



FEATURE ARTICLE

# Realizing a diagnosis of autism spectrum disorder as an adult

Laura Foran Lewis

College of Nursing and Health Sciences, University of Vermont, Burlington, Vermont, USA

**ABSTRACT:** *Many individuals with autism spectrum disorder are not diagnosed until adulthood, yet little is known about their experiences. This descriptive phenomenological study aimed to explore the experience of realizing a diagnosis of autism spectrum disorder in adulthood. A purposive sample of 77 adults was asked to describe their experiences of realizing a diagnosis as adults via an open-ended online survey. Data were analysed using Colaizzi's method and six themes were derived: feeling different from others, riding an emotional rollercoaster, striving to accept themselves, strategizing to improve their lives, maintaining normalcy, and wandering into the future. Nurses must realize the importance of screening for depression following a new diagnosis. Barriers to reaching a formal diagnosis should also be evaluated.*

**KEY WORDS:** *Asperger's syndrome, Autism Spectrum Disorder, Diagnosis, Mental health, Qualitative research.*

## INTRODUCTION

Recent statistics suggest that the prevalence of autism spectrum disorder (ASD) is as high among adults as children, affecting as many as one in 100 individuals (Brugha *et al.*, 2011). Nearly half of individuals with ASD have normal to above average IQ and are able to function independently (Centers for Disease Control and Prevention, 2014). In this population, delayed diagnosis and under-diagnosis are common and have a significant impact on quality of life (Gillberg, 1998; Lehnhardt *et al.*, 2013; Spencer *et al.*, 2011; Tantam, 2003).

Using Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria, reports estimate that 50–60% of individuals with Asperger's syndrome are undiagnosed (Baron-Cohen *et al.*, 2009; Myhill & Jekel, 2008). This undiagnosed population is likely to rise, as new DSM-5 criteria for ASD have consistently under-identified those previously diagnosed with pervasive developmental disorder and Asperger's syndrome (Mayes *et al.*, 2014). Without knowledge of their diagnosis or supports in place,

this undiagnosed population is likely at a higher risk of depression, anxiety, and suicide.

A recent study found that 66% of adults with newly diagnosed Asperger's self-reported suicidal ideation, and 35% reported having a plan or attempted suicide (Cassidy *et al.*, 2014). These rates are higher than in the general population, in groups with medical or psychotic illnesses, and in previous studies of adults with ASD who were diagnosed in childhood or adolescence. Studies report 31–43% of adults with ASD also experience depressive episodes (Cassidy *et al.*, 2014; Sterling *et al.*, 2007). Researchers hypothesize that depression is under-reported in this population due to alexithymia or difficulty finding words to express self, and to symptoms of depression being misattributed as symptoms of ASD.

The experience of 'being diagnosed' has been well studied in physical disorders. Researchers emphasize the emotional impact of the event of receiving a diagnosis (Kralik *et al.*, 2001; Robinson *et al.*, 2005). In a study of service users of mental health services, Gallagher *et al.* (2010) concluded that receiving a mental health diagnosis is a unique phenomenon, and similarities to receiving a physical diagnosis should not be assumed. Individuals and their families are vulnerable to developing depression, anxiety, and distress when receiving a new diagnosis, and nurses play an ongoing role in screening for these comorbidities (Stafford

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**Correspondence:** Laura Foran Lewis, RN, PhD, College of Nursing and Health Sciences, University of Vermont, 105 Rowell Building, 106 Carrigan Drive, Burlington, VT 05405–0068, USA. Email: Lforanlewis@gmail.com  
Laura Foran Lewis.  
Accepted November 2015.

*et al.*, 2013; Streisand *et al.*, 2008). To empower and advocate for a newly-diagnosed individual, nurses must have an understanding of the diagnosis itself and of the unique experiences of those who are diagnosed.

Only one peer-reviewed study has explored the experience of being diagnosed with ASD (Punshon *et al.*, 2009). Participants in Punshon *et al.*'s study described negative life experiences and difficulty fitting in prior to diagnosis. After diagnosis, they found a sense of belonging and positively reframed life around the diagnosis despite still facing challenging symptoms. Punshon *et al.*'s study was limited by homogeneity of the sample. All 10 participants were selected from a single service site for adults with ASD. There is a need to explore this experience from a broader population, and it is critical to examine the experiences of those not receiving support services.

