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March 25, 2024

Autism and Gender Variance Co-occurrence

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2024

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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts with Honors

Biology

2024

Abstract

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The relationship between autism and gender variance (GV) is complex and needs further exploration. To fill the gap in the research, this study aimed to look at the number of GV individuals seeking an autism diagnosis by surveying autism diagnosticians on how many GV individuals they are assessing and diagnosing with autism. Through a qualitative and supplemental quantitative analysis, the authors found that clinicians are progressively seeing an increase in GV individuals presenting in their clinics and that there is a definitive need for further research into the co-occurrence. The authors also use the data to provide recommendations for the field and clinicians moving forward.

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Acknowledgments

Thank you to Dr. Allison Schwartz and Dr. Michael Morrier for your expertise, guidance, dedication, and willingness to take a chance on my project. Your help is deeply appreciated, and this paper would not be possible without you.

Thank you to Dr. Eladio Abreu and Dr. Stormy Pulver for serving on my thesis committee, I appreciate your time and commitment to helping me throughout this process.

Thank you to my friends for listening to me talk about this project for two years. I love you all!

Thank you to my parents and siblings for their unwavering support. Everything I am is because of you.

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Introduction

Autism

The American Psychiatric Association describes autism as “a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behavior” (Vahabzadeh, 2024). Recent studies on autism prevalence in the United States based on a 2020 national data sample with the US Centers for Disease Control and Prevention (CDC) found that approximately 2.78% or one in every 36 8-year-olds in America is diagnosed with autism. They also determined that autism is 3.8 times as prevalent in boys as it is in girls (Maenner et al., 2023). This statistic is based on tracking within 11 communities in the United States. Neither this study nor any other study conducted with this data set included data regarding individuals who identify as gender variant.

Gender Variance

Gender variance (GV) is an umbrella term used to describe any variation between the sex assigned at birth and gender identity, expression, or behavior consistent with culturally defined and expected norms of the gender an individual is assigned at birth (Janssen et al., 2016; Simons, 2014). The term includes those that are gender non-conforming (i.e., those that do not conform to the expectations of their gender assigned at birth), transgender (i.e., those that identify as a different gender than the one they were assigned at birth), nonbinary (i.e., those that identify with no gender or with certain parts of multiple genders), gender dysphoric (i.e., those that feel uncomfortable in their body due to their gender expression), and genderqueer (i.e., those that identify outside of the gender binary). While the total number of GV individuals in the United States is hard to ascertain, in June 2022, the Williams Institute at the UCLA School of Law

conducted a study finding that approximately 1.4% of youth age aged 13 to 17 in America identify as transgender and 0.5% of adults in America identify as transgender (Herman et al., 2022). Given that being transgender is one identity within the GV umbrella, the results of this study indicate a minimum approximate number of GV individuals in America. A second study by the Pew Research Center (Brown, 2022) attempted to estimate the number of transgender and nonbinary individuals in the United States and found that about 1.6% of US adults fall into that category. Additionally, data has been collected internationally regarding broad gender differences, resulting in similar findings. An international study that included a 27-country digital global survey collected 19,069 responses and reported that on average, “1% of adults describe themselves identify as ‘transgender,’ ‘non-binary/non-conforming/gender-fluid’ or ‘in another way’ rather than as ‘male’ or ‘female’” (Ipsos, 2021). This study included all types of GV individuals.

