

Chapter #14

AN INSIDER'S PERSPECTIVE: THE EXPERIENCE OF PARENTS AND GENDER VARIANT YOUTH WITH AUTISM SPECTRUM DISORDER

Wallace Wong¹, Jaime Semchuk², Veronique Nguy², & Melissa Jonnson³

¹*Diversity Emotional Wellness Centre, Canada*

²*University of British Columbia, Canada*

³*Simon Fraser University, Canada*

ABSTRACT

While a growing body of research has documented the co-occurrence of autism spectrum disorders (ASD) and gender variance, only a handful of published studies have investigated the perspectives and experiences of gender variant youth with ASD. Current clinical care guidelines for this population have generally been obtained through expert knowledge and fail to consider the perspectives of key stakeholders with an insider perspective such as youth and their caregivers. As such, two semi-structured focus-groups and an individual interview were conducted to explore the experiences and perspectives of four gender variant youth with ASD and three of their parents. Interviews were transcribed and analyzed for themes. This study seeks to increase our understanding of this population, identify avenues for future research, and contribute to improving the quality of clinical services for gender variant youth with ASD.

Keywords: gender variance, autism spectrum disorders, gender identity, access to services, youth perspectives, parent perspectives.

1. INTRODUCTION

Accumulating research indicates that children and adolescents with co-occurring autism spectrum disorders (ASD) and gender variance (GV) are identified at higher rates than would be expected by chance (de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Dorelihers, 2010; Skagerberg, Di Ceglie, & Carmichael, 2015; Janssen, Huang, & Duncan, 2016; Shumer, Reisner, Edwards-Leeper, & Tishelman, 2016; van der Miesen, Hurley, Bal, & de Vries, 2018). Studies investigating rates of clinical ASD diagnosis in youth referred for gender-related treatment suggest a co-occurrence rate of 6.3 to 13.3% (de Vries et al., 2010; Holt, Skagerberg, & Dunsford, 2016; Nahata, Quinn, Caltabellotta, & Tischelman, 2017; Shumer et al., 2016). However, recognition of this comorbidity is fairly recent and, as such, research with this population is in its infancy.

The American Psychological Association (2015) has identified a significant gap in research related to the quality of treatment approaches with transgender and gender nonconforming people, especially youth. The clinical assessment and treatment of gender-variant children and youth with ASD can prove even more complex due to the developmental challenges associated with ASD (de Vries et al., 2010; Strang et al., 2018a). Recently, clinical care guidelines for this population were developed by obtaining consensus among professionals with expertise in the field (Strang et al., 2018a). However, these guidelines lack the contribution of expertise afforded by those with lived experience. To our

knowledge, there are only a handful of studies to date that address the clinical needs, perspectives, and experiences of gender-variant youth with ASD (Strang, et al., 2018a; Strang et al., 2018b) or of their caregivers (Katz-Wise, et al., 2017a; Katz-Wise et al., 2017b; Kuvlanka, Mahan, McGuire, & Hoffman, 2018; Kuvlanka, Weiner, Munroe, Goldberg, & Gardner, 2017).

To better understand and provide effective clinical services for this population, it is important to learn about the perspectives of key stakeholders with an insider perspective (Strang et al., 2018a; Strang et al., 2018b). The present exploratory study aims to identify avenues for future research by asking the following questions: 1) what are the experiences of gender-variant youth with ASD related to understanding their identities and accessing clinical services and 2) what are parents' experiences when accessing clinical services for these children and youth?

2. BACKGROUND

It is important to distinguish between GV and gender dysphoria (GD). GV occurs when one's gender identity or expression is incongruent with their sex assigned at birth (Strang et al., 2018a). Youth who experience this incongruence may identify as transgender, gender nonconforming, gender non-binary, or another identity. GD, on the other hand, is a diagnostic category referring to the distress that sometimes accompanies GV (American Psychiatric Association, 2013). GD can often be ameliorated through therapy and/or other interventions such as social transitions, gender affirmative therapy, skill-building strategies, hormone therapy, and gender affirming surgeries.

Mechanisms leading to the co-occurrence of ASD and GV are unclear. Some research suggests that ASD and GV might be simultaneously influenced by developmental processes related to high birth weight (VanderLaan, Leef, Wood, Hughes, & Zucker, 2015). Other research indicates the GV may be associated with neurodevelopmental and childhood psychiatric disorders more generally, rather than with ASD specifically (May, Pang, & Williams, 2016). Although GD and ASD are both more prevalent in natal males than natal females (American Psychiatric Association, 2013), it is unclear whether rates of comorbid GD and ASD differ across assigned sex.