Portway and Johnson (2005) interviewed young adults with ASD and concluded that providing a diagnosis to these individuals had short- and long-term benefits. A core category of 'not quite fitting' emerged, where young adults with Asperger's described the challenges of not appearing different, but feeling different from their peers. They described issues with bullying, isolation, depression, anxiety, and feeling misunderstood.

Philip Wylie (2014, 2015), an individual diagnosed with Asperger syndrome as an adult, proposed the 'nine degrees of autism'. In this developmental model, individuals journey from the 'pre-identity alignment', struggling to understand why they feel different from others, to the transitional 'identity alignment', self-identifying as ASD and beginning to accept the diagnosis, and finally to the 'post-identity alignment', learning to master their identity and viewing themselves positively with knowledge and acceptance. This model has not yet been researched or validated.

The purpose of the present study was to qualitatively explore the experience of realizing a diagnosis of ASD in adulthood. Using a phenomenological approach, I aim to answer the research question: What is the essence of the experience of being diagnosed with ASD as an adult?

## METHOD

### Research design

I explored this lived experience using descriptive phenomenology. Phenomenology is both a philosophy and a method. As a philosophy, phenomenology is the study of the structure of a conscious experience. Experiences can be understood by examining intentionality, or the memories and perceptions and emotions that surround the experience for the individual experiencing it (Husserl, 1954). Husserl prescribes that one

must suspend his or her own preconceptions about the experience, which he calls 'phenomenological reduction'.

As a method, phenomenology is used to explore the meaning of an experience. Researchers select participants who have experienced the phenomenon of interest, and their accounts serve as data. Researchers must commit to bracketing preconceived judgments and beliefs, often through reflexive journaling, in which the researcher journals these ideas to bring them to awareness and prevent them from biasing analysis. No underlying theoretical framework is preselected. Researchers must be open to accepting the meaning that participants place on the experience, called 'intuiting'. The goal of a descriptive phenomenological study is to describe the phenomenon as it truly exists in the world (Husserl, 1954; Munhall, 2007).

### Participants

Participants in this study were diagnosed with ASD at age 18 years or older. The inclusion criterion was individuals who self-reported being formally evaluated for ASD or informally evaluated by a mental health-care professional as meeting the diagnostic criteria for ASD. Individuals meeting both the DSM-IV and DSM-V criteria were included because it was presumed that many individuals were not re-diagnosed since the release of the DSM-V. These individuals might have been diagnosed with ASD, Asperger's syndrome, high-functioning autism, pervasive developmental disorder, or classic autism.

### Procedure

Ethics approval was granted by a university institutional review board. Data collection occurred online using an Secure Sockets Layer (SSL) encrypted website. Data were collected online to allow for heterogeneity in the sample, particularly in targeting individuals not receiving ASD services, and to reach participants who wished to remain anonymous. Individuals with ASD who struggle with face-to-face communication might also prefer to participate in online research compared to face-to-face interviews. This allows them to consider questions before responding and does not require them to interact with the researcher in person, which lets them more fully engage and share honest responses (Benford & Standen, 2009).

Participants were recruited via online message boards, forums, and support groups for individuals with ASD, and asked to complete an online open-ended survey. To protect the privacy of all participants, no contact information was collected, so it was not possible to ask participants follow-up or clarifying questions. Participants were asked to respond to the following statement: 'Please describe your experience of being diagnosed with autism spectrum

disorder as an adult. Please share any thoughts, feelings, and specific experiences’. A second online survey tool was created after initial data analysis to review findings. Participants were presented with an exhaustive description of the phenomenon, and were asked provide feedback about how this summary did or did not accurately describe the phenomenon of interest.