Previous Research on Autism and GV

The relationship between autism and GV is a topic of interest for both people who study gender and for the autism community. Recent research has shown an overrepresentation of GV among individuals with autism when studies were conducted at autism clinics, gender clinics, and through broad data collections (De Vries et al., 2010; Heylens et al., 2018; Strang et al., 2014; Warrier et al., 2020; Van Der Miesen et al., 2016). Initial studies aimed to discover if an overrepresentation or high correlation was present between GV and autism by looking at individuals already diagnosed with autism who were seeking support for GV at gender clinics. De Vries et al. (2010) sampled 204 children who were referred to a gender clinic in Amsterdam and reported that 7.8% of the individuals coming to the clinic were diagnosed with autism. This is much higher than the autism prevalence rate (without taking GV into account) in Northern

Europe, which was between 0.3% and 1.16% around the time of the study (Eisabbagh et al., 2012; Janssen et al., 2016). A similar study looked at gender clinic charts and reported that 6% of patient files assessed reported an autism diagnosis. This was sixfold higher than the rate of autism in the general population the study assessed (Heylens et al., 2018).

A second method to estimate the number of those with autism who also identify as GV looked at individuals diagnosed with autism first and then found how many of them reported GV. A significant number of studies (Janssen et al., 2016; Strang et al., 2014; van der Miesen et al. 2018) have looked at sex item 110 on the Child Behavior Checklist (CBCL)), which asks for the parent completing the form to confirm or deny that their child has expressed a “wish to be the opposite sex”. In one such study, researchers in the Washington DC metro area conducted a chart review of patients with neuro-developmental disorders and found that 5.4% of parents of children with autism reported that their child expressed a “wish to be the opposite sex” (Strang et al., 2014). This is 7.59 times higher than the 0–0.7 % of parents who reported GV for their neurotypical child. Similarly, Janssen et al. (2016) also looked at sex item 110 on the CBCLs of patients diagnosed with autism at the New York University Child Study Center in midtown Manhattan, New York City between January 2011 and January 2015. The study found that individuals diagnosed with autism were 7.76 times more likely to endorse sex item 110 than individuals from a control group who were not diagnosed with autism. Further, van der Miesen et al. 2018 had similar results as Strang et al. finding that adolescents (6.5%) and adults (11.4%) with autism endorsed sex item 110 more frequently than the general population (3–5%).

Another study conducted through an autism clinic looked at the rate of gender dysphoria (a form of GV) in a sample of the population diagnosed with autism. (Georgia & Stokes, 2018) George and Stokes (2018) found that gender-dysphoria was reported by individuals diagnosed

with autism at a significantly higher rate than typically developing individuals. George and Stokes (2018) contacted autism clinics to obtain data on individuals with autism and used word of mouth and social media (such as Facebook) to contact typically developing individuals. The results showed that the rate of gender dysphoria in the sample of individuals diagnosed with autism was 1.9%, which is approximately 135 times more than that found in the wider population (Zucker & Lawrence, 2009). They also found that the rate of reported non-conforming gender identities was 3.9%, which was approximately 20-40 times higher than prevalence estimates at the time of the study.

Finally, a third method looked at previously collected data in data banks to find out how many individuals identified as GV, how many were diagnosed with autism, and how many were both diagnosed with autism and identified as GV. Using data from five separate databases and literature reviews, Warrier et al. (2020) demonstrated that GV individuals were 3.03 to 6.36 times as likely to be diagnosed with autism compared to non-GV individuals.

Purpose of The Study

No published studies at the time of this paper have been conducted that look at the number of GV individuals seeking an autism diagnosis or surveyed diagnosticians directly to see approximately how many GV individuals they are assessing for and diagnosing with autism. It is necessary to expand the knowledge surrounding the relationship between GV and gender variance because recent research has shown an overrepresentation of mental health concerns in the adolescent population with both gender dysphoria and autism compared to the adolescent population with just autism or just gender dysphoria (Kahn et al., 2023). It is crucial that clinicians begin to understand the relationship between GV and autism so the mental health concerns of these patients can be addressed thoroughly and appropriately.

