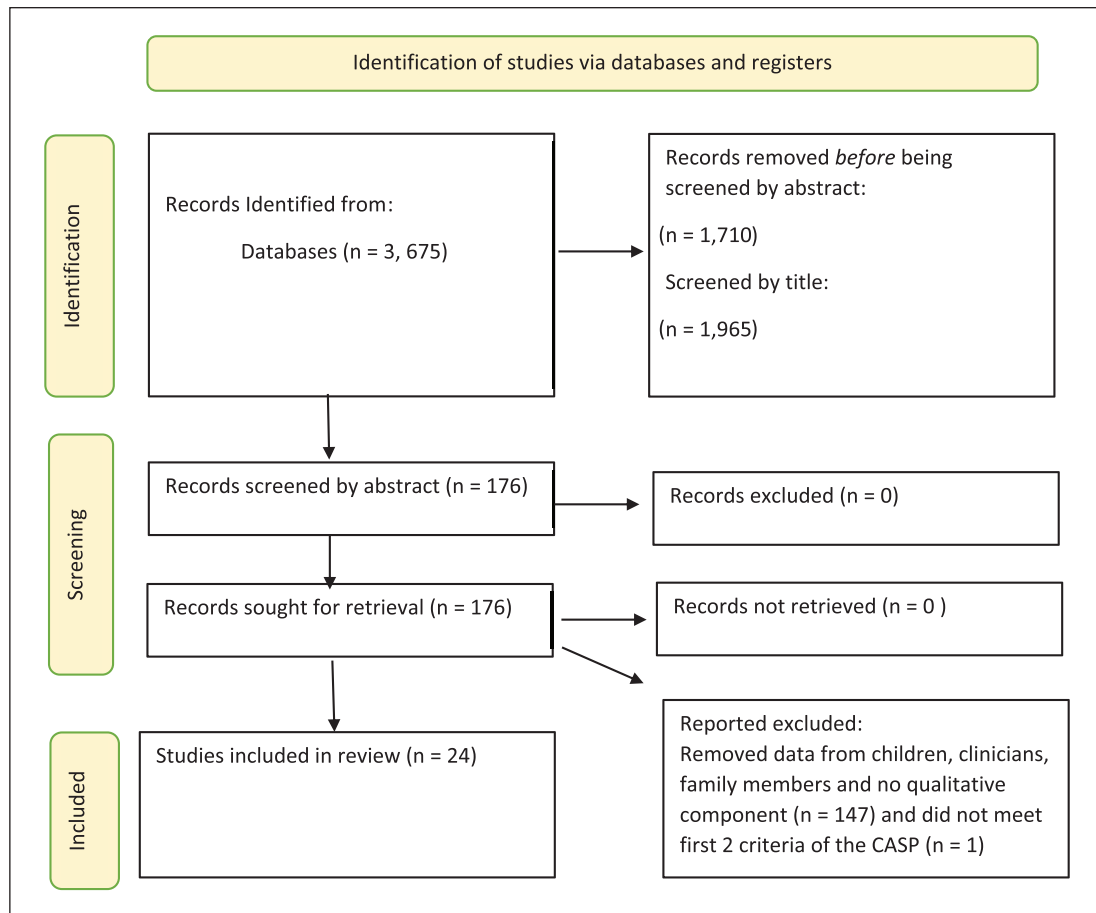


Figure 1. PRISMA diagram of studies assessed for the review.

diagnostic journey and represent the shift from pre- to post-diagnosis (see Figure 2 for a visual representation with the themes below represented as letters in brackets). Experiences with professionals and of the diagnosis itself also emerged in the descriptive themes. These themes described experiences with clinical services (and other public sector professionals—including teachers and social workers). These themes were described separately and are not represented in Figure 2.

Pre-diagnosis

Identity pre-diagnosis. The first and largest superordinate theme was identity.

