J Autism Dev Disord
DOI 10.1007/s10803-017-3168-3

ORIGINAL PAPER

A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults

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Abstract Delayed diagnosis of autism spectrum disorder (ASD) into adulthood is common, and self-diagnosis is a growing phenomenon. This mixed methods study aimed to explore barriers to formal diagnosis of ASD in adults. In a qualitative strand, secondary analysis of data on the experiences of 114 individuals who were self-diagnosed or formally diagnosed with ASD in adulthood was used to identify barriers. In a quantitative strand, 665 individuals who were self-diagnosed or formally diagnosed in adulthood were surveyed online to examine incidence and severity of barriers. Fear of not being believed by professionals was identified as the most frequently occurring and most severe barrier. Professionals must strategize to build trust with individuals with ASD, particularly when examining the accuracy of self-diagnosis.

Keywords Autism spectrum disorder · Adult · Mixed method · Diagnosis · Self-diagnosis · Barriers

Introduction

Autism spectrum disorder (ASD) affects 1% of the population worldwide and is as prevalent in adults as in children (Brugha et al. 2011; Centers for Disease Control and Prevention [CDC] 2014). Approximately half of those with ASD do not have concurrent intellectual disability, and delayed diagnosis is common even into adulthood for this population (CDC 2014; Lehnhardt et al. 2013; Mayes et al. 2014; Spencer et al. 2011).

Many of these adults without cognitive impairment are able to function independently in their work, social, and/or living situations. Up to half live independently or with only minimal support, others have dated and/or participated in serious relationships, and many are able to maintain part-time or full-time independent employment (Farley et al. 2009; Lewis 2016a; Tobin et al. 2014). Yet, these outcomes are extremely variable, as some face social isolation, challenges completing educational programs, and difficulties maintaining employment (Orsmond et al. 2013; Shattuck et al. 2012).

These individuals also face significant psychological challenges that impact quality of life. As many as 70% experience comorbid disturbances such as depression, anxiety, and suicidal thoughts (Cassidy et al. 2014; Lehnhardt et al. 2013; Sterling et al. 2007). These effects are likely amplified when the individual lacks self-awareness and support, as is the case for the estimated 50–60% of the population with ASD who remain undiagnosed (Baron-Cohen et al. 2009; Myhill and Jekel 2008; Wylie 2014).

Impact of Diagnosis

Studies on individuals who were diagnosed with ASD in adulthood reveal that the diagnosis generally has a positive impact. In a previous phenomenological study on the experience of being diagnosed with ASD in adulthood, participants felt the formal diagnosis gave them a sense of self-acceptance, offered strategies for quality of life improvement, and helped them attain and maintain their own sense of normalcy (Lewis 2016a). Individuals who were self-diagnosed only were likely to struggle with self-doubt and cyclic grief (Lewis 2016b).

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Several studies show that adults often face significant challenges pre-diagnosis, which are improved post-diagnosis. In a phenomenology of 10 adults who received a diagnosis of Asperger syndrome, participants reported that they had many negative life experiences before diagnosis and felt that they did not fit in with others (Punshon et al. 2009). Their own lack of self-understanding of their diagnoses influenced identity formation, and many believed it also contributed to other mental health difficulties. Knowledge of Aspergers allowed them to positively reframe their lives.

Portway and Johnson (2005) found an emergent core category of "not quite fitting" among young adults who were believed to have Asperger's syndrome. These adults were described as "being on the margins of normality" (p. 73); in other words, they subjectively felt different and perceived themselves to be different from the norm, but did not exhibit outward difficulties enough to be recognized, diagnosed, or supported through intervention. Authors proposed that there were significant risks to those who felt othered but lacked a "label" to help them understand themselves, including: "misunderstanding others and being misunderstood, bullying, isolation, loneliness and few close, confiding friendships," (p. 77) as well as long-term risks such as: "underachievement, prolonged dependency upon parents," and "depression, anxiety, obsessions and expressions of suicide" (p. 78). Authors suggested that these risks might have been avoided through diagnosis.

Philip Wylie, an individual who was diagnosed with ASD in adulthood, developed a 9-stage model that describes the stages of diagnosis of ASD for adults (2014). Wylie stresses the importance of self-diagnosis and formal diagnosis on the mental wellbeing of adults with ASD. He writes:

> It is very difficult for the late-diagnosed Aspie *not* to feel 'broken' following self-identification, especially if we don't have access to significant emotional, financial and therapeutic support. … Without appropriate post-diagnostic [including self-diagnosis] support during the identity alignment stage, our mental health is likely to deteriorate. (2014, p. 46)

Wylie's model indicates that self-acceptance and enjoyment of a sustainable future are possible through diagnosis and self-understanding.

Barriers to Formal Diagnosis

Several studies identify common barriers to formal diagnosis among adults who believe they have ASD. For example, Punshon et al. (2009) found that participants reported negative experiences with mental health services, including misdiagnosis, lack of knowledge about Asperger's syndrome, and feeling misunderstood and blamed by professionals, which caused anxiety about and mistrust of mental health professionals.

In his model, Wylie also acknowledged significant barriers to formal diagnosis of ASD for adults, including distrust of health care professionals, personal history of misdiagnosis, and low self-esteem and other mental health issues. He also identified that "we may have spent decades pretending to be normal, so observation-based diagnostic techniques may fail if we successfully managed to hide our autistic traits" (2014, p. 65).

A framework analysis of 14 females diagnosed with ASD in late adolescence or adulthood explored their diagnostic experiences and found that participants often felt misunderstood or blamed for their symptoms, and their suspicions of ASD were frequently dismissed by health professionals (Bargiela et al. 2016). Rutherford et al. (2016) conducted a retrospective case note analysis of 150 children and adults recently diagnosed with ASD in Scotland and also found evidence of delayed recognition of ASD in females compared to males.