This study uses the International Collaboration for Diagnostic Evaluation of Autism (IDEA) members (referred to as participants here on out) as a representative group of clinicians who diagnose autism. The study's primary objective is to use data from clinicians who are members of IDEA to determine the total number of clients and the number of GV clients they assess and diagnose with autism. Using that data, the authors aimed to determine if GV individuals were being assessed for and/or diagnosed with autism at a higher rate than is representative of the GV rate in the broader population. Due to the recent COVID-19 pandemic, and its impact on direct services, the data was collected across two time periods: January 1, 2019 to December 31, 2021, and January 1, 2022 to present (the time the participant completed the survey). The study looks at correlation, not causation. Based on the results of this study, the authors provided recommendations for the field and next steps.

It was hypothesized that participants would assess a greater percentage of GV individuals than is representative of the population. It was also hypothesized that GV individuals were diagnosed relative to their intake rate at a higher frequency than the total population. This study aims to provide evidence of the need for additional research into the correlation between GV and autism.

Methods

Participants

Registered clinicians and researchers who perform diagnostic assessments of autism were contacted via email through the IDEA listserv and asked to complete a survey titled "Gender Variance and Autism: An Autism Assessment Survey" (referred to as 'the survey' from here on out). The IDEA listserv was comprised of approximately 500 clinicians, therapists, researchers, and autism clinic administrators at the time of the survey's administration.

Measures

The study was conducted via a survey consisting of twenty questions which can be broken down into four sections to answer the primary questions of the study: (section 1) participant biographical information, (section 2a) total number and total number of GV individuals seeking an autism assessment from January 1, 2022 to the time the survey was complete (present), (section 2b) total number of all individuals and total number of GV individuals who were diagnosed with autism by the participant for January 1, 2022 to the time the participant completed the survey (present), (section 3a and 3b) the same as section two but for the time period of January 1, 2019 to December 31, 2021, and (section 4) an open-ended comment section. The survey was designed to take no more than 20 minutes to complete.

Specifically, section 1 of the survey asked the participant for biographical information regarding country/region of employment, work setting, job title, and participation in a team to assess and diagnose autism. The region breakdown is modeled after the US Census Bureau (2021) state divisions. See Appendix A for the states included in each range. These questions were meant to make sure that the appropriate people were filling out the form, discern where participants are assessing and diagnosing the greatest/least number of GV individuals, and avoid data overlap. To protect the anonymity of the participants, no protected health information (PHI) was collected, including participant names and clinic names. Because of this, there is no way to be certain that individuals only completed the survey once or that participants from the same clinic did not report the same client twice. However, many steps were taken to avoid replicant data, including carefully combing through all the data to find replicant reports. Also, the survey specifies participants should only report on the cases in which were the primary assessor to prevent clients (i.e., the same data) from being reported twice.

Section two asked for estimated data regarding the total individuals that the participant assessed and diagnosed between January 1, 2022, to when the participant filled out the survey. The first series of questions (section 2a) requested information on the estimated total number of individuals seeking a diagnosis and the estimated total number of individuals diagnosed with autism. The second series of questions (section 2b) used the same questions as above but specifically requested information about GV individuals.

The questions regarding the number of clients were multiple choice and included ranges (e.g., 1-25, 26-50, etc.). Ranges were used to allow participants to estimate the number of clients they assessed/diagnosed as opposed to requiring exact numbers. This was intended to encourage participation by making it less burdensome for participants, especially when asking for past data. Additionally, many people do not keep records of the number of clients they assess or the number of GV clients they assess, so the ranges enable them to provide a rough estimate. See Appendix A for the ranges offered in each question. All the questions specified the time period in question and the specific population (total or GV) being queried. If a participant selected either 251+ or 10+ (i.e., the highest multiple-choice option depending on the question), they were branched to a separate question asking them to input their own approximation of the number of individuals they assessed or diagnosed.

The third section asked the same questions as part two but specifically for January 1, 2019, to December 31, 2021. This provided longer-term data, including pre-, during, and post-COVID-19 assessments. It also allowed the comparison of intake and diagnosis rates across time periods.

In the final section, section four, participants were told, “Please provide any additional comments,” and presented with an open box. The comments provided were used for a qualitative analysis of clinician experiences around the topic.

