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Roadblocks and detours on pathways to a clinical diagnosis of autism for girls and women: A qualitative secondary analysis

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Abstract

Background: Autism is not always considered for girls and women until later along their clinical diagnostic pathways. Misdiagnosis or late diagnosis can pose significant disadvantages with respect to accessing timely health and autism-related services and supports. Understanding what contributes to roadblocks and detours along clinical pathways to an autism diagnosis can shed light on missed opportunities for earlier recognition.

Objective: Our objective was to examine what contributed to roadblocks, detours, and missed opportunities for earlier recognition and clinical diagnosis of autism for girls and women.

Design: We conducted a qualitative secondary analysis using data from a Canadian primary study that examined the health and healthcare experiences of autistic girls and women through interviews and focus groups.

Methods: Transcript data of 22 girls and women clinically diagnosed with autism and 15 parents were analysed, drawing on reflexive thematic analysis procedures. Techniques included coding data both inductively based on descriptions of roadblocks and detours and deductively based on conceptualizations of sex and gender. Patterns of ideas were categorized into themes and the 'story' of each theme was refined through writing and discussing analytic memos, reflecting on sex and gender assumptions, and creating a visual map of clinical pathways.

Results: Contributing factors to roadblocks, detours, and missed opportunities for earlier recognition and diagnosis were categorized as follows: (1) age of pre-diagnosis 'red flags' and 'signals'; (2) 'non-autism' mental health diagnoses first; (3) narrow understandings of autism based on male stereotypes; and (4) unavailable and unaffordable diagnostic services.

Conclusion: Professionals providing developmental, mental health, educational, and/or employment supports can be more attuned to nuanced autism presentations. Research in collaboration with autistic girls and women and their childhood caregivers can help to identify examples of nuanced autistic features and how context plays a role in how these are experienced and navigated.

Keywords

autism, clinical diagnosis, gender, girls, healthcare, parents, qualitative research, sex, stereotypes, women

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Background

Gendered assumptions about autistic traits and behaviours, as well as gendered socialization processes, may influence the expression, as well as recognition, of autism for girls and women.[1] Gender (social) and sex (biological) are viewed as different but interrelated concepts.[2] Yet, most autism studies on sex and/or gender do not clearly differentiate between sex and gender.[3] Social assumptions about gender (e.g. girl, woman, boy, man, gender-diverse, feminine, masculine) characteristics that map onto assigned-sex-at-birth (e.g. female, male, intersex) can shape how people think about gender expressions and identity labels. Assigned-sex-at-birth is closely linked to gendered experiences, and potentially inseparable, thus an important consideration for autism research examining sex/gender differences Some literature opts to use 'sex/gender' to recognize that they are interrelated and potentially inseparable concepts or when the impact of sex versus that of gender is difficult to delineate when sex-related and gender-related constructs have not been measured separately.[4] For example, prevailing perceptions and assumptions about gender held by people surrounding an individual are often closely and stereotypically linked to the sex that the individual was assigned at birth. Thus, these gendered perceptions and assumptions play key roles in a person's daily life experiences, such as interactions with healthcare professionals. Sex, gender, as well as age and generation By 'age' we refer to the number of years a person has lived. By 'generation', we refer to childhood, adolescence, and adulthood as social categories that construct a generation. biases, may be embedded in autism diagnostic practices.[5] For example, a male-centric and childhood-oriented understanding of autism may construct a stereotyped representation of autism.[6] This may direct the attention of physicians, educators, parents, and caregivers (who are positioned to recognize autistic characteristics in childhood) to autism presentations prevalent for boys and men, while nuanced presentations that may be more common for girls and women are overlooked or misinterpreted.[7,8]

The male-to-female ratio of diagnosis has decreased from approximately 5:1 to 2.5:1 with changes in diagnostic practices over the past decade.[5] However, a sex/gender discrepancy in diagnosis persists. This discrepancy is more marked in childhood compared to adulthood. Girls and women are often misdiagnosed, or diagnosed with autism significantly later in their lives than boys and men.[9–15] Autism is not always considered until later along their pathways of seeking assessments, services, and supports for challenges they are experiencing in their lives. Misdiagnosis or late diagnosis can pose significant disadvantages for girls and women with respect to accessing timely health and autism-related services and supports.[9] Many girls and women experience obstacles – or roadblocks and detours – along the pathway to a clinical diagnosis of autism. Understanding what contributes to these roadblocks and detours can shed light on missed opportunities for earlier recognition of autism.