Regardless of the processes underlying ASD-GV comorbidity, many gender-diverse youth with ASD report that they first became aware of their gender nonconformity in elementary school or earlier (Strang et al., 2018b). Consistent with research on GV in children without ASD, initial signs of GV in those with ASD include a preference for spending time with children of the other gender, an interest in cross-gender activities and clothing, and an aversion to clothing associated with their sex assigned at birth (Strang et al., 2018b). Research involving youth who have co-occurring ASD and GV also suggests that, although GV desists over time for some youth, it persists and/or intensifies for others (de Vries et al., 2010; Strang et al., 2018b).

Interviews with youth highlight a complex relationship between GV and ASD such that each interacts with and informs the other. For instance, some youth with both conditions report that their ASD symptoms make it challenging to communicate about their gender nonconformity with others (Strang et al., 2018b). Clinicians have also noted that characteristics associated with ASD, such as concrete thinking and limited self-awareness, may delay and/or distort some youths' recognition and understanding of their GV (Strang et al., 2018a). Conversely, some youth note that gender nonconformity can exacerbate the social challenges associated with ASD and heighten the risk for discrimination (Strang et al., 2018b). They also point out that a diagnosis of either GD or ASD may increase the likelihood

that the other diagnosis will be undetected or dismissed by others (Strang et al., 2018a; Strang et al., 2018b). Finally, some youth emphasize that co-occurring GV and ASD can foster resilience (Strang et al., 2018b).

Few studies have sought opinions from caregivers of gender-variant youth (Katz-Wise, et al., 2017a; Katz-Wise et al., 2017b; Kuvalanka et al., 2017) and, to our knowledge, only one has involved parents of gender-variant youth with ASD (Kuvalanka et al., 2018). The latter study interviewed three mothers of gender-variant children with ASD and identified themes in their narratives. One theme related to worries about their child being ostracized due to their co-occurring GV and neurodiversity, while another theme related to doubts about whether their child's ASD was influencing their GV (Kuvalanka et al., 2018). Such concerns initially prevented the mothers from fully embracing their children's gender transitions. The mothers also highlighted that the co-occurrence of ASD and GV made it difficult to disentangle the sources of their children's social and emotional difficulties.

In sum, prior research highlights that gender-variant youth with ASD face a variety of unique challenges. However, research on youth and caregiver perspectives is limited. As such, more information is needed to identify the existence of important phenomena and chart a course for future research (Institute of Medicine, 2011). Including the perspectives of GV clients themselves is crucial if we wish to develop effective and ethical clinical guidelines and treatments (American Psychological Association, 2015). In addition, most relevant studies to date have been conducted in the United States; studies from other countries are needed to determine whether prior results are generalizable. The present study adds to the prior literature by exploring the perspectives of four transgender youths with ASD, as well as three of their parents, who were accessing clinical services in Canada.

3. PARTICIPANTS AND METHODS

All participants and their parents were recruited from a community-based mental health services clinic in the Lower Mainland of British Columbia, Canada, using both convenience and purposive sampling methods (Table 1). All participants who met inclusion criteria at the time: 1) between ages 12 to 19, 2) identified as gender variant and had a diagnosis of ASD, and 3) had reasonable verbal skills to participate, were recruited as part of this study. While twelve families were initially identified and invited to participate, only four participants (25%) responded and agreed to take part in this study. The current sample represented several ethnic groups, including African Canadian, Caucasian-white, and Aboriginal. Informed consent was obtained from each participant and their legal guardian to take part in the study. Participation was voluntary and no compensation was provided. This study was conducted in March 2018 using a qualitative semi-structured interview format. Two separate focus groups were initially conducted with three of the participants and their parents; a separate interview was conducted individually with another youth who also wished to participate, but was unavailable during the time of the initial focus group. All interviews were audio recorded, transcribed, and analyzed for emergent themes using qualitative thematic analysis (Braun & Clarke, 2006).

Table 1.
Participant Demographics.

Participant	Age	Gender Identity	Diagnosis	Parent
Participant 1	13	Transgender Female	Pervasive Developmental Disorder-Not Otherwise Specified	Mother
Participant 2	16	Transgender Male	Autism Spectrum Disorder	Mother
Participant 3	17	Transgender Female	Asperger’s Syndrome	Father
Participant 4	19	Transgender Male	Asperger’s Syndrome	Unavailable

4. RESULTS

4.1. Youth perspectives

4.1.1. Understanding gender identity

Participants discussed their **self-awareness** of their gender identity and indicated their transgender identity was something that felt innate to them. For instance, one participant stated, “It is something I’m born with. It wasn’t something I chose to be...I can’t force myself not to be transgender. Either you are or you’re not. That’s the best I can describe it.” Participants also identified **challenges describing their gender identity to others**. The fluid nature of gender made it difficult for participants to communicate with others about their transgender identity. As one participant described, “Because I take things so literal - gender can sometimes be very fluid and vague, the definition, so it’s kind of hard to tell people how you feel.”