Procedures

The survey was field tested with three subject matter experts and edited according to their feedback. Institutional Review Board (IRB) approval (IRB ID: MOD002-STUDY00005470) was obtained. The survey was sent to the IDEA listserv, and all participants were required to “accept” the Emory IRB consent form without a signature before proceeding to the survey questions. The response goal was 80, but after three emails, (sent May 1st, June 1st, and August 8th of 2023) over three months, only 34 individuals of the approximately 500 people who were members of the IDEA at that time, consented to participate. With the limited dataset, a reverse power analysis revealed that section one data has a 90% Confidence Level (CL) and 14.7% Margin of Error (ME), section two data has a 90% CL and 15.5% ME, and section three data has a 90% CL and 20% ME. The study has low external validity because of the low response rate leading to a low confidence level and high margin of error. Additionally, a qualitative analysis is more reliable than a quantitative analysis of the data given the CL and ME.

The data was analyzed in three ways. The first was a descriptive qualitative analysis of the data from sections two and three. The second was a qualitative analysis of the comments provided in section four. The third was a quantitative analysis of sections two and three.

Qualitative Analysis of Sections Two and Three

First, a descriptive qualitative analysis was used to determine the GV assessment and diagnosis rates relative to the total assessment and diagnosis rates. A descriptive qualitative

analysis requires that the data is minimally transformed so there is low interference and no interpretation other than descriptive statistics (Kim et al., 2017).

The data was coded to be grouped by time period and then subdivided by Total Assessed, GV Assessed, Total Diagnosed, and GV Diagnosed. Then, the total number of participants who responded to each range for each subdivision was counted. The percentage of participants who responded to the question with each range was calculated (i.e., the number of participants that selected the range divided by the total number of participants included in the section).

Qualitative Analysis of Section Four

The second form of analysis was a qualitative analysis of section 4: the open-ended comments. The method for grouping and analyzing the comments is modeled after Hobson et al. (2022) and Boyatzis (1998). The comments were used to determine future recommendations for the field.

Quantitative Analysis of Sections Two and Three

Finally, a quantitative analysis was conducted as an alternative analysis for sections two and three. Following a thorough literature review, there does not appear to be a method or previous attempt to quantitatively analyze range data. As such, the authors took a cautious approach and recognized that the quantitative analysis method employed here is novel. Consequently, the data derived from the quantitative analysis is to be used to support the qualitative analysis. Participants were presented with ranges or, if they answered 10+ or 251+, the opportunity to provide their own estimate of the number of individuals they assessed/diagnosed. This proved challenging to analyze as ranges do not allow for typical statistical tools to be used. The authors attempted to transform the data into analyzable numbers using two different methods: calculating a “range percent” (explained below) and a “range

average” (explained below). The range percentages and range averages were each used to answer the question: what percent of the total individuals who were assessed for autism were GV? The range averages were also used to answer the question: what is the percentage of the total individuals and the percentage of GV individuals being assessed for autism who were diagnosed with autism?

Quantitative Approach One: Range Percent. A range of values was calculated to determine the percentage of people who were assessed for autism who were GV. To obtain this range for each participant, the highest number in the range from the “total assessed” was divided by the lowest number in the range from the “GV assessed” - this provided the minimum value (i.e., smallest possible percent assessed given the multiple-choice range option selected). Then, the lowest number in the range from the “total assessed” was divided by the highest number in the range from the “GV assessed” - this provided the maximum value (i.e., largest possible percentage assessed given the multiple-choice range option selected). For this paper, the calculated range is called the “range percentage”. See Figure 1 for a sample calculation.

Figure 1

Sample Calculations: The Minimum and Maximum Values of the Percentage of Clients Diagnosed with Autism Who Were GV

Sample Calculation: Participant X for 2022-Present period

Number of total individuals assessed for autism: 76-100

Number of GV individuals assessed for autism: 8-9

$$\text{Maximum Value: } \frac{\textit{Highest GV}}{\textit{Lowest Total}} = \frac{9}{76} = 11.8\%$$

$$\text{Minimum Value: } \frac{\textit{Lowest GV}}{\textit{Highest Total}} = \frac{8}{100} = 8.0\%$$

Note. The calculations were repeated for each participant in each time period.