Recent research suggests that autistic characteristics and behaviours may be expressed differently in part for some girls and women, often in a more nuanced way.[3] For example, clinically diagnosed autistic girls and women tend to have fewer restricted patterns of behaviour, interests, or activities than boys and men but comparable social-communication–interaction challenges.[16] Girls and women seem more likely to 'camouflage' or 'mask' autistic characteristics, which may contribute to missed or belated clinical diagnosis.[17–19] Broadly speaking, camouflaging or masking, as a kind of impression management 'performance' during human social interactions,[20] refers to conscious or subconscious strategies employed by autistic people to 'hide' their autistic characteristics or to adopt non-autistic behaviours for the purpose of fitting into the predominantly neurotypical social world.[17–21] Girls may tend towards being characterized as perfectionistic and strong-minded compared to boys and their focused interests (e.g. reading, animals, celebrities) are less likely to be recognized diagnostically as restrictive and repetitive behaviours of autism.[22] Autistic girls and women also experience more internalized symptoms, such as those associated with anxiety or depressive disorders, rather than externalized symptoms, such as those associated with attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder, or conduct disorder. The latter are more commonly observed of autistic boys and men.[22,23] Taking a gender-lens can help to 'zoom out' from sex-based or biological differences from boys and men and to consider the social influences (e.g. socially constructed roles and behaviours ascribed to women, men, and gender-diverse people) on how and when autism is recognized and diagnosed for girls and women. Examining what led to an eventual clinical diagnosis of autism for girls and women can provide insights into missed opportunities for earlier diagnosis. Such insights can inform the refinement of clinical autism screening and assessment practices, enhance the training of health and education professionals for more nuanced understandings of autism, and increase public awareness of autism across sexes and genders.

Objectives

Our objective was to examine what contributed to missed opportunities for earlier recognition and diagnosis of autism along the clinical pathways for girls and women. We conducted a qualitative secondary analysis using a subset of data from a primary Canadian study that examined the health and healthcare experiences of autistic girls and women from their perspectives and from the perspectives of parents of autistic girls. In the primary study, our participants discussed challenges that they had experienced along their pathways to a clinical diagnosis of autism, which resulted in a delayed diagnosis for many of them. We coined these challenges as ‘roadblocks’ and ‘detours’ to earlier recognition,[24] which raised a new research question: what contributed to these roadblocks and detours and thus potential missed opportunities for an earlier clinical diagnosis of autism?

Design of primary study

The primary study involved individual and focus groups interviews (The individual and focus group interview guides can be made available upon request by contacting the corresponding author.) with autistic girls and women and parents of autistic girls in Canada, about their healthcare and diagnostic service experiences. We collaborated with a not-for-profit autism organization to create a project advisory of three autistic women and three parents that provided advice on autism-friendly data collection strategies, interpretations of analytic summaries, and recommendations for practice based on the results.

Participants

Participants for the primary study included (1) girls and women on the autism spectrum and (2) parents/guardians of an autistic girl (not necessarily a study participant). For the first group, inclusion criteria were as follows: (a) over the age of 12 years old, (b) assigned female at birth (AFAB), and (c) self-reported diagnosis of autism without intellectual disability or psychotic disorder (participants with common co-occurring psychiatric conditions, such as anxiety or mood disorders, diagnosed by a clinician, were included). Inclusion criteria for the second group consisted of (a) parents/guardians providing care or support to a girl or woman diagnosed with autism. Our intention for including AFAB as a criterion for inclusion in the primary study was not to conflate sex and gender but to recognize that assumptions about gender held by the people around an individual are often closely and stereotypically linked to assigned-sex-at-birth (i.e. female) and therefore have substantial influences on their daily living experiences. This approach allows for integrating a gender-lens in the analyses and interpretation of findings about how others’ gendered assumptions of the autistic AFAB individuals have impacted their healthcare and diagnostic service experiences.

Recruitment

Following Research Ethics Board approval from the hospital, potential participants were recruited through the autism organization and hospital-based autism diagnosis services using purposive and snowball sampling. A recruitment advertisement was posted on the organization and hospital websites and sent by e-mail to the organization’s members. Recruitment advertisements were posted at local hospitals and social service agencies that provide services to autistic girls and women.

Methods

For the primary study, six focus groups and 20 individual interviews were conducted from June 2017 to April 2018, which involved 41 participants consisting of girls and women with a clinical diagnosis of autism, self-diagnosed women, and parents. To address accessibility considerations, participants chose to participate in an interview or focus group based on their communication and interaction preferences. For the focus groups, participants were grouped by girls (12–18 years), women (18 years+), and parents/guardians. Two focus groups were held with each participant group, and there were four to six participants in each group. A researcher experienced in both clinical and research interviewing with this population (Y.H.) conducted all the interviews and focus groups. A research assistant (C.K.) was present for all focus groups to take notes about the discussion. All interviews were audio-recorded and transcribed professionally for the purpose of analysis.

Qualitative secondary analysis methods

For the qualitative secondary analysis, we used data from the interview and focus group transcripts of 22 girls and women clinically diagnosed with autism and 15 parents with a daughter clinically diagnosed of autism to examine what may have contributed to missed opportunities for earlier recognition and diagnosis of autism. The transcript data from both sources were combined and treated as a whole at face value. Data from four self-diagnosed participants were excluded as in this analysis we were interested in experiences leading up to a clinical diagnosis of autism, and not all self-diagnosed participants were seeking a clinical diagnosis. Two parent–girl dyads participated together, two mother/father pairs discussed one daughter together, and one parent had two daughters diagnosed with autism; thus, the unique data related to 34 girls and women with a clinical diagnosis of autism were represented in this analysis. The age range of participants on the autism spectrum was 12–71 years old and of the daughters of parent participants was 12–22 years old at the time of interviews. Participants or the daughters of the parent participants were diagnosed with autism between the ages of 2–63 years old. Table 1 shows the number of participants for each age category of diagnosis.