The most dominant descriptive theme identified throughout the pre-diagnostic phase was an awareness of difference from others (see (B) in Figure 2). For many individuals, the experience of a sense of their difference went hand-in-hand with feelings of confusion (A). Individuals struggled to understand themselves within a largely neurotypical social framework, describing a painful struggle to make sense of their experience:

The first 51 years of my life were absolute misery not knowing what I had, or why. I would get terribly depressed. I would think that I was a terribly wicked person because I couldn't do many of the achievements that are "expected" of "good" people. Why me? How come I'm the way I am, and other people aren't? (Jones et al., 2001)

This intersected with and was reinforced by the themes of "reactions of family members, teachers and peers" and "being bullied," discussed below.

In the midst of the feelings of alienation, people recognized themselves in descriptions of ASD. At times, this was triggered by the diagnosis of a family member. Some became so convinced of their self-diagnosis, that the clinical diagnosis was viewed as a formality (C):

"I felt like I could have written half the stuff I was reading," and "It was both an incredible relief and very unsettling to hear them more-or-less tell me my life story in their own words, from their own experiences." (Lewis, 2016b)

Relationships pre-diagnosis. The sense of being different from others was reflected in the reactions of family members,

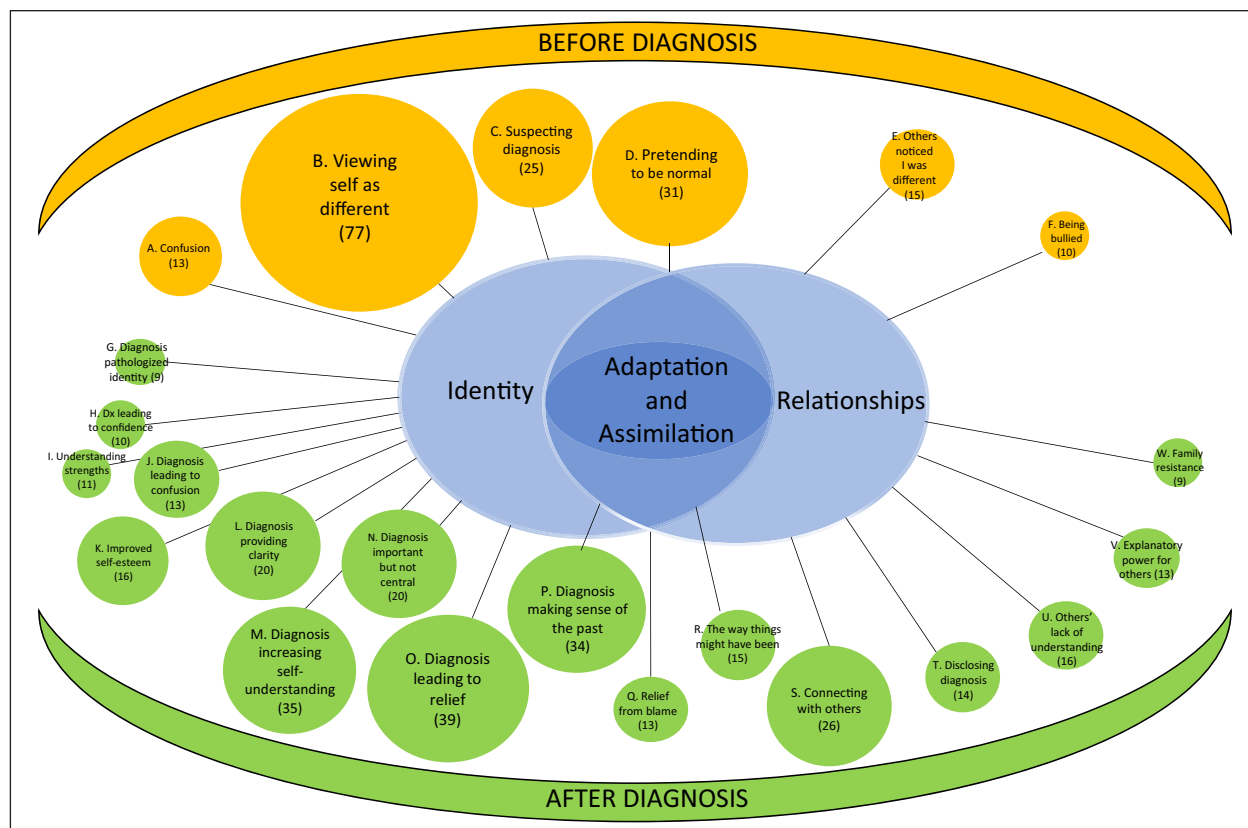


Figure 2. Descriptive themes identified before (yellow circles) and after (green circles) diagnosis, intersecting with the superordinate themes of Identity, Relationships and Adaptation and Assimilation.

teachers, and peers (E). Many described experiences of bullying in school (F). Individuals often framed bullying as a reaction to “being themselves” and described attempts to not be as fully themselves in order to minimize mistreatment.