**Data analysis**

Colaizzi’s (1978) method was used for the data analysis. Transcripts of data were read line by line to ‘extract significant statements’ about the phenomenon, and a ‘formulated meaning’ was derived from each statement. Clusters of these statements formed themes. An example of translating significant statements into formulated meanings is provided in Table 1. The researcher developed an exhaustive description of the phenomenon from these themes, which was presented back to participants for validation. Ten participants reviewed the descriptive summary, and based on their feedback, only minor revisions were made.

The researcher’s background in ASD includes extensive reading, attending conferences on ASD, and experiences with a family member with ASD. The researcher used bracketing and reflective journaling throughout the research process to attempt to identify and remove biases from these experiences. Lincoln and Guba’s (1985) evaluative criteria for trustworthiness were also considered. Member checking was used to ensure credibility of data by soliciting feedback from participants. Verbatim quotes of rich data have also been provided as thick description (Geertz, 1973).

**RESULTS**

**Sample**

This sample included 77 individuals diagnosed with ASD at age 18 years or older. The demographic characteristics of this sample are provided in Table 2. The majority of participants were male, and the average age was 39 years. Participants described an average of 3.25 years between the point when they self-diagnosed and the point when they were

formally diagnosed with ASD, reaching up to 39 years. The age of formal diagnosis ranged from 18 to 60 years old, with an average age of 35.3 years. A majority of participants were in long-term relationships, and nearly half had children. Of the 33 participants with children, 20 reported having at least one child with suspected or diagnosed ASD. Twelve countries and 24 states of the USA were represented in this sample.

Participants described six themes that captured their experience of being diagnosed with ASD as adults. Participant identification numbers are provided after each quote.

**Theme 1: I always knew I was different**

Many participants used the phrase, ‘I always knew I was different’ (010, 045, 051, 066). Some viewed differences positively. For example, one said, ‘I always thought I was unique’ (009), and another, ‘I knew I didn’t think like others, but knew I was, in many ways, superior to them’ (002). However, it most often led to a negative self-image. One said, ‘I’d always assumed there was something wrong with me’ (028). Another wrote, ‘I always felt like I was just different enough to be able to recognize it, but not smart enough to figure out what my differences were so that I could fix it’ (032). Several described feeling ‘misunderstood’ (067), ‘misunderstanding others’ (065), ‘thinking I was an anomaly’ (009), or ‘being a freak’ (025, 069).

Many participants described hearing about ASD for the first time from a family member or friend, or reading about it and feeling ‘intrigued’ (002) or ‘curious’ (039, 047), leading them to seek more information. One participant shared, ‘I became obsessively curious, doing as much research as I could’ (039). Participants often reached a self-diagnosis before seeking a formal diagnosis. Others only heard of ASD at the suggestion of a health-care professional; for example, saying, ‘Until that moment, I’d never read or heard the name or word Asperger’ (008). Many were formally diagnosed while being treated for issues, such as depression, anxiety, or sensory processing disorder, and in several cases, these individuals were initially misdiagnosed. In almost all cases, a feeling of being somehow different from others led participants to seek help and/or a diagnosis.

**TABLE 1:** *Examples of formulated meanings derived from significant statements*

<b>Significant statements</b>	<b>Formulated meanings</b>
‘I had a strong feeling that I was different from a young age’	He felt different from a young age
‘I always thought I was unique and only, very rarely did I encounter anyone who thought at all like me’	He felt like he was unique and thought differently from others
‘I’d always assumed there was something wrong with me, until a doctor brought up the possibility of being on the AS’	She assumed there was something wrong with herself
‘I had gone through 20 years of my life thinking I was just some anomaly’	She believed she was an anomaly her whole life

AS, Autism Spectrum.