Jones et al. (2014) explored adults' satisfaction with the ASD diagnostic process, though it is significant that participants in this study were not necessarily diagnosed in adulthood. Overall, 40% of respondents reported that they were "very" or "quite" dissatisfied with their diagnostic experience. Researchers determined that satisfaction was significantly influenced by delays in diagnosis, number of professionals seen, quality of information about diagnosis, and level of post-diagnostic support. Age at time of diagnosis was not explored as a potential influence.

Despite this evidence and expert opinion that many adults with ASD face barriers to formal diagnosis (Lai and Baron-Cohen 2015; Sarrett 2016), no studies examine barriers to diagnosis among adults with ASD. The purpose of this mixed methods study was to examine barriers to formal diagnosis for adults with ASD.

Methods

The aim of this study was to answer the qualitative research question: What barriers do adults with ASD face in reaching a formal diagnosis?; and the quantitative research question: What is the incidence and severity of each of these barriers? This study was conducted using an exploratory sequential research design (Creswell and Plano Clark 2011). In this mixed methods design, qualitative and quantitative strands occurred independently of one another, with the qualitative strand occurring first and informing the quantitative strand.

Qualitative Strand

The qualitative strand of this study was a secondary analysis of data gathered during two phenomenological studies on the experience of: (1) being formally diagnosed with ASD as an adult (Lewis 2016a) and (2) being self-diagnosed with ASD as an adult (Lewis 2016b). Participants were recruited via public, private, and secret online forums and message boards for individuals with ASD with permission from site moderators. Interested participants were directed to participate via an online open-ended survey. Participants were originally asked to describe in writing their experiences of self-diagnosing and being formally diagnosed, and then in a follow-up phase were asked to read and reflect on a description of findings, including a description of emergent barriers to formal diagnosis.

For the current study, qualitative data were analyzed using Krippendorff's (2013) method for content analysis. According to Krippendorff, "Content analysis is a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (2013, p. 24). Thematic unitizing was used to extract any words or phrases that were pertinent to the overall subject of barriers or facilitators to formal diagnosis. These included general thoughts about the value of the diagnosis, descriptions of the diagnostic process, interactions with healthcare professionals surrounding the diagnosis, perceptions about how the diagnosis was received by family and friends, and post-diagnostic support. Dendrograms, or tree-like diagrams, were used to sort relevant units into theme clusters. Clustering was conducted by the primary researcher. Dendrograms were reviewed with a second Masters-prepared nurse to discuss alternative points of view and interpretations of the data, as Morse (2015) recommends that this strategy is more effective in achieving validity than committee consensus for analyzing open-ended interviews. After discussions with a second reviewer, the theme of "stigma" was divided into two themes, including "stigma" and "mistrust of healthcare providers." No other changes to theme clusters were made. Emergent themes informed the quantitative strand of this study.

Quantitative Strand

Based on qualitative themes derived from data, the researcher developed a list of potential barriers to formal diagnosis for adults with presumed ASD, including those who were self-diagnosed and/or formally diagnosed (Table 1). Participants were asked to read each barrier and respond to a 4-point Likert-type scale to indicate if this factor was: "1: Not a barrier/no influence," "2: Somewhat of a barrier," "3: Moderate barrier," or "4: Extreme barrier" to obtaining a formal diagnosis.

Participants were also asked to complete the Autism Spectrum Quotient (AQ) to explore symptom severity (Baron-Cohen et al. 2001; Woodbury-Smith et al. 2005). The AQ is a valid self-report instrument consisting of 50-items designed to explore ASD traits in adults with normal intelligence. Scores range from 0 to 50 with higher scores indicating presence of more ASD symptoms. Though the AQ is not used alone as a diagnostic tool for ASD, it is commonly used to screen for ASD and has shown discriminative validity at a threshold score of 32 to as low as 26 (Baron-Cohen et al. 2001; Woodbury-Smith et al. 2005). In a large systematic review of studies using the AQ, Ruzich et al. (2015) reported an average score of 16.94 among individuals without ASD and an average score of 35.19 among individuals with ASD.

Demographic data were also collected. This online quantitative survey was distributed among online forums and message boards for individuals with ASD with permission from site moderators via LimeSurvey, an SSL encrypted survey tool. Data were collected from September 2015 to August 2016. Descriptive statistics were examined using SPSS software. Independent samples t-test and ANOVA were used post-hoc to explore differences in severity of barriers between subgroups based on gender and country of residence.

Results

Qualitative Strand

Sample Characteristics

The qualitative sample included 77 participants who were formally evaluated and diagnosed with ASD ($n=60$) or were informally evaluated and told they likely had ASD ($n=17$) (Lewis 2016a) and 37 participants who were self-diagnosed only (Lewis 2016b), for a total sample size of 114 individuals. Demographic data are described in Table 2. Eighteen countries were represented in this sample, with most participants from the United States (US) (52%), United Kingdom (UK) (15%), and Canada (12%). Nine overall themes emerged as potential barriers to formal diagnosis among adults who believed they had ASD, including: anxiety, cost, access to adult ASD specialists, fear of not being believed, inability to describe symptoms, mistrust of healthcare professionals, stigma, complexity of the healthcare system, and lack of perceived value of formal diagnosis. The qualitative impact of each of these themes on formal diagnosis is discussed in the following sections. Individual survey items derived from each theme are shown in Table 1.