Why I was saying I wanted to be a girl was that I didn’t fit in with the boys at school ... The girls didn’t seem to get bullied and picked on. So it was kind of like ... logical to me [laughs] you know ... I could see that it was going to hurt less if I was a girl. (Punshon et al., 2009).

Adaptation and assimilation pre-diagnosis. Prior to diagnosis, people tended to make adaptations to fit into the neurotypical social framework. Following the realization that that individuals felt—and were perceived—as being different from those around them, some began a struggle to appear more “normal.” This theme was overwhelmingly present in the data, with many individuals describing efforts to “pretend” or mask their differences (D):

I was trying to cover it up and pretend I was “normal” and pretend that everything was okay when inside I was dying of pain ... (Punshon et al., 2009)

This suggests that pre-diagnosis, this sense of difference was often perceived negatively and that adaptations,

including efforts to “mask” difference, were costly to people’s identity.

Post-diagnosis. The data reviewed in this study were disproportionately representative of the post-diagnostic phase. While recency bias may be at play, such asymmetry also reflects the profound effect of diagnosis on individuals’ lives and the magnitude of interior and exterior tasks faced in the wake of diagnosis.

Identity post-diagnosis. The data overwhelmingly revealed that most individuals ultimately found the diagnosis to be beneficial. Many experienced a profound sense of relief after diagnosis (O); for some, this came from having a name or an explanation for their differences. Others reported a newfound sense of clarity that came with diagnosis (L).

If anything, it was a relief to find out—much like finding that last piece to a puzzle. (Lewis, 2016a)

After 50 years of not understanding the “why” of myself, finding out I was an aspie was a light in the darkness, best thing that happened to me. (Lewis, 2016a)

Although it was less prevalent in the data, for some, having received a diagnosis was devastating, as it seemed

to pathologize their individuality and/or remove hope for change (G):

I had to go through a mourning period, as I thought I was a unique individual because I was different, but it all seems to be autism that made me think/ behave this way. (Lewis, 2016a)

Rather than providing clarity, some felt thrust into a new experience of uncertainty or confusion (J). Some individuals described a process of coming to terms with the ASD diagnosis; after spending many years of their life conceptualizing their experiences differently, it took time to reframe past experiences and accept their implications:

Slowly I have become more accepting of my condition, but it still causes me a lot of grief. (Lewis, 2016a)

The post-diagnostic data reflected a process of assimilating the diagnosis and reshaping identity that resulted in varying degrees of identification with their ASD diagnosis. For some, “autism” became central to their identity, leading to either improved confidence or, in some cases, feelings of being “defective” or “abnormal.” Others took efforts to keep the diagnostic label peripheral to their sense of self. In most cases, ASD was felt to be important but not central to one’s identity (N):

I feel more confident and comfortable in my own identity, which allows me to accept the things I have difficulty with and appreciate the things I am good at. (Lewis, 2016a)

Whether individuals ultimately saw their ASD diagnosis as a key aspect of their identity or an external force, many experienced an increase in self-understanding following diagnosis (M):

Once I discovered myself as an Aspie, I became overjoyed and delighted in my self-discovery. Up until the mid-forties, my life was confusing and misunderstood. (Clarke & Van Amerom, 2008)

For many, the process of integrating an ASD diagnosis into their life narrative led to improved self-esteem and confidence (H, K). Participants felt “valuable,” “empowered,” and “proud” of what they had achieved in spite of their condition (Sandell et al., 2013; Lewis, 2016b). They reconceptualized qualities formerly labeled “faults” as assets (Powell & Acker, 2016). For some, this newfound confidence was rooted in a belief that ASD conferred certain strengths, advantages or even made them superior to others (I):