**TABLE 2:** Demographic characteristics of the sample

	<b>n</b>	<b>%</b>
Sex ( <i>n</i> = 76)		
Male	40	53
Female	32	42
Other	4	5
Age ( <i>n</i> = 76)		
Mean: 39 years		
Range: 18–65 years		
Diagnosis method ( <i>n</i> = 77)		
Formal evaluation	60	78
Informal evaluation	17	22
Type of autism spectrum disorder ( <i>n</i> = 76)		
Asperger's Syndrome	62	82
PDD	1	1
Autism spectrum disorder	24	32
Unknown	1	1
Relationship status ( <i>n</i> = 76)		
Currently married	27	36
Currently in a long-term relationship, unmarried	14	18
Not currently in a long-term relationship	35	46
No. children ( <i>n</i> = 76)		
0	43	57
1–2	25	33
3+	8	10
Highest level of education ( <i>n</i> = 73)		
Some high school	3	5
High school graduate	3	5
Trade/technical/vocational training	4	6
Some college	21	29
College graduate	24	33
Some postgraduate work	4	6
Postgraduate degree	12	16
Employment status ( <i>n</i> = 71)		
Employed	34	48
Unemployed or disabled	22	31
Student	9	12
Homemaker/child care	4	6
Retired	2	3
Race/ethnicity ( <i>n</i> = 73)		
American Indian	2	3
Asian	3	4
Black	3	4
Hispanic	1	1
White	64	88
Country ( <i>n</i> = 74)		
Australia	4	6
Belgium	1	1
Canada	9	13
Finland	2	3
Ireland	4	6
The Netherlands	1	1
Norway	1	1
Scotland	1	1
Singapore	1	1
Sweden	1	1
UK	11	15
USA	38	51

PDD, Pervasive Developmental Disorder, \*multiple selections allowed.

## Theme 2: Riding the emotional roller coaster

Once formally diagnosed, accepting a diagnosis took time and reflection. For some, the diagnosis was 'expected' (061) and 'didn't change anything' (038). One participant said, 'Since this is something I have had from birth, it wasn't a big surprise' (059), and several said, 'It made sense' (001, 002, 010, 034, 037, 053, 054, 059, 062). Others were 'devastated' (048) by this news, saying it was 'another nail in the coffin' (036). Some described going 'into a funk' (013) or a depressive episode for months following the formal diagnosis. One said, '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' (009).

Many participants described a period of 'denial' (007, 048, 066) and 'confusion' (003, 005, 009, 028, 041). One participant said, 'At first I felt a sense of denial...that it was unlikely I had something so significant' (019), and another, 'I was confused and kept doubting the diagnosis' (042). Individuals often spent a lot of time researching ASD before accepting the diagnosis.

Reading about ASD often brought on an immediate sense of belonging. Many described feeling 'shocked' (005, 009, 046, 058) to hear others describing their own experiences, saying, 'The more I read, the more examples I found of people like me and of feelings and experiences like mine, things I had never heard or seen outside of my own mind' (067). Several described reading stories written by others diagnosed with ASD as adults and said, 'She was describing my childhood; it was riveting and felt like finding a glove that fits perfectly' (008), and 'I cried when I read (a book about ASD) because I recognized myself in every paragraph' (024). Through online and in-person encounters with others with ASD, these individuals described finding a place in the world. One said, 'I finally knew that I was not alone who felt different' (048), and another, 'It was like I found my people!' (057). Another said, 'This was a revelation, that I was indeed part of a much larger group of people how have similar experiences' (002).

Most of all though, participants described feeling 'relief' (005, 009, 011, 014, 016, 019, 028, 032, 034, 037, 037, 038, 040, 043, 045, 054, 062, 067, 070). One participant said, 'It was an expected outcome, but I felt relieved that my experiences were legitimized' (061), and another said, 'If anything, it was a relief to find out – much like finding that last piece to a puzzle' (050). Having always felt different, the diagnosis 'explained a lot' (007, 065) One said, 'After years of essentially feeling defective, I finally had the answers. I felt empowered' (051). Another said, 'An entire lifetime of struggles to understand social difficulties fell

away in a moment' (040). One individual diagnosed at age 51 wrote, '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' (060). Several also described the relief of 'having a name' (011, 062) for ASD; for example, '(It was) almost immediate relief to be able to put a name to the combination of symptoms I've had my entire life' (028).

### Theme 3: Striving for self-acceptance

Once participants had accepted the diagnosis, they described a period of learning to accept themselves. This often meant re-evaluating how they viewed themselves, and participants described 'a need to find a sense of self again, who is ME and how does autism contribute to who I am' (009). Individuals spent time looking back on their childhood experiences 'rewriting my past with autism lenses' (057).