Guided by an interpretive description approach[25] and the six phases of reflexive thematic analysis proposed by Braun et al.,[26] this secondary analysis involved both inductive and deductive approaches to generate themes and with an awareness that ‘“what” we talk about and “how” we

Table 1. Age of clinical autism diagnosis.

Diagnosed between 0 and 5 years old	Diagnosed between 6 and 15 years old	Diagnosed between 16 and 30 years old	Diagnosed after 30 years old
Four participants	Twelve participants	Nine participants	Nine participants

talk about it are highly social constructed'.[25] Thus, we examined not only what participants said but also explored prevailing assumptions about sex, gender, and autism reflected in their accounts of their diagnosis experiences, as well as in our readings and interpretations of their accounts. Three team members (Y.H., M.W., C.K.) read all transcripts and made notes about content related to roadblocks, detours, and missed opportunities (inductively), and to key challenges and barriers to an autism diagnosis for girls and women from the literature and key sex and gender concepts proposed by the Canadian Institutes of Health Research (CIHR)[2] (deductively). CIHR refers to sex as biological or physical attributes and gender as socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender-diverse people.[2] They then met to discuss key ideas and patterns within and across the transcript data, and to identify preliminary labels for codes.

Two team members (M.W., C.K.) coded the data and worked together to categorize the codes and generate initial themes. Any discrepancies between coders were reviewed and resolved during a second analysis meeting with Y.H. and M.-C.L. Throughout the meeting and subsequent meetings, we identified examples of both explicit and implicit assumptions about sex, gender, and autism in the data and had reflexive discussions about how these assumptions, as well as those held by the team, shaped our collective interpretations of the data and the 'story' of each theme. At this point, the team also identified that the age of diagnosis and age-related social roles were relevant to participants' diagnostic experiences. M.W. and C.K. collated and re-read the data based on age groups of diagnosis (0–5 years, 6–15 years, 16–30 years, 30+ years; see Table 1) and created analytic memos with a view on further developing the themes with respect to broader patterns of meaning related to age, social roles, and their intersection with sex and gender. These memos were discussed in a third analysis meeting that involved creating a visual 'map' to represent a collective account of the participants' pathways, roadblocks, and detours to a clinical diagnosis of autism and to refine and name the themes.

Results

A variety of factors contributed to roadblocks and detours to earlier recognition, referrals, and diagnosis of autism and are categorized as: (1) age of pre-diagnosis 'red flags' and 'signals'; (2) 'non-autism' mental health diagnoses first; (3) narrow understanding of autism based on male stereotypes; and (4) unavailable and unaffordable diagnostic services. Quotes from the transcript data were selected to illustrate analytic points and edited for clarity. Pseudonyms are used for all participant quotes.

Age of pre-diagnosis 'red flags' and 'signals'

The age at which pre-diagnosis 'red flags' and 'signals' led to consideration of autism varied for girls and women in this study with the age of diagnosis ranging from 2 to 61 years old (see Table 1 for age ranges). Approximately half of the girls and women were diagnosed before 16 years of age and half after 16 years of age (16 and 18 participants, respectively). For some participants, signs of autistic traits may have gone unnoticed or were attributed to something else (e.g. mental health, learning disabilities) at younger ages and autism was not considered until they were older. For other participants, they were functioning well, or appeared to be functioning well, up to a certain age then began to experience challenges with social behaviours and roles later in their lives. The girls and women were less likely to be considered for autism as they aged unless and until they experienced significant challenges with functioning in their daily lives. In essence, autism was less likely to be considered and more likely to go unrecognized as the girls and women aged.

Recognition and diagnosis of autism occurred early during the toddler years for some participants. They described themselves as having been quiet and reserved as young children and did not interact or engage with their parents or other children in expected ways for their age, which led to their parents seeking consultations from a family doctor or paediatrician and a diagnosis by 2 years of age. For example, as Simone explained,

> I was quiet. I wasn't reacting like the other kids. So they [her parents] thought they'd check it out, and then that's when they were told. (Simone, diagnosed at 2 years old)

Thus, her parents had noticed developmental and behavioural differences compared to other children, which led to a clinical autism assessment and diagnosis early in life.

For other participants, 'red flags' and 'signs' of autism occurred later along their developmental and social role trajectories. They talked about being diagnosed during their primary and elementary school years (between 4 and 13 years of age) when demands for academic performance and social interactions (e.g. with peers and teachers) increased. Several girls experienced academic challenges compared to their peers, despite being considered capable of learning the material. Martha, one of the parent participants, described the pathway to her daughter's diagnosis and the 'red flags' that arose in school:

> We had put her in French immersion and she was sort of a flunk out, which was – I'm going to tell everything very positively – those are wonderful red flags. We've got a bright kid flunking out of something that shouldn't be happening. Why is this happening? (Martha, mother of Jenny, diagnosed at 11 years old)

From Martha's perspective, there was a mismatch between her daughter's capabilities as a 'bright kid' and her performance in school. Likewise, several autistic participants described themselves as intelligent and advanced in reading and academics in childhood, as did parent participants of their daughters. Yet, they also described struggling to keep up academically with peers, even receiving failing grades in some cases, when pressures and demands for learning performance increased.