Table 1 Barriers to formal diagnosis derived from qualitative strand with corresponding incidence and severity of barriers from quantitative strand

Barriers to formal diagnosis		Incidence	Severity			N
Theme	Item	% Participants report this as a barrier (slight, moderate, or extreme)	Mean Likert score (1–4)	SD	% Participants report this as an extreme barrier	
Anxiety	Anxiety about making an appointment with a mental health professional	85.2	2.88	1.064	36.4	664
	Anxiety about going to an appointment with a mental health professional	82.1	2.75	1.093	32.4	664
	Anxiety during an appointment with a mental health professional	80.5	2.64	1.082	27.5	663
	Concern about sharing my life story/private information with a stranger, e.g. mental health professional I have not met before	76.5	2.57	1.138	28.8	663
Cost	Cost of appointment with a mental health professional	70.4	2.57	1.231	33.8	663
	Cost of travel to see a mental health professional	49.1	1.87	1.049	11.3	662
	Cost of formal evaluation for a diagnosis	72.9	2.68	1.223	36.7	660
	I do not have health insurance or recently did not have health insurance	28.4	1.64	1.112	14.5	660
	Cost of appointment would not be covered by health insurance	52.8	2.13	1.229	22.6	659
	Cost of formal diagnosis would not be covered by health insurance	57.7	2.28	1.264	27.4	657
Access to adult ASD specialists	Difficulty finding an ASD specialist who would diagnose adults	85.6	2.83	1.035	32.1	661
	Difficulty finding an ASD specialist who also specializes in adults	84.7	2.96	1.081	41.1	661
	Difficulty finding an ASD specialist who also specializes in my gender	71.2	2.63	1.227	34.7	657
	Difficulty finding any mental health professional	60.1	1.96	0.972	9.1	661

Table 1 (continued)

Barriers to formal diagnosis		Incidence	Severity			N
Theme	Item	% Participants report this as a barrier (slight, moderate, or extreme)	Mean Likert score (1–4)	SD	% Participants report this as an extreme barrier	
Fear of not being believed	Concern that I will not be listened to	92.3	3.21	0.950	50.1	659
	Concern that I will not be believed	94.4	3.28	0.897	52.6	663
	Concern that I will be told I am "making up" symptoms	92.0	3.19	0.968	50.0	662
	Concern that I will be evaluated but will not be diagnosed with ASD	86.9	2.89	1.030	35.1	663
	Concern that I will be evaluated but will not be diagnosed with ASD because I am an adult	86.7	2.96	1.033	38.2	662
	Concern that I will be evaluated but will not be diagnosed with ASD because of my gender	76.5	2.80	1.191	39.4	663
Inability to describe symptoms	Inability to adequately communicate symptoms to a provider, e.g. due to anxiety or not having the right words	87.6	2.80	1.013	30.9	663
Mistrust of healthcare professionals	Poor past experiences with a healthcare professional prevent me from making an appointment	58.0	2.14	1.150	18.0	662
	Poor past experiences with a mental health professional prevent me from making an appointment	64.1	2.31	1.181	23.1	661
	Past experiences being "misdiagnosed"	67.1	2.45	1.221	29.2	662
	Past experiences being "blamed" for symptoms	70.1	2.56	1.227	32.9	662
	Mistrust of mental health professionals	75.5	2.43	1.086	22.1	664
	Mistrust of healthcare professionals	70.0	2.30	1.076	17.3	663
	Mistrust of institutions in general, e.g. healthcare system, schools, employer	68.8	2.34	1.126	20.9	664
	Concern about having a formal record of ASD, e.g. needing to report diagnosis to employer, school, etc.	63.3	2.29	1.182	22.7	664

Table 1 (continued)

Barriers to formal diagnosis		Incidence	Severity			N
Theme	Item	% Participants report this as a barrier (slight, moderate, or extreme)	Mean Likert score (1–4)	SD	% Participants report this as an extreme barrier	
Stigma	Cultural norms where I live do not recognize adults with ASD, e.g. ASD is seen as a childhood disorder only	81.0	2.52	1.007	19.2	663
	Personal stigma about ASD	37.9	1.63	0.933	6.8	663
	Personal stigma about "mental illness"	37.8	1.64	0.961	8.1	664
	Stigma about ASD from friends and/or family	67.7	2.28	1.105	18.6	662
	Stigma about ASD from others in my community	67.9	2.22	1.063	15.7	663
Complexity of healthcare system	I am unable to navigate the healthcare system to get insurance	32.3	1.61	1.010	9.9	657
	I am unable to navigate the healthcare system to make an appointment with a mental health professional	48.3	1.87	1.055	11.1	658
	Being "bounced around" between providers	60.0	2.11	1.081	13.5	660
	Long wait times when booking appointments with mental health professionals	73.4	2.39	1.083	20.0	659
Lack of perceived value of formal diagnosis	Personal belief that there is no way to diagnose ASD in adults	12.2	1.19	0.575	1.8	663
	Experience being told that there is no way to diagnose ASD in adults by a professional	35.3	1.60	0.934	6.9	663
	Experience being told that there is no benefit to being diagnosed as an adult by a professional	59.9	2.14	1.135	17.9	663
	Confidence that I have ASD and do not need formal evaluation to confirm	50.2	1.77	0.924	7.1	663
	Belief that there is no benefit to being diagnosed because I am already self-aware	46.9	1.74	0.929	6.6	663
	Belief that there is no benefit to being diagnosed because there is no "treatment" or "cure"	32.9	1.58	0.950	7.4	662
	Belief that there is no benefit to being diagnosed because there are no services available for adults	61.1	2.08	1.055	12.8	663
	Belief that there is no benefit to being diagnosed because I do not need any services/assistance	35.4	1.58	0.907	6.4	661