Participants described finding a new understanding of themselves. One said, 'I finally was able to understand and explain me' (008), and another, 'I felt whole for the first time' (034). Understanding led to acceptance. One participant said, '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' (039). Another wrote, 'Once I started to understand it, it was ok. I look at things different, and I am ok with that' (036).

They also felt that the diagnosis allowed them to uncover parts of themselves they had hidden from others and even from themselves. One wrote, 'It was like I discovered a part of me that was there all along but was hiding' (042), and another, 'I realized...a desire to embrace parts of myself that I had squelched over the years in order to 'fit in' and blend with society that was unforgiving and judgmental about differences' (055). Another said, 'The stress of having to 'fake it' is gone. I can be myself' (032). One described how others reacted to his new sense of self: 'It has been pointed out to me that I seem to have been more 'aspie like' for a while after diagnosis. My reply: I've always been like this now I don't feel I have to hide it' (056).

For many, this process was slow, painful, and ongoing. As one participant said, 'Slowly I have become more accepting of my condition, but it still causes me a lot of grief' (066). Some still felt that they could not be themselves. One participant described, 'The feeling of looking out at people and knowing I had to hide aspects of myself and invent others never left' (067). Participants described a period of trying to understand and accept themselves.

### Theme 4: Strategizing towards a better life

Participants reported that knowledge of their diagnosis gave them 'tools' (033) to improve their lives, ranging from learning effective communication strategies, to learning to 'stim' (042), to just having a name for ASD to give to health-care professionals when describing their challenges. One participant wrote, 'I was able to take advantage of resources in the community, now that I had a diagnosis, and I benefitted greatly' (050), and another:

Having a context in which to place many of my actions helps me to understand what I have to deal with as someone with ASD and what is necessary for me to have as close to a normal life as possible. (053)

Participants described learning to see the benefits of having ASD and to embrace their differences. As one said, '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' (024).

Several participants described that, although they had some new tools, they also felt the diagnosis added new pressure to change themselves. One participant said, 'I feel like my life now revolves around trying to change the things that for 30 years. I've just accepted as being part of me' (001). Another said, 'I feel like I have even more to work on now, in terms of self-improvement, and it can be frustrating' (065).

A few participants mentioned advantages of not being diagnosed until they reached adulthood, as they were forced to find their own ways to adapt and had no preconceived notions of their abilities. One participant wrote, 'I'm sort of glad that I was placed in 'gifted' programs rather than some sort of special education' (044), and another acknowledged, 'I don't think I would have gone to college if I knew I was on the spectrum' (062). One summarized, 'Living without a diagnosis was a hard teacher, but a good one' (006).

Most, however, described feeling 'angry' (009, 062, 069), 'outraged' (063), and 'heartbroken' (066) that they were not diagnosed earlier. One participant diagnosed at age 27 said, 'It has left me a little bereft of a life that could've been' (044). Another diagnosed at age 37 said:

I was quite distressed and very sad about the lost years in my life and angry about why I hadn't been diagnosed much earlier. Angry because of all the bad things that had happened to me in my life and sad because I had lived so many years in the dark. (046)

Another participant described:

Disappointment, deeply felt, that I had to wait until I was 45 years old to get a diagnosis. Saddened, too, for all the lost opportunities that would likely have come about had I known and received intervention and loving understanding as a child. (047)

Participants felt that the diagnosis gave them new resources or skills, and almost all felt that simply knowing they had a diagnosis improved their lives through self-understanding.