Several parent participants discussed their child's challenges with peer interactions in school, which manifested in several ways, such as 'turning away from peers' (Carol, mother of Hayley, diagnosed at 11 years old), being explicitly bullied and excluded by peers (Jane, mother of Rachel, diagnosed at 12 years old), or playing alone during recess (Steven, father of Caitie, diagnosed at 11 years old). Steven explained the circumstances leading to further assessments for his daughter Caitie:

> She fell into a bit of a depression by first grade and so we were starting to see these signals that something wasn't quite right and it seemed to be focused around self-regulation and social skills. So then, . . . I'd get a call saying that Caitie's in the principal's office. (Steven, father of Caitie, diagnosed at 11 years old)

Thus, Caitie's social skills and behaviours in school signalled that she was experiencing difficulties starting in first grade (at approximately 6 years old), which persisted. Although they sought help, Caitie did not receive a clinical diagnosis until she was 11 years old. All of the parent participants talked about noticing or teachers noticing their daughter's mental health and/or social interaction challenges at school, which flagged referrals for specialist consultations (e.g. psychology). However, these referrals did not always directly result in an autism assessment and diagnosis.

Significant social and academic challenges were experienced for the first time in high school or in post-secondary education for some participants. These girls and women discussed having more struggles with the social aspects of student life and with academic performance compared to their experiences in elementary school. In addition, sensory aspects of larger educational institutions played a role in their wellbeing. For example, Sandra, a focus group participant described her experiences in high school:

> My mood just kind of slid lower and lower until like eventually I hit high school and . . . between like the sensory stuff, cause I was in a really big school that year. {Ellen: yeah} and so I couldn't deal with the sensory stuff. I hadn't received a support for executive functioning needs I didn't even realize I have, and it just got really bad for me. (Sandra, diagnosed at 15 years old)

Sandra sought mental health supports related to the challenges she experienced with the sensory, social, and academic aspects of high school, and Ellen, another participant in the focus group, indicated having similar experiences. For these participants, challenges in the school context led to referrals for psychological assessments and an eventual autism diagnosis.

For other participants, autism was first considered in the context of work when they experienced challenges with the social aspects of working with managers and co-workers. For example, Sue talked about challenges she had with navigating social interactions in her workplace, which led to her seeking counselling supports and an autism assessment and diagnosis. Donna experienced a build-up of stress in her workplace, which she attributed to difficulties with social dynamics and interactions involving co-workers. As Donna explained,

> I lost it at work. And at that point from February to May the more that they [co-workers] were doing this, like they were isolating me and all the classic stuff. I was getting sort of worse and worse, I was feeling sort of suicidal, and that breakdown is what finally made people open their eyes and go okay, there's a problem here. And that's when they said we can't let you come back to work until you have an assessment, psychiatric assessment. (Donna, diagnosed at 51 years old)

Thus, social interactions in the workplace became significantly distressing for Donna. With the support of her employer, she was encouraged to seek further evaluation, which led to an autism assessment and diagnosis.

For the most part, autistic characteristics of girls and women from this study were unnoticed or unremarkable until later along their developmental and social role trajectories between childhood and adulthood. Autism was less likely to be considered along the clinical pathway as the girls and women got older and not until a significant event or challenge related to daily life functioning was experienced. Recognition and diagnosis of autism occurred when demands for social interaction, academic, or professional performance increased, often at points of life stage transitions (e.g. elementary school to high school, post-secondary school to work).

'Non-autism' mental health diagnoses first

Mental health and/or behavioural concerns were the initial reasons that several girls and women were referred for psychiatric or psychological consultations, which tended to direct attention to mental illness diagnoses rather than considering autism. Some referrals were made by a family doctor or paediatrician, while others were self-referrals. For example, Natalie, a parent participant, discussed consulting with her primary care provider about her daughter's experiences of 'anxiety', 'depression' and 'tantrums':

> We were having major tantrums where she would rage beyond belief, and then her anxiety became – we couldn't control it, and then she just fell into a huge depression. So we went to our doctor–she [family doctor] just said that maybe [name of hospital] can help you . . . after about five minutes of sitting with Megan they [hospital diagnostic team] asked her to sit down and called us in and said they thought she had autism. (Natalie, mother of Megan, diagnosed at 11 years old)