I also understand that some of the personality traits which others led me to believe were faults or failings are not so and may be applied in ways which render them as assets. (Lewis, 2016a)

Relationships post-diagnosis. One of the most prominent post-diagnostic themes was the value individuals found in connecting with other autistic individuals. They spoke of the sense of community and belonging that this brought about, whether through reading books, participating in online chat rooms, or attending groups (S):

It was like I found my people! (Lewis, 2016a)

After receiving an ASD diagnosis, individuals were faced with decisions regarding disclosure. Choices were shaped by a desire for understanding, a fear of stigma, and worries about consequences (T):

I disclosed at the end of 2007 that I had Asperger’s ... and I told the head teacher that I’d like to disclose. I told the head of the whole program that I wanted to and it was like she was almost trying to talk me out of it ... But I wanted to because it was a stressful job anyway and I thought everybody would kind of help me and it would smooth out all my inner anxiety and worry and everything. (Johnson & Joshi, 2016)

Disclosure decisions were closely related to individuals’ awareness of the limited understanding of ASD held by those around them (U). It was common for people to report some level of resistance by family members upon first learning of the diagnosis; for some families, this resistance persisted (W):

My mother and father won’t accept [my diagnosis] ... [they accepted my son’s diagnosis] after a long time, but my mum will still produce newspaper clippings of what an autistic child is and she’ll say, that’s not what [child] is, he’s not autistic, he can’t be. (Crane et al., 2018)

Individuals also found diagnosis to be a helpful explanatory framework that they could provide to others, supporting disclosure, to clarify current or future behaviors (V):

I can always say “Sorry, I have got Asperger syndrome” ... the excuse if you like but excuse is not a very good word ... the reason ... the explanation. (Punshon et al., 2009)

Adaptation and assimilation post-diagnosis. Across studies, individuals reflected on the utility of the ASD diagnosis in making sense of the past. After decades of struggling to make sense of differences and difficulties related to their neurodivergence, they were able to reflect on past experiences in light of this new information (P). Through this process of reflection and reevaluation of the past, many felt relieved of blame for the difficulties they had previously conceptualized as stemming from personal shortcomings (Q):

I got the letter saying that I had Asperger syndrome, it was a bit like standing up in court and hearing the jury say “not guilty.” (Punshon et al., 2009)

A prominent theme throughout the data was an awareness of how life might have been different with an earlier diagnosis. People mourned the lives they might have led, goals they might have accomplished, and happiness they had been denied (R):

It has left me a little bereft of a life that could've been. (Lewis, 2016a)

However, going forward, this newfound clarity and understanding meant that previous attempts to better fit in, adapt and mask difference could now be more informed by choice. Bargiela et al. (2016) describes how the diagnosis gave participants more confidence in asserting their opinion; while prior to diagnosis participants would have “just kept quiet,” following diagnosis they described being more able to ask for clarification if unsure of a situation.

Interactions with professionals, the process of diagnosis, and post-diagnostic support. Themes were identified that pertained specifically to experiences of the process of diagnosis and post-diagnostic support. These have not been reflected in Figure two as this is separate from the analytical themes of Identity, Relationships, Adaptation and Assimilation.

There was a widespread sense of frustration that the ASD diagnosis was missed by teachers and professionals, perceived as specialists who were well-poised to catch such a diagnosis earlier. There was further frustration that professionals not only missed their ASD diagnosis but misdiagnosed them with other psychiatric and developmental disorders instead, adding to the delay and damage done:

I have had lifelong problems with eating (due to sensory issues) misdiagnosed and was therefore wrongly treated for 25 years prior to ASD diagnosis. (Baldwin & Costley, 2016)

Unsurprisingly, given the heterogeneous paths by which people arrive at diagnosis, the data represented both positive and negative experiences with the diagnostic process. Some described clinicians who conveyed a sense of clarity, understanding, and respect, while others were invited to participate in the process:

You got to know things [and] all the time you got to take part in the results when doing the tests ... you got to take part in what was written in the chart and so on ... then you really see [the diagnosis] is a written thing, it's not any damned guesses. (Sandell et al., 2013)