Table 2 Demographic characteristics of the qualitative sample (N = 114)

	n	%
Gender (n = 106)		
Male	57	54
Female	45	42
Agender	2	2
Gender fluid, gender queer, or non-binary gender	2	2
Age (n = 112)		
Mean 36.2 years		
Range 18–65 years		
Highest level of education (n = 104)		
Some high school	3	3
High school graduate	8	8
Trade/technical/vocational training	7	7
Some college	35	35
College graduate	32	32
Some postgraduate work	4	4
Postgraduate degree	15	15
Employment status (n = 105)		
Employed	58	55
Unemployed	18	17
Homemaker	3	3
Student	17	16
Retired	2	2
Unable to work/disabled	7	7
Ethnicity (n = 108)		
White, non-Hispanic	95	88
Hispanic or Latino	2	2
Black or African American	5	4
Native American or American Indian	2	2
Asian/Pacific Islander	4	4

Sample size is provided for each demographic characteristic to account for missing data. Total sample size N = 114

Anxiety

Participants frequently referred to their social anxiety as a challenge for making and going to professional appointments. For example, one participant said, "My aunt made contact with a psychiatrist for me because I was paranoid and anxious." Another shared:

> I went to my [general practitioner] to request an official diagnosis a few weeks ago, in order to initiate the diagnosis process, and I was terrified. I realized that even if I hadn't been in significant denial as a teen, I would never in a million years have been capable of going to the appointment because of the severity of my social anxiety. I'm sure many others are going through worse anxiety and are unable to make that first step.

Others talked about anxiety during appointments: "Mostly it's the extreme anxiety during appointments and thinking that I would be told that I don't have ASD [that prevents me from seeking a formal diagnosis]," and, "I still have problems talking to the therapist due to my anxiety." Another shared, "I do not know how to ease the threat of going to give my life story to a stranger."

Cost

Participants frequently commented on the cost of a formal diagnosis, even when they viewed the diagnosis as important to them. One participant said, "I would like to seek a formal diagnosis, but currently lack the funds. It is a priority, however." Another said, "A diagnosis is too costly for me at the moment."

Others described a vicious cycle, in which they were unable to work due to symptoms they believed were related to ASD, and then lacked funds to pursue a diagnosis due to unemployment. For example, one participant reported:

> The reason I haven't gotten the formal diagnosis is that I resigned from my job due to the stress of figuring it out. My employer gave me severance because they were aware of what was going on and basically I ran out of money while waiting for the specialist to get back to me.

Lack of insurance also contributed for some: "Since I'm poor and have never had insurance, I never received very much interest from any of the doctors I've seen."

Access to Adult ASD Specialists

Many individuals described challenges finding a diagnostician that was willing to diagnose adults. Participants said, "Unfortunately, it proved difficult to find someone who specialized in Autism spectrum disorders in my city that would diagnose adults," and, "I searched for someone who could officially diagnose me. Everything seemed geared towards children." One said:

> For some reason, autism isn't considered an "adult disorder" in my country. It is not taken seriously and there are no specialists I could find. I contacted an institution for children with ASD, but I got no response. For now, I don't urgently need a formal diagnosis, but I'll get one abroad as soon as possible.

Some felt that the professionals they had access to prevented them from moving forward with a diagnosis: "My general practitioner will not pay attention to my requests to be assessed," and, "My therapist at the time laughed when I told him my suspicion."

Besides finding a diagnostician who was willing to evaluate them, several participants described that it was important to them that their diagnostician had experience with adults or females with ASD, as they feared that they would be evaluated and told that they did not have ASD since their symptoms differed from presentations of ASD in children. As one participant said, "I'm actually looking into getting a formal diagnosis, but I'm scared of getting it wrong, as the majority of doctors here (in my country) are focused in autism diagnosis for children." Another said:

> I will want to have enough money to pay for a specialist that I choose rather than being dependent on health insurance that may or may not pay for an evaluation with someone who may or may not be qualified to diagnose autism in an adult female.

Fear of Not Being Believed

Participants also mentioned that, though they felt sure that they had ASD, they were afraid that they would be evaluated and would be told that they did not have ASD. Some felt concerned that they would be accused of "making up" their symptoms: "I always have concern in general I'll be told off by a doctor telling me I'm making things up resulting in me trying to cover as much up as I could for decades," and "I am not obviously autistic so I fear being told by others that I am making it up and/or I just like making out I am a 'special snowflake.'"

Several participants also felt that their concerns were not listened to by professionals:

> [The therapist's] continual refusal to even consider ASD as a contributing factor left me feeling pigeonholed. Like he was more interested in fitting me into the category he wanted than actually listening to me and respecting my own thoughts and feelings on the issue.
>
> Another said:
>
> I actually tried going to psychotherapy a year ago, but it wasn't what I was looking for, as I felt like she dismissed everything I told her I thought was important, and focused on other things, or not from the right perspective.

Inability to Describe Symptoms

Participants also expressed that their inability to describe their own symptoms was a barrier to formal diagnosis. One participant said: "I needed a lot of help filling in the form due to, well, anxiety at not expressing my difficulties properly," and another, "Sadly enough I both suck in recognizing feelings, and knowing what's normal and what's not." Another gave an example:

> I answered questions literally, so he asked me how I slept, and I said heavily. But had he asked if I ever had insomnia? HELL, yes. Since December 1989, and since about this period, really bad sleep issues. Severe issues getting to sleep, but when I'm asleep, it's deep as I'm exhausted.

Another explained challenges communicating his symptoms to a professional without a self-diagnosis and knowledge about ASD:

> I drew pictures … I was trying to describe how I don't pick up on all forms of communications and how my theory of mind isn't great. I have bad sensory issues, but how can one describe them when you don't have a word for it? I know what anxiety is, I know about adrenaline and fear and pain, but sensory overload can be a combination of all of these. I only had the words NTs [neurotypicals] use to describe themselves. Trying to seek help is impossible without a self diagnosis. … Only after knowing the words to describe what I have always gone through was I able to get help.