Autism had not been considered as a possible primary or co-occurring diagnosis for Natalie's daughter until the initial diagnoses and symptoms of anxiety and depression exacerbated and expressions of anger through 'tantrums' affected emotional and social wellbeing. Many of the participants described diagnoses of depression, anxiety, obsessive-compulsive disorder, bipolar disorder, eating disorders, and ADHD, among others, prior to being diagnosed with autism. However, many girls, women, and parents discussed how the initial diagnoses did not capture the full breadth of what was being experienced emotionally, psychologically and externally in daily life functioning and interactions. For example, Ada, one of the parent participants, talked about her daughter being diagnosed at first with attention deficit disorder (ADD), which Ada did not agree with but accepted in order to get help:

> She was formally diagnosed with ADD at second or third grade. I kept on saying she doesn't have ADD, but if you like that, then knock yourself out, call her ADD. As long as she gets an IEP [Individual Education Plan] and she's, you know, eligible for things. But she really – she has learning disabilities and she has Asperger's. The ADD, I don't think she had ADD. (Ada, mother of Tova, diagnosed at 19 years old)

Like Ada, several participants questioned the initial diagnosis and wondered about misdiagnosis or having another diagnosis, which led them to seek further consultation. Ada's experiences of seeking a diagnosis for her daughter reflected many participants' accounts. That is, the initial 'non-autism' diagnoses did not resonate with their experiences and daily life challenges. However, Ada recognized the benefits of having the ADD diagnosis, even if temporary, because it afforded access to educational supports and interventions that could assist Tova at school.

For some of the girls and women, the interventions to address the initial diagnoses did not help, were ineffective, or did not address the situational challenges they were experiencing in their daily lives. Sandra described her experiences with cognitive behavioural therapy (CBT) that had been recommended to address her low mood:

> Eventually my parents referred me to a psychologist . . . they kind of explained to the psychologist that I was experiencing some really low mood and she basically just said, oh yeah, she just needs cognitive behavioural therapy. So I did a few months of that, didn't really help. So then my parents took me to an actual psychologist [autism specialist] at [name of hospital], and the first thing they asked was, 'when was the last time she had an assessment?' So they issued assessment and I got diagnosed with Asperger's. (Sandra, diagnosed at 15 years old)

Sandra's parents sought a specialized assessment that resulted in a diagnosis of Asperger's because her low mood did not improve with the CBT intervention. Similar to Ada's daughter's experience, Sandra was referred by the attending healthcare provider for further specialized assessments when the initial diagnosis and related interventions did not improve her psychological or emotional state or the challenges she was experiencing. Many of the participants talked about their first diagnosis being a misdiagnosis and about autism being overlooked as an alternative or co-occurring diagnosis. Thus, there was a longer, indirect path to an autism diagnosis.

Narrow understandings of autism based on male stereotypes

Preconceived ideas about autism traits based largely on studies of boys and social stereotypes of 'male' presentations, combined with a lack of awareness of nuanced autism presentations seen more often in girls, contributed to experiences of being referred and diagnosed later in life. Participants discussed the ways in which their autistic characteristics presented in their daily lives, which did not align with prevailing stereotypes of autism. People in their lives (e.g. parents, friends) and professionals in their education and healthcare settings that they approached for support (e.g. teachers, psychologists, primary care physicians) did not consider autism as a possible diagnosis. Some of the girls and women talked about their parents not considering autism because their behaviours (e.g. being quiet, preoccupied with reading books) did not align with prevailing stereotypes of autism, and were considered positive and unproblematic. Amanda, a parent participant, described how people responded to her concerns about her daughter's behaviours:

> Because she was quiet and joyful a lot of the time . . . and because she didn't have a lot of sensory seeking activities, people kind of thought 'oh she's just a cute and quiet girl' . . . I think they were less likely to believe me because she was this smiley girl that looked cute. (Amanda, mother of Ava, diagnosed at 2 years old)

Amanda's example suggested that her daughter's behaviours were considered acceptable for girls and not indicative of a need for further evaluation. Thus, Amanda did not pursue further assessment, even though she had a hunch that there was something more underlying her daughter's behaviours that was in need of being recognized and addressed.

Several parents discussed bringing concerns about their daughters' development and behaviours to their family physicians, often numerous times, but the possibility of autism was dismissed or minimized. Carol described the challenges of ascribing autistic traits to her daughter's behaviours and a healthcare professional's ambiguity to do so:

> It wasn't clear. And there was no real strong repetitive behaviour per se . . . I think personally that he thought you've got parents who are researchers, PhDs, they're overthinking this, the child is fine and these are things she'll just develop, the parents are making more of this than they need to. That's the impression I got. (Carol, mother of Hayley, diagnosed at 11 years old)

In another example, Giselle talked about autism stereotypes playing a role in later recognition of autism for her compared to her sister:

> My sister got diagnosed first, but hers was the more stereotypical obvious case, and anytime, my dad would bring it up to doctor whatever, they just, yeah, they just never followed up on it cause I seemed like, you know, like normal, compared to my sister. (Giselle, autistic woman, diagnosed at 22 years old)

For several participants, gendered stereotypes and narrow ideas of autism contributed to whether or not further neurodevelopmental assessments for girls and women were considered.