However, data reflecting poor experiences far outweighed data reflecting positive ones. These often cited the impersonal, critical nature of the process:

It was cold, it was calculating and there was nothing else there, as if they didn't see it as any sort of potential issue in my life really, it was just yes or no. (Crane et al., 2018)

Many didn't know what to expect going into the assessment or were left feeling unsure of what would come after:

Only now, looking back, can I see the big picture—how it all fits together, how all the people involved in the system work together. It's a big system...at the time, I didn't know who was who, what they did or anything. (Crane et al., 2018)

Others were “devastated” (048) by this news, saying it was “another nail in the coffin.” (Lewis, 2016a)

People mourned the lives they might have led, goals they might have accomplished, and happiness they had been denied. Some expressed resentment toward those they viewed as having had the power to diagnose them sooner:

It has left me a little bereft of a life that could've been. (Lewis, 2016a)

Many viewed a formal diagnosis as a gateway to resources, such as support services or treatment, with some reporting that they pursued a diagnosis precisely for this reason. Some found that doors were opened in ways that improved their lives. Much more predominant was data highlighting a profound lack of appropriate support available to individuals following their diagnosis. Many found that services were largely targeted to children or more severely disabled individuals:

I'm on the high-functioning end [of the autistic spectrum] and so I don't fit mental health, I don't fit learning disability. I just fall through the gaps between departments, whether it's in the health service or social services. I just don't fit anywhere. (Griffith et al., 2012)

Sub-analysis: female experience of diagnosis. The sub-analysis around the female experience identified strongly in the pre-diagnostic phase reinforces the main findings such as that of awareness of difference from others (B). However, the theme of pretending to be normal (D), adapting and assimilating this into their everyday, and thus “masking” their authentic autistic self were particularly relevant to the female experience, which included developing coping strategies for or avoiding the social world altogether (Leedham et al., 2020).

The reward for trying hard to be normal was to be ignored because you were acting normal and I look at stories online of kids who were going off the rails and I think, I should have just burnt more cars. (Bargiela et al., 2016)

At the post-diagnosis stage, while diagnosis reshaped identity for autistic females, in contrast to the main analysis, females reported that at times they doubted their abilities and the diagnosis particularly due to the length of time that had passed before diagnosis was made (Bargiela et al., 2016; Leedham et al., 2020).

... I thought “am I just anything other than these symptoms?” Um, that really upset me ... I sort of started doubting my ability to do my job. (Leedham et al., 2020)

As a result of “camouflaging” and “masking” from an early age, females felt that they were more often misdiagnosed by professionals, as their difficulties were frequently mislabeled as depression, anxiety, or as a personality or eating disorder (Happé et al., 2016) or missed entirely (Hull & Mandy, 2017).

In “unmasking,” or in discovering where females have developed these coping strategies, females often felt perplexed by the lack of post-diagnostic support to allow them to be comfortable in their diagnosis. As such, they felt that connecting with others allowed them validation and acceptance, increasing their pride and confidence in diagnosis (Bargiela et al., 2016).

Women framed grief as a “fluid and ever-changing process” (Leedham et al., 2020) particularly in appreciating the lifelong nature of autism. This differed from that in the main analysis where grief was framed around the past yet the women in this analysis focused their grief on the future:

I went through several stages of feeling ... First of all, I was thinking ... It was strange, because although I knew it, I kind of felt some sort of disbelief as well. And there were times also, not long after as well, I felt angry and thinking why me? And other times it was the relief, and other times I was pleased. So it was a lot of different emotions, really. I think there’s always going to be an element of the why me, so it sort of robs you of that right to be like everyone else. (Stagg & Belcher, 2019)

Discussion

We synthesized qualitative data on the experience of receiving an adult ASD diagnosis, identifying themes that informed our model of the diagnostic journey. This is the first meta-synthesis of the experience of adult diagnosis of ASD that the authors are aware of. We identified themes that map onto a journey of pre- to post-diagnosis. Prior to diagnosis, the dominant themes revolved around feeling different and pretending to be “normal.” Through a process of assimilation, the initial relief of diagnosis supports people to make sense of the past, have a better understanding of themselves, and connect with other people. Across these themes there was a sense that post-diagnosis, people

were able to make more informed choices about how they adapt to, or choose to fit into, a largely neurotypical world—leading to a possible transformation, via assimilation, to more informed choices regarding adaptation. However, diagnosis was also found to lead to confusion and pathologize identity in some cases. Therefore, the recommendations below are designed to maximize the potential benefits of the diagnostic journey that were identified from the meta-synthesis.