4.1.2. Understanding autism spectrum disorder

During interviews, participants highlighted the **perceived stigma and stereotypes** others attribute to ASD. One participant shared, “People think I’m just great with anything with science and math. And anything to do with socializing, I’m bad at. Like two extremes.” Relatedly, another participant stated, “Living with autism, it sucks. To be honest, just because of the fact you’re different from other people, you receive doubts from other people because they think you’re not mentally capable of comprehending things.” Due to perceived negative stereotypes, participants reported they were **unlikely to disclose their ASD diagnosis to others**. According to one participant, “No, I just mostly ignore it. I don’t talk about being autistic at all.”

4.1.3. Intersection of ASD and gender identity

Participants reported experiencing **invalidation of their transgender identity due to their ASD diagnosis**, including having others disregard their gender identity, or expressing disbelief. A participant shared, "Because people always assume because someone has a disorder like autism or something, they don't understand anything... just people trying to tell you how you are feeling, just assuming." Participants also identified the **benefits of having both ASD and a transgender identity**. For instance, participants perceived that living in their affirmed gender helped facilitate an increase in social interactions, addressing a deficit associated with ASD. Further, another participant indicated that symptoms of ASD helped them when facing mental health challenges related to their transgender identity, as illustrated in the following excerpt, "I think having Asperger's helped me with my transgender identity, especially during times you get depressed... I know having Asperger's made me stick with my schedule... it helped keep me going."

4.1.4. Navigating systems

Finally, participants identified **additional challenges** navigating systems when accessing clinical services related to their ASD and transgender identity. Specifically, communicating with professionals to access services, relying on others for help, and misunderstanding information all posed challenges for participants. A participant shared, "To be transgender you have to make a lot of phone calls with people you've never heard of... and having autism can be difficult. You have to rely on other people to help." However, participants also experienced **helpful supports** when accessing services. These supports included having parents who validated their child's gender identity and were willing to attend appointments with their children. One participant highlighted, "My mom was always with me at appointments because sometimes I wouldn't understand the doctor. She's known me a lot longer and she would know how to explain it to me." Other helpful supports included accessing services from professionals who were willing to simplify information and provide extra time during appointments. A participant suggested, "Definitely try to outline steps more clearly... try talking more slowly."

4.2. Parent perspectives

4.2.1. Challenges "find[ing] the right doctor"

All three parents expressed **challenges finding the right professional with expertise and experience** in ASD, gender-diversity and mental health for their child. One parent stated, "[We're] just having a little hard challenge finding the right doctor for transgender issues... but we just recently found another general practitioner (GP) for [our child] because the other one - her [original] GP - probably wasn't the right person, a person coming out of school and didn't really have any specific instances of what this is. Maybe we're better off finding someone who has done this before." Despite these challenges, parents highlighted the fact that **once they were able to find the right professional, they were usually able to move through the system and get connected to services quickly**. For instance, a participant shared, "I went to the family doctor and we got a referral to the [local] hospital... the hospital social worker contacted us and put us through... we got shipped in this direction quickly and got really good advice and [my child] continues to come and see counsellors here, which is great."

4.2.2. Improvement in mental health with appropriate clinical services

During the interview, parents consistently reported **improvements in their child's mental health after coming out**, receiving appropriate support(s) and/or working with the right professional(s). One parent stated, "Since she came out things have gotten so much better...the tantrum behavior has gone down, depression and anxiety and ability to focus...so many things have gotten so much better." Another parent shared, "In high school...[my child] started having anxiety and depression andshe was suicidal...so we went to the youth services and they put her on medication and [she] started getting better and then [my child] started coming to see [the gender health specialist]."

4.2.3. Professionals' tunnel vision approach to services

Parents expressed frustrations as they found professionals often **focusing on the treatment of one aspect of their child's problems** (e.g., attention deficit/hyperactivity disorder (ADHD), mental health, ASD) rather than seeing their child as a whole. One parent explained, "When [my child] gets to be a little anxious she has lots of sensory symptoms, and she really is quite mobile, she will bounce all over the room ... it was kind of frustrating because her mental health is getting worse and we're just piling on more Adderall, like you're clearly not listening ... she was clearly saying at this point, *I'm not a boy, I'm a girl*. There's no doubt in that statement. She would come home and have bite marks all over her arm and she wasn't eating...she would come home from her school and just throw on a tantrum for an hour. It was just the mental health issues were so big, and they were just like, *uh, no, ADHD*."