In some situations, physicians completed a diagnostic screening and the girls did not meet diagnostic criteria. Participants discussed screening tools as not being specific enough to capture the way autism presented for them or for their daughter. For example, Amanda talked about her developmental paediatrician doubting autism as a diagnosis for her daughter:

Amanda: every year I walk out of that developmental paediatrician's office after doing the ADOS (ADOS refers to the Autism Diagnostic Observation Schedule, which is a standardized, semi-structured, interaction-based assessment of the key behavioural features of autism (e.g., communication, social interaction, play, restricted and repetitive behaviours) revealed during a one-on-one interaction with a trained assessor.) and they still tell me she is moderately autistic. I'm like, 'Really, but it's there'. But I guess because she's generally content and she actually wants to engage socially, so she's highly motivated to be engaged on her terms. She doesn't want to look at you when she's talking to you, when she's done talking to you she'll look.

Interviewer: So, she's not necessarily fitting a stereotype of autism?

Amanda: No not at all, and they play it off . . . If you asked her about does she point? . . . Does she use her body to express herself? Blah, blah, blah. Yes, yes, yes. But for some reason, because she's very happy and bouncy and the long hair and isn't she cute and she did answer my question, that they – even my community paediatrician last year said to me, 'Do you think I made the right diagnosis?' {sound of hand coming down on table} Are you serious? Yes! (Amanda, mother of Ava, diagnosed at 2 years old)

Thus, Amanda suggested that the screening and assessment tools were not sensitive to nuanced presentations of autism that may be more likely expressed by girls and women.

Unavailable and unaffordable diagnostic services

Availability and affordability of neurodevelopmental screening and assessment services became increasingly challenging as girls and women progressed across life stages, which contributed to when or at what age they were formally diagnosed with autism. Participants discussed accessing privately funded assessments when publicly funded options were unavailable or had long waitlists. For example, girls and women who were diagnosed during their school years (under 18 years of age) could potentially have accessed psychoeducational assessment services offered by public school boards, but there were long wait times. Parents discussed the high costs associated with private assessments as prohibitive, but, regardless, pursued this route because they felt it was necessary to explore a diagnosis and appropriate supports right away. Amanda explained her decision to seek a private assessment for her daughter:

> You know every day is important, especially at this age. I'm like 'we are losing time and I'm not going to lose any more time'. (Amanda, mother of Ava, diagnosed at 2 years old)

Like Amanda, several parent participants talked about the importance of a timely assessment to address concerns about their daughters' health and education, thus paid for a private neurodevelopmental assessment out-of-pocket or with assistance from their employment health benefit plans.

Women participants who were diagnosed after their formal public school years found it increasingly difficult to navigate the public healthcare system and locate counsellors and physicians who specialized in diagnosing autism in women. Through discussions with people familiar with autism or reading information on autism, these participants had an inkling that autism was a possible diagnosis and sought a formal assessment to confirm. However, they experienced financial barriers to paying for a private clinical assessment, even if they had coverage through private health benefits through their employers. As Becky explained,

> I know mine was over 5 grand and we did it over two years because of the health benefits on my plan was that you could get a certain amount of psychologists in one year and then so we did it we planned it November/December/January for that one reason. So that was one way to get around it was to get two years of benefits but it is expensive to get proper testing and yet that's the only way for me that I believed it. (Becky, autistic woman, diagnosed at 37 years old)

Like Becky, many adult women participants experienced obstacles to timely and earlier diagnosis, including lack of access to affordable or publicly funded autism screenings and assessments for adults, long waitlists for these assessments, and diagnostic services and tools not tailored to adult women.

Discussion

We examined what contributed to missed opportunities for earlier recognition of autism for girls and women along their pathways to a clinical diagnosis. Contributing factors to missed opportunities were: (1) the later age at which pre-diagnosis 'red flags' signalled autism as a possibility; (2) 'non-autism' mental health conditions being diagnosed first; (3) narrow understandings of autism based on male stereotypes directing attention away from autism presentations more common for girls and women; and (4) unavailable and unaffordable diagnostic services, particularly as girls and women aged. Autism was identified as a possibility when the girls and women experienced challenges with social roles (e.g. as a family member, friend, student, employee) and interactions within contexts (e.g. home, school, work) associated with their age and life stage. Within these contexts, behavioural differences (e.g. social interaction differences) compared to peers and challenges with interpersonal, school and/or work roles were noticed by girls and women themselves and/or by other people (e.g. parents, teachers, or employers).

As a neurodevelopmental condition, diagnostic features of autism should be present in early childhood. Despite this, many participants in this study were diagnosed in later life stages. The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5) criterion C for autism spectrum disorder specifies, 'Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)'.[27] The spirit of this criterion, especially the text in the parenthesis, recognizes that challenges can emerge in different (later) stages of life, which may lead to a diagnosis first given beyond childhood. Many autistic people who are clinically diagnosed with autism in adulthood represent a subpopulation with unique life experiences compared with those diagnosed in childhood, especially regarding having autism features recognized, experiencing autism-related challenges more prominently in later life stages, and challenges accessing autism diagnostic services.[28] Moreover, recent research suggests that girls and women diagnosed with autism using the Autism Diagnostic Observation Schedule (ADOS) may present with the characteristics that are closer to those of boys and men and may not be representative of autistic girls and women more broadly.[29] Thus, inclusion of lived experiences of autistic girls and women across the lifespan in this study enriches our understandings of what contributes to a later diagnosis of autism.