Prior to diagnosis, people viewed themselves as “different” (the most prevalent theme in the data) this was reinforced by other people noticing their difference and by early experiences of being picked-on or bullied for this difference. This often led to attempts to fit-in, adapt or mask difference, which in turn, seemed costly to people’s identity.

Themes of self-understanding and self-esteem were well represented in the post-diagnosis data. The effect of diagnosis on identity was linked to both relief and frustration (Portway & Johnson, 2005). However, the experience of receiving a diagnosis was most commonly met with feelings of relief. Horn et al. (2007), found that change in self-understanding was one factor mediating the benefits of diagnosis. In our data synthesis, this appeared largely due to the explanatory power of the diagnosis, both in terms of recent and distant struggles and interpersonal experiences. The superordinate theme of Adaptation became more one of assimilation, where this understanding could shape identity often in more positive (or at least less confusing) ways. This is also echoed in a study that was conducted too late to be included in the meta-synthesis (de Broize & Evans, 2022), where diagnosis was described by one participant as a “constant learning process and adapting process,” and that another described as “learn[ing] more about me and how I function and what I need, to do that well but with the least toll on myself.” These quotes capture that assimilation is an ongoing process—but that the diagnosis offers more informed choices in terms of how to adapt and assimilate. Assimilation interacts with the superordinate theme of Relationships, whereby people were able to make informed choices about how to disclose their diagnosis as well as find and connect with other people with similar experiences and interests, which in turn likely fed back into more positive framing in terms of identity. Sandell et al., (2013) highlight the benefits of developing one’s “occupational identity” after diagnosis by better understanding of one’s strengths, limitations, and interactions with others (Kielhofner, 2008). The process of integrating an ASD diagnosis into one’s identity often involves a nonlinear parallel progression toward acceptance of diagnosis. Lewis (2016a) found that, in most cases, progression toward

self-acceptance was only possible through diagnosis, even if symptomatology was mild. The narratives in this review reflect experiences of hurt and confusion prior to diagnosis; diagnosis was not a solution but rather a catalyst for the process of healing and acceptance to begin.

Individuals and families found profound relief in the opportunity to reframe current and past difficulties within the context of an ASD diagnosis. This was captured powerfully by the individual who said that receiving their diagnosis “was a bit like standing up in court and hearing the jury say ‘not guilty’” (Punshon et al., 2009). This highlights both the internal experience of reframing the past and the external utility of providing an explanation for difference (Hickey et al., 2018; Powell & Acker, 2016; Sandell et al., 2013).

In a world where people with developmental disabilities are devalued and autistic media characters are presented as socially awkward geniuses, diagnosis comes with a heavy weight of societal presuppositions. The ubiquity of stigma and stereotypes is a significant barrier to acceptance of the diagnosis, making decisions around disclosure of diagnosis much more fraught (Haertl et al., 2013; Kanfischer et al., 2017). The prevalence of stigma both undergirds and results from the lack of understanding that individuals experienced in those around them (Baldwin & Costley, 2015). It also contributes to bullying and feelings of alienation.

Some of the studies included in this review found themes of isolation and loneliness, while these did not emerge in our analysis (Hickey et al., 2018). After a lifetime of feeling like an outsider, many individuals described profound feelings of belonging upon connecting with other autistic people. Individuals found comfort and relief in the “collective identity” they experienced through online and in-person groups for autistic individuals (Haertl et al., 2013; Webster & Garvis, 2017). A similar phenomenon has been found among the broader population with mental health diagnoses; Crabtree et al. (2010) found that group identification predicted increase in perceived social support and stigma resistance, which in turn predicted higher self-esteem.