4.2.4. Unhelpful advice from professional

Some parents experienced professionals who gave them **unhelpful advice about their child**. One parent shared, "If you don't find someone who specializes in this, you never know what they're gonna say. I know a therapist, not an autism one, said, *just let her wear pink underwear and ignore the rest of it because she'll be okay*. Like finding someone who really specializes in the gender issues is so essential. It can be challenging."

5. CONCLUSION/DISCUSSION

Learning how to navigate the medical and mental health systems can be difficult and confusing, especially for this special population. The findings from this study reveal some of the specific challenges youth and their parents face when accessing gender- and ASD-related services. For instance, despite having a clear understanding of their gender identity, the youth in this study found it challenging to explain their identity to others. Indeed, youth participants' greatest challenges were caregivers', professionals', and the public's lack of understanding of their intersecting transgender and ASD identities. Youth with ASD commonly experience challenges with social communication, which could contribute to challenges discussing one's identity (American Psychiatric Association, 2013). This communication deficit may lead some caregivers or professionals to underestimate these youths' ability to understand their gender identity. Additionally, others may question the authenticity of a transgender identity for a youth with ASD. As such, some trans-youth with ASD reported that they were unlikely to disclose their ASD diagnosis to others, fearing that it may negatively impact their ability to access services for their gender dysphoria. However, when a transgender youth with ASD withholds such information it may, at times, limit services and impede opportunities for them to receive specialized services and appropriate care.

In sum, both youth and parents found it challenging to navigate our medical system and access appropriate clinical services. Youth found comfort in having a supportive adult by their side during appointments, while parents struggled to find doctors with enough specialized knowledge and understanding of their child's complex needs. Collectively, participants' responses suggest that medical and mental health professionals may lack training and expertise in working with children who have complex neurodevelopmental and gender-health needs, which has the potential to affect the quality of services. However, once these families found the right professional, they were usually able to navigate the system and access appropriate services quickly. Therefore, additional education and training for healthcare professionals (and the general public) may be necessary and beneficial to address potential bias and misinformation that relates to this population. Professionals are encouraged to gain additional knowledge and awareness of their own biases to ensure that they can provide a sensitive and comprehensive approach to services.

We are clearly still in the infancy stage when it comes to determining the best treatment approach for GV youth with ASD. Although this study has its limitations, we believe that our results provide a starting point for future research to build upon as we learn more about transgender youth with ASD. A multi-disciplinary, wraparound approach to services may prove beneficial for these youth by providing them with more comprehensive and continuous care that is tailored to their complex needs (e.g., developmental, psychological, behavioral, medical, gender-related). Future studies should investigate the feasibility and efficacy of such an approach.

6. LIMITATIONS

The sample size of this study is small. Participants consisted of four transgender youth with ASD accessing publicly funded mental health and medical services. They all came from middle class families, had a basic level of family support and were under the age of twenty. Thus, the generalizability of our results to other transgender youth who are not accessing healthcare services, not supported by family, of different socioeconomic status, or older than nineteen years old is unknown. From a developmental perspective, our limited sample and variation in the age range further challenges our ability to generate themes related to developmental phases of this population (e.g., early adolescence versus emerging adulthood). Further, a larger sample size may have elicited different themes. That said, the current findings are relatively consistent with past research on youth with GV and ASD (Strang et al., 2018a; Strang et al., 2018b) and their parents (Kovalanka et al., 2018). In addition, given that GV youth with ASD are small in number, geographically-diverse, and hard-to-reach, it can be costly and impractical to recruit a large enough sample for quantitative analyses (American Psychological Association, 2015; Institute of Medicine, 2011). As such, although large, probability studies are needed, nonprobability samples can nevertheless yield valuable descriptive information and ideas for future research, especially when taken together with findings from other studies; specifically, nonprobability samples are important in the initial phases of studying a newly-identified phenomenon in order to generate hypotheses and identify potential relationships between variables (Institute of Medicine, 2011). Furthermore, considering the historical exclusion of transgender people from research, it seems unethical to exclude GV youth with ASD from future research due to their relative rarity in the general population. A final limitation of the present study is that the psychologist who acted as a focus group facilitator was also involved in supervising some of the participants' clinical treatment, which may have biased the responses of the participants who were also under his care.