Autistic features going unnoticed by professionals, such as physicians, teachers, psychologists, or behaviours being considered unremarkable or acceptable, were a recurring point of discussion across the participants' accounts of their diagnostic experiences. It is possible that the challenges they experienced fell 'under the radar' or were subtle compared to their non-autistic peers, thus went unrecognized. While this suggests that the girls and women were missed or overlooked for an autism diagnosis early in life or that they were functioning well in their daily lives until certain point of life, it may also suggest that some of them had developed strategies, such as camouflaging or masking, to align with social expectations to behave in particular (neurotypical) ways in their cultural contexts. Such strategies may have been consciously or subconsciously developed in order to hide their autistic ways of being and interacting, even if these ways were not yet recognized as autism, and to fit in with social norms of non-autistic people.[17–21] Examples might include mimicking socially accepted gestures or facial expressions and learning to make or approximate eye contact during conversations. Research has suggested that masking is associated with mental health difficulties, such as anxiety, depression, low mood, and burnout,[17,21] as this impression management effort may be uniquely challenging for autistic people in neurotypical contexts.[20] Many of our participants talked about being diagnosed with a mental illness prior to being diagnosed with autism. They might have been 'doing well',[30] or appeared to be, until they experienced a mismatch between their autistic ways of being and the social expectations for their roles and functioning (e.g. school, work). Camouflaging or masking may have played a role in being recognized for an autism diagnosis later in life and may also be associated with mental health difficulties. Thus, it is important for diagnosticians to have tools for exploring camouflaging and masking and for assessing mental health in the context of autism assessments for girls and women at all ages and life stages.[7]

The later age of many of the girls and women for pre-diagnosis 'red flags' leading to a diagnosis compared to boys and men resonated with recent health science research examining sex/gender differences for autism.[9–15] While this might suggest that clinical presentations of autism came to light later in their lives, it might also suggest that autism was not recognized earlier because there was a 'bend' towards male and childhood presentations in diagnostic criteria and practices. In other words, there may be implicit assumptions about sex and gender, as well as age/generation, underlying the ways in which autism is conceptualized, recognized, and diagnosed. Moreover, neurotypical norms for social roles and behaviours and their development are the reference points for identifying atypical behaviours and development categorized as autism. In this regard, autism may not have been recognized earlier if girls were 'doing well' or functioning within gendered neurotypical norms and expectations, or appeared to be doing so (e.g. through masking or compensation), or if there was a good person-environment fit.[20] Autism may have been recognized later in their lives because they were no longer functioning within gendered neurotypical norms and expectations, there was no longer a person-environment fit, and/or interventions for other diagnoses (e.g. mental health) inadequately addressed the health problems they were experiencing. Together, assumptions about sex, gender, age, generation, and neurotypical norms for behaviours may function together to shape particular representations of autism associated with childhood and/or boys and men. Embedded in diagnostic tools and practices, these implicit assumptions may direct attention away from presentations more common for girls and women (as well as for gender-diverse people) across the lifespan. This is not to suggest a purposeful neglect of diverse autism presentations by health professionals, but rather that diagnostic practices underpinned by prevailing representations of autism may inadvertently pose disadvantages for girls and women who seek clinical diagnostic services and help.

Assuming that earlier recognition of autism would have been beneficial for girls and women, rethinking and revising current assessment tools and practices as well as clinical training around autism are needed – especially in raising awareness of both contextual factors affecting clinical practices (many of them gendered) and nuanced autism presentations of individuals of different sexes and genders. For example, enhanced assessment practices by clinicians could include sex-informed and gender-informed questions and taking histories of person-environment fit across diverse settings over the life course. At the health systems level, availability and affordability of autism assessment services for adults should be addressed.[31] This study was conducted in Ontario, Canada, where publicly funded autism assessment services are available but limited for adults (over 18 years of age) compared to children. Even when private assessment services are available, the fees can be costly and prohibit people and families from being able to pay out of pocket or their extended health benefits through their employers do not cover them. Earlier autism recognition could afford opportunities for girls and women to access services and supports (e.g. peer supports, psychoeducation, mental health services, and therapies) tailored to their autistic characteristics and experiences and potentially prevent social, academic and work challenges, as well as repercussions due to extensive efforts to fit into gendered contexts and expectations.[27]

Predominant representations of autism as a childhood diagnosis for mostly boys contributed to girls and women not being considered for autism. Many clinicians have noted differences, albeit subtle, in autism presentations modified by sex and gender. For example, girls tend to be more motivated to be social, mask their autistic characteristics to fit in, and have more internalizing and less externalizing expressions of autism compared to boys.[7,32–34] Yet, subtle differences in autism presentations of girls and women may not be recognized by clinicians, educators, family members, or girls and women themselves.[35–38] Moreover, standard or some autism screening and assessment tools may not capture such differences.[7,39] Thus, subtle and nuanced presentations of autism may go unrecognized for girls and women, which may also be true for some boys, men and gender-divergent peoples. It is important to expand on behavioural exemplars of autism across sexes and genders.[3] Working closely with autistic girls and women and their families, future research can expand on knowledge about gendered experiences and exemplars across the life course.