Mistrust of Healthcare Professionals

Many participants described a history of being misdiagnosed before discovering ASD, which affected their perception of the competence and caring of healthcare professionals in general: "I had been diagnosed with so many disorders that it was enough to make a revolving door dizzy. … I honestly stopped paying attention." Another described being misdiagnosed several times before being diagnosed with ASD and said, "I had an entire medical history indicating AS if anyone cared to look, but no one did."

Several resented healthcare professionals for "missing" the diagnosis earlier or for their apparent lack of understanding of ASD beyond stereotypes:

> Its (sic) not even funny to look back on, it (sic) just infuriating, as you know full well they continued raking in money but fucking over all their patients, just cos they're too lazy to keep up with periodical and are welded to whatever stereotypes about autism they read when they were undergrads. Its (sic) obscene.

Others felt "misunderstood" or "blamed" by professionals. For example:

> [My partner and I] went to therapy together and the therapist was sweet, but he made things worse. I got blamed for everything and then suddenly I needed

> to change to save our marriage even though I did not feel as though I was doing anything wrong.

For some, a mistrust of institutions in general prevented them from seeking formal diagnosis: "Because of my past issues in dealing with institutions such as school, hospitals, large companies, I do not have a strong interest in getting a formal diagnosis at this time," and: "Granted, when you have that paper you are forced to tell your boss or you're committing fraud, but its (sic) not like I can hide it."

Stigma

Similar to mistrust, some participants reported that they feared that their schools or employers would stigmatize them if they received a formal diagnosis of ASD. One participant shared:

> Autism is stigmatized; society is not educated about it, often associates it to someone who is mentally retarded (forgive me for using this term), not able to function normally and disabled. The thought of being treated less then (sic) a normal human came to mind.

Several participants reported that their parents' stigma likely prevented them from being diagnosed with ASD earlier in life and continued to play a role in how they perceived ASD as adults. One participants described seeing a childhood medical record with references to Asperger's syndrome and reported:

> I suspect that if a doctor at any time uttered the word autism to my mother, that was all it took for her to bury the information. Having an autistic child would have been totally unacceptable for my mother, for her social status, for any reason.

One reported that her spouse had similar stigma about the diagnosis: "My husband was less thrilled [than I was to find out about the diagnosis] and doesn't want me to be open about it because he thinks people (like his mother) will call me a 'retard.'" Another shared: "My family couldn't understand why I wanted the label and to be put in a box."

Others reported that their own stigma about mental illness affected their decision: "I had a negative view of mental differences and did not pursue research in the area for myself," and, "I am in my fifties, so there is the additional factor that I grew up with a large amount of stigma associated with the diagnosis of a mental disability or mental illness."

Complexity of the healthcare system

For some individuals, navigating the healthcare system to obtain a diagnosis was an overwhelming task that did not seem worthwhile to overcome: "I'm not against a formal diagnosis, but I'm not sure what benefit it would provide, nor how to go about obtaining one."

Other participants said: "Ultimately, I would like a diagnosis for further peace of mind, but what it really comes down to is the complexity of the health care system," and, "I do not have health care [insurance] at the moment, and I do not know how to go through the process."

Participants frequently described being "bounced around" between professionals and enduring long waits between appointments. For example, one participant described the aftermath of one of many visits in which she asked to be evaluated for ASD:

> This was at the start of June that year. By late September I'd heard nothing, despite my request to be properly tested, so got a patients (sic) liaison service to help out. He called me after they contacted him, and said crossly that he'd just written up his notes that day and I shouldn't be so impatient.

During this arduous process, several participants reported that they "gave up" on seeking a formal diagnosis.

Lack of perceived value of formal diagnosis

Many participants wondered if the value of the formal diagnosis was worth the effort to overcome the barriers. One who obtained a formal diagnosis after 2½ years of seeking a diagnosis reported, "I went through hell just to get diagnosed, and the expert didn't tell me anything I didn't already know." Several reported that, since there was no "treatment" or "cure" available, they did not see the value of a formal diagnosis:

> My primary reason for not getting a formal diagnosis is that I don't see any benefit to it. There's no pill, no treatment, or anything like that that would improve my life or mitigate the remaining symptoms. There's no assistance or help that I would get from it. There is really no upside to it for me as a functioning adult.

Another said: "I've never sought a formal diagnosis mostly because I don't think it would help with anything. There's no drugs that can 'cure' me, so why bother involving doctors?"

For some participants, their decision not to seek a formal diagnosis was influenced by healthcare professionals. One said, "The psychologist said that there would be no point in doing this formally [getting a diagnosis] as I was already an adult and there were no services in place for my situation.

Then counselling ended." Another shared, "I mentioned [my self-diagnosis] to my psychologist, and he told me he's suspected that I might be autistic but that there is no point to getting a diagnosis as an adult so he didn't think it was worth mentioning."

Quantitative Strand

Sample Characteristics

The quantitative sample consisted of 665 participants. Demographic characteristics are reported in Table 3. Participants who were formally diagnosed reported an average of 2.5 years between self-diagnosis and formal diagnosis, ranging from 0 to 22 years, and participants who were self-diagnosed only reported that they had been self-diagnosed for an average of 3.2 years, ranging from 0 to 18 years. Mean score on the AQ was 37.9, ranging from 18 to 49. Thirty countries were represented in this sample, primarily from USA, UK, Canada, and Australia.