7. FUTURE RESEARCH DIRECTIONS

To date, only a handful of studies have queried the perspectives of youth who experience concurrent GV and ASD. As such, future research should continue to explore the unique challenges faced by these youth and their families. However, most research with this population, including the current study, has been qualitative in nature. While qualitative approaches provide rich, nuanced data that facilitate exploration of understudied topics and populations, it is important to complement such research with quantitative and mixed-methods designs. Hence, future studies should aim to recruit larger samples that would enable such analytic approaches. Finally, there is currently no standard of care available to health professionals who work with this crossover population. Indeed, it is often up to professionals and parents to determine the best care approach for this vulnerable population. As such, there appears to be substantial variation in practices, and some crucial aspects of care may be overlooked (e.g., differential diagnoses). Therefore, it is imperative for future research to develop a structured, empirically-supported model for the assessment and treatment of youth with GV and ASD. Such guidelines will not only assist professionals, but also provide some direction to parents and guardians of youth who have concurrent GV and ASD.

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AUTHORS' INFORMATION

Full name: Wallace Wong, Dr., PsyD, R.Psych

Institutional affiliation: Diversity Emotional Wellness Centre, Canada

Institutional address: 212-2902 West Broadway, Vancouver, BC v6k 2g6

Short biographical sketch: Dr. Wallace Wong is a registered psychologist in both California and British Columbia. He has been working with the LGBTQ population since 1996. While he continued to work with the LGBTQ population, he has also worked especially with children and youth who present with different sexual health issues for 23 years. He currently works at the Ministry of Children and Family Development as a clinical psychologist of the Children and Adolescence Sexual Health Program (ACSH) and Gender Health Program (GHP). He also has a private practice where he sees children and youth with different sexual health issues. Dr. Wong has been doing research on topics of transgender children and youth for numbers of years, and they can be found in different professional journals. He is also an author of two transgender related children books called, *When Kathy is Keith*, and *It's So Gay and It's Okay*.

Full name: Jaime Semchuk, M.A.

Institutional affiliation: The University of British Columbia

Institutional address: 2125 Main Mall, Vancouver, BC, Canada, V6T 1Z4

Short biographical sketch: Jaime Semchuk is a Ph.D. Candidate from the School Psychology Program at the University of British Columbia in Vancouver, BC. From 2017-2019, she completed a practicum placement at the Ministry of Child and Family Development under the supervision of Dr. Wallace Wong where she provided clinical services to children and youth referred through the Adolescent Sexual Health and Gender Health Programs. Additionally, since 2016, she has worked as a school psychologist in an elementary school. Jaime has conducted applied and qualitative research focused on school-based mental health services, and the clinical service needs of gender diverse children and their families.

Full name: Veronique Nguy, M.Ed.

Institutional affiliation: The University of British Columbia

Institutional address: 2125 Main Mall, Vancouver, BC, Canada, V6T 1Z4

Short biographical sketch: Veronique Nguy is a doctoral student from the School Psychology Program at the University of British Columbia (UBC). Veronique worked as an Applied Behavior Analysis (ABA) therapist before completing her Master's degree in School Psychology at UBC. Veronique has been working in schools as a School Psychologist in British Columbia (BC) since 2012. Over the years, she has also worked in university clinics, hospital settings and private clinics in different roles and capacities. As a multilingual practitioner, Veronique's research focuses on understanding multicultural assessment practices of psychologists in BC. She has also recently completed her specialty practicum training with Dr. Wallace Wong at the Ministry of Children and Family Development, where she provided clinical services to children and youth referred through the Child and Youth Mental Health Clinic (CYMH), Children and Adolescence Sexual Health Program (ACSH) and Gender Health Program (GHP).

Full name: Melissa Jonnson, M.A.

Institutional affiliation: Simon Fraser University

Institutional address: 8888 University Drive, Burnaby, BC, Canada, V5A 1S6

Short biographical sketch: Melissa Jonnson is a doctoral student in the Clinical Psychology program at Simon Fraser University (SFU). Her research focuses on sexual and gender minorities, recidivism risk assessment, and intimate partner violence. She has published six peer-reviewed journal articles and presented her work at national and international conferences. She is also an ad-hoc reviewer for *Translational Issues in Psychological Science*. Clinically, she has worked with adolescents involved in the justice system, adults at risk for homelessness, children with selective mutism, and a variety of other clients in general outpatient settings. She is currently completing her second graduate-level practicum with the Ministry of Children and Family Development (MCFD), where she is providing assessment and treatment services to children and youth with mental health, sexual health, and gender-related concerns under the supervision of Dr. Wallace Wong.