Our participants' experiences of encountering obstacles to being recognized clinically as autistic (and getting an autism diagnosis) corresponds well with empirical evidence that girls and women often need to present with more pronounced autistic characteristics, or more psychiatric or developmental challenges, to be clinically recognized or diagnosed with autism compared to boys and men.[4,39–41] For this reason, targeted training of key people (e.g. developmental paediatricians, family physicians, mental health professionals, teachers) about gendered and contextual presentations of autism across the lifespan can support earlier identification. An important step for building capacity for earlier recognition and referral for autism assessments is to increase awareness of the diverse and nuanced presentations of autism across sexes, genders, ages, and life stages. For example, continuing education initiatives (e.g. workshops, online modules) for 'first contact' health and education professionals and students in professional training programmes can help to dismantle preconceived ideas of autism based on male- and child-centred stereotypes and barriers to autism assessments for girls and women. Mental health service providers may need training to incorporate autism screenings into their assessments for mood disorders, ADHD, and other mental illnesses and to consider autism as a possible diagnosis. Equipped with an autism 'lens' on behavioural differences and interpersonal, academic and work challenges that girls or women may be experiencing can assist health and education professionals in making observations through this lens and asking girls and women about their subjective experiences across life stages and contexts.

Considerations

The primary data were not generated with the specific research question for the secondary analysis in mind. For this secondary analysis, data from the primary study were combined, taken as a whole, and treated at face value. It is important to highlight that interviews and focus groups produce data differently, thus another approach to analysis could involve theorizing the data with a lens on its production.[42] This might involve examining how prevailing discourses and assumptions about sex, gender, and autism shaped how participants talked about and interpreted their experiences, as well as how the researchers interpreted these experiences across the interview and focus group data, and theorizing the data as being produced interactionally through each method.

The data included rich qualitative descriptions of 34 participant accounts of their healthcare and diagnostic experiences, which offered sufficient information power[43] and insights into what contributed to missed opportunities for earlier diagnosis. For inclusion in this study, participants self-reported that they (or their daughter) had a clinical diagnosis of autism. Further work needs to examine the relevance and transferability of the results for understanding the diagnostic 'roadblocks' and experiences of autistic girls and women who were not included in this study, that is, autistic girls and women with intellectual disabilities, profound autism, and/or psychotic disorders, or self-diagnosed. Data from self-diagnosed autistic women were not included as our interest was in examining experiences leading to a clinical diagnosis and they were not necessarily seeking a clinical diagnosis. Future studies might explore their decisions to self-diagnosis, and if this was related to experiencing barriers to clinical assessments.

Considerations for future research include advancing conceptual and methodological approaches to understanding sex and gender, particularly in non-binary ways, and critically examining the rationales for and effects of inclusion criteria based on assigned-sex-at-birth (e.g. AFAB, assigned male at birth (AMAB)) and/or gender identities (e.g. women, men, gender-diverse people). Our analysis also raises questions about the ways in which prevailing social assumptions about sex and gender shape how autistic differences are experienced, viewed, recognized, and addressed. Examining social experiences of autism from neurodiversity and critical social science perspectives may also offer insights for re-envisaging diagnostic practices in ways that place more emphasis on social context and less on an individual's assumed deficits.

Conclusion

Professionals providing developmental, mental health, educational, and/or employment supports can be more attuned to the subtle and nuanced presentations of autism and autistic characteristics that may be coming into play when girls and women experience challenges in their daily life contexts, even if these challenges are not or were not previously experienced in other contexts. Future research in collaboration with autistic girls and women can help to identify examples of subtle and nuanced autistic features, how they are experienced and navigated by girls and women in their daily lives, how such features are perceived, understood, or misunderstood by potential referral sources for clinical recognition, and how and when a referral for an autism diagnosis would be helpful.

Declarations

Ethics approval and consent to participate

Research ethic approval for this study obtained from Centre for Addiction and Mental Health Research Ethics Board (REB #047/2017). Informed consent to participate was obtained verbally and in writing from all participants.

Consent for publication

The authors affirm that participants provided informed consent to publish de-identified and aggregated data.

Author contribution(s)

Yani Hamdani: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing.

Caroline Kassee: Conceptualization; Data curation; Formal analysis; Methodology; Project administration; Writing – review & editing.

Meaghan Walker: Conceptualization; Formal analysis; Methodology; Project administration; Writing – review & editing.

Yona Lunsky: Conceptualization; Formal analysis; Writing – review & editing.

Brenda Gladstone: Conceptualization; Formal analysis; Methodology; Writing – review & editing.

Amanda Sawyer: Conceptualization; Formal analysis; Writing – review & editing.

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