Incidence of Barriers

Incidence of each barrier was determined by the percentage of respondents who reported that an item was a barrier to formal diagnosis, regardless of whether they reported it as a slight, moderate, or extreme barrier. Findings are summarized in Table 1. Almost all participants reported that concerns about not being believed (94.4%), not being listened to (92.3%), or being told that they were "making up" symptoms (92%) were barriers to their ability to obtain a formal diagnosis. Other barriers that occurred most frequently were inability to adequately communicate symptoms (87.6%), concerns about being evaluated and not being diagnosed with ASD (86.9%), anxiety surrounding appointments (85.2, 82.1, 80.5%), and feeling that cultural norms did not recognize adults with ASD (81%).

Severity of Barriers

Severity of each item was first determined by the mean score on the 4-point Likert-type scale. Severity was also determined by the percentage of respondents who reported that an item was an "extreme barrier" to formal diagnosis. Findings are summarized in Table 1. By both measures of severity, participants rated concerns that they would not be believed (M = 3.28, SD = 0.897), would not be listened to (M = 3.21, SD = 0.950), and would be told that they were "making up" symptoms (M = 3.19, SD = 0.968) as most severe, with each of these occurring as extreme barriers for at least 50% of participants.

Other barriers that ranked as most severe included: difficulty finding an ASD specialist who also specialized

Table 3 Demographic characteristics of the quantitative sample (N = 665)

	n	%
Gender (n = 634)		
Male	90	14.2
Female	363	57.3
Agender	90	14.2
Gender fluid, gender queer, or non-binary gender	69	10.9
Transgender	15	2.4
Unsure/questioning	7	1.1
Age (n = 636)		
Mean 30.9 years		
Range 18–68 years		
Diagnosis method (n = 631)		
Formally evaluated and diagnosed	216	34.2
Informally evaluated, no formal diagnosis	135	21.4
Self-diagnosed only	280	44.4
Autism spectrum quotient score (n = 607)		
Score 32 or greater	534	88.0
Score under 32	73	12.0
Sexual orientation (n = 625)		
Heterosexual	190	30.4
Gay or lesbian	57	9.1
Bisexual	167	26.7
Unsure	41	6.6
Other	170	27.2
Marital status (n = 627)		
Single, never married	378	60.3
Married or domestic partnership	198	31.6
Widowed	4	0.6
Divorced	47	7.5
Highest level of education (n = 626)		
Some high school	25	4.0
High school graduate	51	8.1
Trade/technical/vocational training	29	4.6
Some college	258	41.2
College graduate	135	21.6
Some postgraduate work	43	6.9
Postgraduate degree	85	13.6
Employment status (n = 627)		
Employed	261	41.7
Unemployed	77	12.3
Homemaker	27	4.3
Student	143	22.8
Retired	6	1.0
Unable to work/disabled	113	18.1
Health insurance status (n = 623)		
Primary source from government	179	28.7
Primary source from employer	87	14.0
Primary source through family member	211	33.9
Primary source self-funded	41	6.6
No insurance	105	16.9

Table 3 (continued)

	n	%
Ethnicity (n = 619)		
White, non-Hispanic	538	86.9
Hispanic or Latino	19	3.1
Black or African American	11	1.8
Native American or American Indian	5	0.8
Asian/Pacific Islander	11	1.8
Mixed race	35	5.7
Country of origin (n = 625)		
Australia	24	3.8
Canada	42	6.7
UK	61	9.8
USA	436	69.8
Other	62	9.9

in adults (extreme for 41.1%; M = 2.96, SD = 1.081), concern that individuals would be evaluated and not diagnosed because of their gender (extreme for 39.2%; M = 2.80, SD = 1.191) or age (extreme for 38%; M = 2.96, SD = 1.033); anxiety about making an appointment (extreme for 36.4%; M = 2.88, SD = 1.064); cost of a formal diagnostic evaluation (extreme for 36.4%; M = 2.68, SD = 1.223); and inability to adequately communicate symptoms (extreme for 30.9%; M = 2.80, SD = 1.013).

An independent samples t-test was used to compare mean scores of severity of each barrier as rated by males versus females. The researcher determined that a "clinically significant difference" existed if difference in means for an item was >0.5 between groups on the 4-point Likert scale. Table 4 indicates items that yielded clinically and statistically significant differences in scores. In all cases, females rated these barriers as more severe than males.

One-way ANOVA was used to compare mean scores of severity of each barrier as rated by participants from the three countries with highest representation in this sample (US, UK, and Canada). Again, a clinically significant difference was identified if difference in means between two or more groups was >0.5 on the 4-point Likert scale. Table 5 indicates items that yielded clinically and statistically significant differences in scores.

Discussion

Adults with ASD face a number of barriers to obtaining a formal diagnosis. A significant phenomenon that emerged from this study was the fear that professionals would not listen to or believe the symptoms reported to them. This perception was the most frequently occurring and most severe barrier to diagnosis reported by adults in this sample, which has implications for practice and research.

Practice Guidelines

In practice, healthcare professionals must consider ways to build trust with this population. First and foremost, professionals should not dismiss a self-diagnosis until it has been thoroughly explored, as this may cause a block in future communication. Professionals should instead engage in a discussion to gather more information, such as: "Tell me more about your self-diagnosis. What led you to believe you have ASD?" Open ended questions allow the individual to describe what is important to them and reduces the potential for miscommunication based on literal interpretation.