### Theme 5: Maintaining normalcy

Most participants reported that they struggled with issues related to ASD. However, many also stressed that they did not feel disabled or that there was anything wrong with them. One participant said, 'The overall thing that I must emphasize is that I have never had the feeling that there was anything wrong with me. Different – yes, special – yes, unique – yes, able – very much so, superior – yes, special – yes, but defective – never!' (002). Another said, 'I have learning differences, but I am not 'less' than other people' (010). Several pointed out that they encountered challenges, but were still able to find success. For example:

I don't see myself as disabled....Did I have anxiety attacks, depression, feel awkward socializing, have some difficulty with things like routine changes, and seem obsessive? Sure. But I graduated from high school with good grades, I went to college, and got married just like everyone else. (007)

Several discussed their own misperceptions prior to diagnosis and extreme stigmas about ASD promoted in the media, describing 'Rain Man' (019) or 'non-verbal children who rocked themselves' (025). One participant wrote:

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 is disabled. The thought of being treated less than (sic) a normal human came to mind. And I am far from being disabled. (048)

Others described a much grimmer picture of ASD. Participants said, 'AS is torture' (069) and 'It is very lonely' (032). One wrote, 'I wouldn't even want to wish this on my worst enemy (if I had one). The feeling of isolation is miserable, and no one should go through something like this at any time in life' (013). Another said, 'Being yourself comes with a price apparently' (041), and another, 'Frankly, I consider having Asperger's a curse. My 'life' is hell' (003).

Almost all participants described negative effects of ASD, but most participants emphasized that they worked hard to manage these issues within their normal lives. Many described challenges in romantic relationships, including

issues with sexuality and intimacy, facing bullying, challenges making and maintaining friends, and inability to maintain appropriate eye contact. Self-reported depression and anxiety were very common in this sample, and two participants mentioned that they had considered or attempted suicide. Other reported challenges included sensory hypersensitivity, insomnia, meltdowns or shutdowns, obsessive qualities, agoraphobia, substance abuse, addiction, taking a long time to complete education, difficulty maintaining employment, and issues with planning and organizational skills. Even with these challenges, many participants described that they lived 'a normal life' (007, 053), despite having ASD.

### Theme 6: Wandering into the future

Participants voiced their concerns for the future. Many participants felt that others were not understanding of their diagnosis when disclosed, either viewing them as 'disabled' (048) or as 'using it as an excuse' (024) for certain behaviours, and several reported that their family or friends denied the diagnosis altogether. One participant described losing friends after disclosing his diagnosis to them: 'People said to me doors will open if I got diagnosed. I think this is not entirely true. Some doors may open. But a lot of them will close' (006). Although many had worked hard to reach self-acceptance, they still struggled to find acceptance from others.

Most felt that they were handed a diagnosis and nothing more, left to navigate their futures independently. Participants described 'wandering left to my own devices' (041) and 'it feels like I'm supposed to figure out what to do next on my own' (001). They reported challenges finding a professional to diagnose them in the first place because they were adults, and several participants reported that they were refused a formal evaluation because they were adults. As one participant said, 'The psychologist said that there would be no point in doing this formally as I was already an adult and there were no services in place for my situation. Then counseling ended' (067).

Most described challenges finding support for adults. One said, 'It is impossible to find professional help as an adult' (017). Another said, 'Now that I see the world through an autistic's eyes, society is less accepting of adult autistics comparing to children....People expect you to put up with it and shut up' (009). One summarized:

I am appalled and lament for the thousands of adult aspies who have struggled – and continue to struggle – to live in a world that is alien to them. I do get weary, admittedly, of hearing about all the wonderful things that are happening for autistic/aspie children. I think, and it's entirely justifiable, what of the adults? Why are we the forgotten ones? (011)

Many wished there was more help available, and several described ‘accepting the future does not look much brighter than the past’ (041). One described losing hope with his diagnosis, saying, ‘I was never social but I thought I was just shy and that it will change eventually. But now I knew that wasn’t the case. So I had no hope for the future and I still don’t’ (042).

Others did not lose hope, but instead saw a personal vocation to help others in their situations. Participants started blogs, became speakers, started online or in-person support groups, and participated in research studies in an effort to help the adult ASD community. Many viewed their diagnosis of ASD and path to self-acceptance and societal acceptance as an ‘ongoing journey’ (006).

## DISCUSSION

The findings from the present study highlight the challenges and triumphs that individuals with late-diagnosis ASD face. Overall, participants described significant benefits to receiving a diagnosis, giving them comfort and relief from understanding themselves and tools to move forward. Participants emphasized that they believed receiving a diagnosis earlier would have positively impacted their quality of life.