Sub-analysis: female experience of diagnosis

While the female experience of late diagnosis ran some parallels to the male experience, females particularly related to the compensatory strategies of “camouflage” and “masking” of autistic traits in favor of neurotypical traits (Bargiela et al., 2016; Hull & Mandy, 2017). Some felt their efforts concealed their need for help and thus delayed diagnosis (Baldwin & Costley, 2016; Bargiela et al., 2016). Recent literature has debated the notion of the “female phenotype” of autism (Hull et al., 2020), with females presenting with a more “subtle” presentation than males. Autistic child studies

have been variable in demonstrating this symptomology (Frazier et al., 2014), with adult studies suggesting autistic women report more autistic traits in adulthood yet *demonstrate* fewer (Lai et al., 2011). Substantiating previous literature, females reported their skills at “blending in” to society and a lack of understanding of the female presentation led to misdiagnosis of mental health disorders that are considered classically female such as eating disorders (Sharan & Sundar, 2015) and borderline personality disorder (Jane et al., 2007; Skodol & Bender, 2003). The notion of the little-researched “female phenotype” (Lai et al., 2011) and the stereotypical views of ASD may have contributed to misdiagnosis with frequent mislabeling (Baldwin & Costley, 2016; Leedham et al., 2020). Some women felt that there was a barrier to autism diagnosis, as they were unable to shake their previous “label.” This was more unique to female experiences in comparison to the main analysis.

While our analysis corroborates and gives a qualitative account of previously reported difficulties with autistic female’s diagnosis, it also details experiences post-diagnosis which are uncommonly reported in research. Females at times felt their late-diagnosis halted progress in their diagnosis shaping identity and self-esteem (Bargiela et al., 2016). Once accepting of the diagnosis, they were able to reframe relationships in light of this, again putting their needs at the forefront (Leedham et al., 2020), thus increasing their sense of pride and confidence. This allowed them permission to meet their own needs and develop identities without the need to “mask” (Leedham et al., 2020), which was previously costly to their self of identity.

We must preface this, however, as this sub-analysis comes not only from the data sources listed but also through live experience of the author and thus can be considered more speculative. Furthermore, the sub-analysis may be biased due to studies that recruited all female participants, thereby highlighting the need for future studies directly comparing the experiences of different genders to better understand the differences in diagnosis between genders. There is a need for more empirical work to understand the female phenotype outside of the pre-existing restrictions and overemphasis on the male autistic experience.

The diagnostic process

Themes relating to the process of diagnosis (i.e. how professionals decided, communicated, and contextualized the diagnosis within people’s lived experience) reflected both positive and negative experiences, concerns of disclosure, stigma, self-discovery, and understanding, consistent with findings pertaining to other mental health diagnoses and other models of ASD (Perkins et al., 2018; Wylie, 2014).

Many found diagnosis initially confusing, as they were overwhelmed by information and unclear about

next steps. Given the impact that mood has on information processing, the powerful emotions individuals reported having around diagnosis may have hindered their ability to process and retain large amounts of information at the initial diagnostic visit (Schmid et al., 2011). Diagnosis was experienced more positively when individuals felt involved and respected as an expert-by-experience (Sandell et al., 2013).

Recommendations

The way that diagnosis is delivered is an opportunity to maximize the benefits of a diagnosis while minimizing possible negative impacts. Our synthesis identifies that diagnosis can lead to clarity and more empowered choices about how to adapt to neurotypical social frameworks and disclosure. Alternatively, diagnosis can lead to more confusion, self-stigma and feelings of hopelessness. Previous findings have identified that the process of diagnosis is critical to diagnostic outcomes in terms of factors such as identity, hope, and connection with others (Perkins et al., 2018). It is recommended that the possible impacts on identity and people's relationships and interactions with others are explicitly considered during the diagnostic process. The diagnosis can serve as a shared language to explain challenges, create community among autistic people, and serve as a pathway to resources. Moreover, the words used to deliver an ASD diagnosis are powerful and should be informed by the need for clarity, sensitivity, and the need to process, assimilate, and discuss, ideally over multiple sessions. Clear, person-centered discussion of the meaning of the diagnosis and next steps should take place over the course of multiple appointments, giving individuals the opportunity to process and reflect, understand and assimilate the impact of the diagnosis on their sense of self and relationships with other people. The benefits of shared decision-making are well-established (NICE, 2019); more robust, patient-centered training is needed to undergird the development of diagnostic, clinical, and support services to meet the needs of autistic individuals.