Professionals should be aware of their body language, tone of voice, and content of speech, particularly when working with an individual who might be prone

Table 4 Clinically significant differences in severity of barriers among males versus females

Item	Mean score on 1–4 Likert scale (SD)		Difference in means	t-Value	df	p-Value
	Males	Females				
Difficulty finding an ASD specialist who also specializes in my gender	1.64 (1.06)	2.75 (1.20)	1.11	8.58	144	<0.001
Concern that I will not be listened to	2.72 (1.10)	3.26 (0.91)	0.54	4.33	120	<0.001
Concern that I will not be believed	2.81 (1.01)	3.36 (0.87)	0.55	4.77	122	<0.001
Concern that I will be told I am "making up" symptoms	2.58 (1.08)	3.27 (0.95)	0.69	5.48	124	<0.001
Concern that I will be evaluated but will not be diagnosed with ASD because of my gender	1.42 (0.89)	3.01 (1.10)	1.59	14.46	161	<0.001
Poor past experiences with a mental health professional prevent me from making an appointment	1.82 (1.08)	2.37 (1.18)	0.55	4.25	142	<0.001
Past experiences being "blamed" for symptoms	2.07 (1.20)	2.64 (1.23)	0.57	3.95	450	<0.001

"Clinical significance" defined as difference in means >0.5 on 4-point Likert scale

Table 5 Clinically significant differences in severity of barriers by country of residence

Item	Mean score on 1–4 Likert scale (SD)			F-value	df	p-Value
	United States	United Kingdom	Canada			
Cost of appointment with a mental health professional	2.82 (1.16)	1.26 (0.73)	2.33 (1.32)	51.83	2, 535	<0.001
Cost of travel to see a mental health professional	2.01 (1.10)	1.41 (0.78)	1.88 (1.15)	8.42	2. 534	<0.001
Cost of formal evaluation for a diagnosis	2.93 (1.13)	1.26 (0.73)	2.69 (1.28)	60.21	2, 532	<0.001
I do not have health insurance or recently did not have health insurance	1.73 (1.16)	1.05 (0.38)	1.67 (1.05)	10.37	2, 532	<0.001
Cost of appointment would not be covered by health insurance	2.39 (1.24)	1.10 (0.47)	1.98 (1.26)	32.98	2, 531	<0.001
Cost of formal diagnosis would not be covered by health insurance	2.59 (1.23)	1.10 (0.47)	2.14 (1.32)	43.42	2, 529	<0.001
Difficulty finding an ASD specialist who would diagnose adults	2.92 (0.97)	2.18 (1.06)	2.90 (1.03)	15.16	2, 533	<0.001
Difficulty finding an ASD specialist who also specializes in adults	3.06 (1.03)	2.21 (1.08)	3.24 (0.98)	19.32	2, 533	<0.001
I am unable to navigate the healthcare system to get insurance	1.71 (1.06)	1.02 (0.13)	1.62 (1.04)	12.81	2, 530	<0.001
Long wait times when booking appointments with mental health professionals	2.25 (1.06)	2.97 (0.98)	2.98 (0.95)	20.11	2, 532	<0.001

"Clinical significance" defined as difference in means between two or more variables >0.5 on 4-point Likert scale

to misunderstanding cues. Professionals should be especially mindful to avoid minimizing or changing the topic when an individual identifies a symptom that they believe is important. Frequently checking in to clarify points might also help the individual recognize that they are being heard. For example, "What I am hearing you say is that X is distressing for you, and you believe that might be related to ASD. Is that correct?" Since female participants in this study were significantly more likely to fear not being listened to or believed, as well as more likely to report being "blamed" for symptoms in the past, professionals should be particularly cautious about verbal and nonverbal cues during clinical evaluations to avoid inadvertent miscommunications.

Professionals must also actively engage in education about phenotypical differences between children and adults and between males and females with ASD. They must be aware that adults with average or above-average intelligence, particularly females, may be able to "camouflage" their social communication abilities as a learned coping strategy (Dean et al. 2016; Lai et al. 2016; Rynkiewicz et al. 2016). Previous studies indicate that adults, especially females, may experience internalizing symptoms but not externalizing difficulties associated with ASD, which increases their risk of delayed diagnosis or non-detection (Bargiela et al. 2016; Lai et al. 2011). As a result, professionals using scales such as the Autism Diagnostic Observation Schedule (ADOS-2) should be mindful that this tool may not be sensitive enough to accurately diagnose ASD in adults with average or above-average intelligence and may be particularly biased to exclude diagnosis of ASD among females (Lai et al. 2011; Wilson et al. 2016). If using the ADOS-2 when evaluating adults, diagnosticians should consider combining this tool with use of the Autism Diagnostic Interview (ADI-R) and/or tools to look at internal perception of ASD symptoms such as the AQ to obtain a complete assessment.

Diagnosticians should be on alert for cases in which an individual appears to meet most diagnostic criteria for ASD but lacks some "classic" signs and should further explore these features anecdotally with the individual. For example, if an adult has learned to mimic eye-contact, the professional must recognize that this learned skill may mask a symptom that was present in childhood. Professionals should include the individual in the assessment and ask specific questions to identify learned coping mechanisms versus naturally occurring symptoms. In this case, for instance, the professional may ask, "Tell me about your experience with eye contact." "Is eye contact a skill that is hard for you?" "If I had met you when you were a child, do you believe I would notice anything different about your eye contact?"

Finally, professionals must examine their own preconceptions about self-diagnosis in general. As identified in this study, there are a number of barriers that might prevent an individual with ASD from ever receiving a formal diagnosis. Of course professionals do not need to accept a self-diagnosis as truth, but they must recognize that an idea should not be dismissed solely because a formal diagnosis has not been made. Instead, a professional might say: "I hear what you are saying, and I think you raise some interesting points. I'd like to start by considering a broader view of the issues that you are describing without focusing on a specific diagnosis for now. That will help me work with you to determine what the most appropriate next steps will be. Does that sound like a plan that will work for you?" If the professional reflects on all of the given information and believes that the self-diagnosis is inaccurate, the professional should bring the focus of appointments to specific symptoms, rather than on identifying a diagnosis. Once trust has been established between the individual and the professional, the professional will be in a better position to discuss why they believe it is unlikely that the self-diagnosis is accurate and propose an alternative diagnosis if appropriate.