The findings from the present study are supported by previous studies that explored the experiences of adults diagnosed with ASD (Portway & Johnson, 2005; Punshon *et al.*, 2009). The data presented fit particularly well with Wylie’s (2014, 2015) model of very late diagnosis of ASD, which includes nine stages: knowing that we are different, getting external feedback and clues that we have ASD, pretending to be normal, reaching the ‘tipping point’ of self-identification, researching ASD and reaching self-discovery, receiving a prediagnostic assessment and a diagnosis of ASD, ‘coming out’ and deciding in whom to confide, finding self-acceptance through enhanced understanding of our strengths, and enjoying a sustainable future (2015, p. 29). This pattern held true for many participants, although most participants in the present study were less optimistic about the future than implied in the final stage of Wylie’s model.

Portway and Johnson’s study (2005) and Wylie’s model (2015) might help to explain a paradox found in the present study, where many individuals described themselves both as being ‘very different, from others, as well as ‘living a normal life’. Participants asked to be accepted rather than changed, while concurrently lamenting that no help was available to them. Portway and Johnson describe ASD as a ‘non-obvious disability’, where participants are ‘normal but different’ from others, while Wylie describes the

transitional stage as the turning point between viewing ASD as a disease versus as a part of self. Individuals might vacillate between two views of themselves, or might transition from a disorder perspective to a personality perspective of ASD over time. Further study into this disorder versus personality view of ASD is warranted.

Nurses must consider that, with or without a diagnosis, these individuals feel different from others and struggle to understand themselves. In most cases in the present study, progression from misunderstanding to self-acceptance was only possible through diagnosis, even if only mild ASD was present. The present study underlines the need to increase diagnostic services and transitional services for adults upon being diagnosed, as well as services for adults with ASD in general. Most participants struggled to find specialists for adults, and many felt abandoned after diagnosis. Many participants also described symptoms of depression in their accounts. Screening for depression and suicide risk at time of diagnosis and immediately following is critical. Finally, given the average of 3.25 years of between self-diagnosis and formal diagnosis, further study on barriers to reaching a formal diagnosis should be explored. The role of nurses in care of individuals diagnosed with ASD as adults is summarized:

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- Listen and validate the individual experience of ASD and diagnosis
  - If ASD is suspected, but not formally diagnosed, assist in identifying and overcoming barriers to formal diagnosis
  - Provide education on typical presentation of ASD, considering age and sex
  - Provide information and resources on:
    - Counselling services, if desired
    - Online/in-person communities of support
    - Community/school/employment services, if needed
  - Assist in identifying individual strengths and transitioning an individual’s perspective from a disorder perspective of ASD to a personality perspective
  - Screen for and treat comorbidities; for example, depression, anxiety, suicidal ideation
  - Arrange for follow up to ensure appropriate transitioning and minimize feelings of abandonment from health-care team
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The present study was limited to a sample recruited and surveyed online. This might have biased the sample to include only those with the resources, physical and cognitive, to use a computer. Online surveys, rather than traditional interviews, also prohibited the researcher from being able to perceive non-verbal communication, including body language, silence, and tone. Furthermore, to protect the privacy of participants, it was not possible to ask follow-up

or clarifying questions. The present study also relied on self-reported diagnoses of ASD, rather than a review of medical records or personal evaluation. However, these limitations must be considered in the context of the study of a population that is specific and difficult to access. Participants also voiced a mistrust of the research community in general during recruitment and data collection, indicating that this sample might have captured a population that would not have been possible if participants had been asked to share personal identifying or contact information. The present study was strengthened by a very large sample for a qualitative study, and findings were validated with key informants.

Studies suggest that a significant number of adults with mild ASD remain undiagnosed, and services for adults who are diagnosed is lacking. The present study highlights the benefits of receiving a diagnosis, at any age. Research and clinical efforts to promote early diagnosis of all ASD, including mild cases, and to improve access and quality of adult support, should be made to improve the lives of those with ASD.

## ACKNOWLEDGEMENTS

Thank you to all of the men and women who shared their stories with me.

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