Further research is needed to understand how the diagnostic process for ASD specifically impacts identity, hopefulness about the future, thoughts about what adaptations or adjustments might reasonably be made (e.g. in the workplace) and relationships with other people.

A diagnostic process that reflects these needs could set the stage for acceptance of the diagnosis and may reduce the need for initial post-diagnostic support to facilitate assimilation and minimize confusion relating to the diagnosis. The process of diagnosis merits further attention, as people's understanding of and acceptance of the diagnosis has implications for sense of self and engagement in treatment (Inder et al., 2010). Families are often grappling with

acceptance and resistance alongside those diagnosed, and this can be a notable source of stress after diagnosis. Ensuring that families also derive clarity from the diagnosis and are supported to consider the implications of the diagnosis and how to adapt to and assimilate the diagnosis is not only beneficial for them but can be a crucial piece in the post-diagnostic support plan. More research is necessary to evaluate the needs of families adjusting to an ASD diagnosis in adulthood.

Themes related to identity, grief and loss were prominent in the data, indicating that autistic individuals may benefit from psychological approaches designed to guide people through the experience of reframing both the past and their identity and make informed and empowered choices about how to move forward. At a minimum, diagnostic and support services should be informed by an awareness of this sense of loss, communicating empathy and validation. Referrals or contact information for ASD support groups, either online or in-person, could be built into the diagnostic process, as individuals placed a high value on the experience of community and understanding achieved through connection with other autistic individuals.

Strengths and limitations

The meta-synthesis included the lens of lived experience to make sense of themes emerging across the included studies—both through a co-author with lived experience and the stakeholder community group involved in validating the analysis. The stakeholder group helped the naming and framing of the descriptive themes, while the authors worked together to generate and refine the higher-level analytical themes. The variation among studies is both a strength and a potential limitation, as it reflects fact that the path to diagnosis is unique and highly varied (though, as our model highlights, there are some common elements) but limits transferability. While it is beneficial to synthesize data across studies, it is important to be aware that we are synthesizing de-contextualized qualitative data, and the resulting themes might not reflect the original meanings held in the data or be relevant to different contexts (Thomas & Harden, 2008). Further empirical work is therefore needed to validate and refine the framework that has emerged from this synthesis.

Conclusion

This meta-synthesis of qualitative research used thematic analysis to capture the qualitative experience of adults receiving an ASD diagnosis. Bringing together a wide range of studies and reflecting on results with service-user and clinician focus groups, we synthesized the experiential data into a visual model. We chose to analyze qualitative

data and to represent these data as a temporal process in order to reflect that the diagnostic experience is not experienced as a discrete task or even a turning point—as clinicians often view it—but rather a transformational journey that impacts identity and relationships with others, beginning before and continuing long after the diagnosis is given (Punshon et al., 2009). As the number of adults living with an ASD diagnosis increases, models such as ours are needed to inform pathways to diagnosis, improvements in the diagnostic process, and development of appropriate support services. Our themes reflect the great impact that diagnosis can have on an individual's life, highlighting current shortcomings and providing an opportunity for positive intervention. Our model provides a guide for those weighing whether to pursue a diagnosis, as key benefits and challenges are highlighted. It may also prove useful for clinicians hoping to shape their practice in ways that improve the experience of diagnosis. More research is needed to validate the model and develop more nuanced recommendations for the diagnostic process and initial post-diagnostic support. Individuals' lives are irreversibly changed when a diagnosis is given; the story of their journeys to and through diagnosis should be heard and allowed to shape diagnosis for the better.

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Supplemental material

Supplemental material for this article is available online.

Note

1. The diagnostic term “ASD” is used here, though the autistic community (and our author with lived experience) prefers the term “Autism” for general use.

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