Other Implications

Researchers must recognize that mistrust of professionals might play a role in recruitment and in responses of adults with ASD. Researchers should promote transparency in their work, clearly identifying any organization affiliates or funding agencies that might affect the research agenda. Researchers should also engage in opportunities to share their findings with the ASD population, not only so that the individuals affected have access to the results, but also as a means to build trust between the research community and the ASD community. Furthermore, researchers should be open to opportunities to engage with the ASD community, formally or informally, to identify potential issues in the language used in recruitment materials, surveys or interview questions, or reports of findings that might exacerbate feelings of mistrust.

Another point raised in this study was the idea that symptoms of ASD themselves may actually prevent an individual who has ASD from reaching a formal diagnosis. For example, an individual with severe social anxiety might not be able to overcome this symptom to make an appointment. An individual with severe alexithymia or poor theory of mind might be unable to express his symptoms to a professional or might be unaware of some of his own symptoms. Future research should explore use of Internet communication to build trust between professionals and individuals before meeting face-to-face to help reduce social anxiety associated with making or going to an appointment. Professionals encountering these individuals might suggest that the individual bring a family member, friend, or other support person to a future appointment to reduce stress and assist the individual in communicating his or her concerns more clearly.

One unexpected finding in this study was the gender distribution of participants. Previous research in children indicates that ASD is approximately 4.5 times more likely to occur in males than females (Christensen et al. 2016). Yet, in the present study, over half of participants were female. In addition, 28.5% of this sample identified with a gender that was not male or female. Given that the inclusion criteria required that participants be formally diagnosed at age 18 or older or that they be self-diagnosed only, these data suggest that non-male gendered individuals may be more likely to experience delayed diagnosis into adulthood compared to males.

Other studies support the claim that delayed diagnosis of females with ASD is common (Bargiela et al. 2016; Rutherford et al. 2016). Further research is needed to continue to explore phenotypical differences between males and females with ASD and to refine existing diagnostic tools for ASD to more accurately assess this population. Further research is also warranted to explore the diagnostic experiences of non-male gendered individuals. The present study also indicates a need to explore identity formation among individuals who identify with a gender other than male or female (e.g. transgender, agender, non-binary gender). Furthermore, nearly 70% of this sample identified that they were not heterosexual, including gay, lesbian, bisexual, unsure, or “other” sexuality. These individuals might be at heightened risk for marginalization.

Findings must also be interpreted with consideration to the healthcare systems of the countries represented. Since participants came from 30 different countries in the quantitative strand, individual responses were likely influenced by cultural and governmental factors affecting cost, access, and stigma. Among the three countries with highest representation in this sample, items related to cost were rated as most severe barrier in the US and least severe in the UK. Access to adult ASD specialists was rated as least severe by participants from the UK. However, long wait times for appointments was a more severe barrier for individuals from the UK and Canada than for those from the US. These differences are likely related to the national health service in the UK, national health insurance system in Canada, and private market system in the US. Overall, participants from the UK reported fewer barriers to formal diagnosis than participants from Canada or the US. Further research should be used to explore methods of reducing systematic barriers unique to country of residence, such as cost assistance and assistance navigating the healthcare system in the US and Canada.

Future research should also further explore differences in the incidence and severity of barriers among subpopulations, such as: those who were self-diagnosed versus those who were formally diagnosed; those with AQ scores 32 or greater versus those with AQ scores less than 32; and heterosexual individuals versus individuals who identify with a sexual minority.

Limitations

Recruitment for this study occurred via online communities for individuals with ASD. This may have excluded those who are not engaged with an ASD online community, therefore missing individuals who rely on in-person communities only or those who lack any support or inclusion in a larger ASD community. During data collection, several individuals reported deep skepticism in response to the recruitment notice and therefore declined to participate. This sample did not likely capture the views of those who strongly mistrusted research or institutions in general.

This study also relied solely on insight on the part of individuals with ASD in identifying barriers to diagnosis and therefore may not have captured significant barriers from the perspective of diagnosticians. For example, a provider may view the inaccessibility of a parent or childhood caregiver as a significant barrier to diagnosis, while an individual with ASD may misinterpret this example as a diagnostician's refusal to evaluate him because of age alone. This study should be replicated to identify barriers to diagnosis of ASD in adulthood from the perspective of diagnosticians.

Finally, this sample relied on self-report and intentionally included those who were self-diagnosed only rather than relying on medical records or personal evaluation. Therefore, this sample may have unintentionally included individuals who do not have ASD. Given the previously identified barriers to formal diagnosis for adults with ASD (Lewis 2016b; Sarrett 2016), the researcher determined that this was a necessary risk in order to capture the true experience of those who are seeking a diagnosis of ASD. The large sample size and diverse diagnosis methods of participants should ameliorate this influence.

Conclusions

Adults with ASD face significant barriers that challenge their ability to obtain a formal diagnosis. Participants in this sample reported that the most frequently occurring and most severe barriers to diagnosis were the perceptions that professionals would not believe them, would not listen to their concerns, or would accuse them of making up symptoms. Professionals must actively engage in strategies to build trust with this population. Self-diagnosis should not be refuted until carefully considered, and professionals should recognize that adult presentations of ASD may appear different than childhood presentations of ASD due to learned coping mechanisms. Future research should also explore barriers that are specific to different subpopulations and should pilot interventions to facilitate formal diagnosis.

Acknowledgments The researcher would like to thank the participants of this study for sharing their experiences.

Author Contributions LFL conceived of the study, designed and implemented data collection and analysis, and drafted the manuscript.

Funding This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Compliance with Ethical Standards

Conflict of interest The author has no conflicts of interest to report.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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