Quantitative Approach Two: Range Average. Approach two answers the same question as the first quantitative approach but uses a different method of determining the percentage of GV individuals that were assessed by each participant. The average of the ranges (e.g., 1-25 was averaged to 13) was calculated for each range selected for questions in sections two and three. This number for each range is called the “range average.” The range average for the number of GV individuals assessed was divided by the range average for the number of total individuals assessed. This provided the percentile of the total individuals assessed who were GV.

Quantitative Approach Three. Calculations were done to determine the percentage of the total individuals and the percentage of GV individuals being assessed for autism who were diagnosed with autism for each participant. To obtain a range of values for each participant, the highest value in the “assessed” range was divided by the lowest number in the “diagnosed” range – this provided the minimum value possible. Then the lowest value in the “assessed” range was divided by the highest value in the “diagnosed” range – this provided the maximum value. See

Figure 2 for a sample calculation. These calculations were interpreted based on the cutoff of 50% and 100% of participants' clients. The percentages 50% and 100% were chosen as markers because 50% shows that more than half of the assessments resulted in diagnoses, and 100% represents the maximum diagnosis rate. This data was used to determine if participants were diagnosing GV individuals with autism at a higher rate than the total population relative to their assessment rates.

Figure 2

Sample Calculations: The Minimum and Maximum Values of the Percentage of Clients

Diagnosed with Autism

Sample Calculation: Participant X for 2022-Present period	
Number of total individuals assessed for autism: 76-100	
Number of total individuals diagnosed with autism: 51-75	
Number of GV individuals assessed for autism: 8-9	
Number of GV individuals diagnosed with autism: 4-5	
Maximum Value (total population):	$\frac{\textit{Highest Diagnosed}}{\textit{Lowest Assessed}} = \frac{75}{76} = 98.7\%$
Minimum Value (total population):	$\frac{\textit{Lowest Diagnosed}}{\textit{Highest Assessed}} = \frac{51}{100} = 51.0\%$
Maximum Value (GV):	$\frac{\textit{Highest Diagnosed}}{\textit{Lowest Assessed}} = \frac{5}{8} = 62.5\%$
Minimum Value (GV):	$\frac{\textit{Lowest Diagnosed}}{\textit{Highest Assessed}} = \frac{4}{9} = 44.4\%$

Note. The calculations are shown for the total population and the GV clients. The calculations were repeated for each participant in each time period.

Results

Participants

Initially, 34 participants completed the consent form, but only 31 completed demographic data (i.e., section one), and only 30 were included in the analysis. Of the 34 participants, three were excluded because they did not complete the consent form, and one participant endorsed that they did NOT diagnose according to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR; American Psychiatric Association, 2022)* or the *International Statistical Classification of Diseases and Related Health Problems, Eleventh Edition (ICD-11; World Health Organization, 2019)*. Of those 30, 27 participants were included in section two data analysis. Three participants were excluded from section two because they did not work at the same job for the time period specified (i.e., 2022 to present). Of those 27, 17 participants were included in section three data analysis. Ten individuals were excluded from section three because six of them did not work at the same job for the time period (i.e., 2019 to 2021), three exited out of the survey before it was complete, and one reported assessing zero individuals during that time frame. Section four was completed by six participants. One comment was excluded from the analysis of section four because the content was not relevant to the study's goals. The comment said: "Looking forward to seeing the results." See Appendix B for a chart showing the inclusion and exclusion of participants for each section of the survey.

Of the 30 participants that were analyzed for section one, two participants (6.67%) were located abroad, nine (30.00%) were located in the Mountain region, five (16.67%) were in the West South Central region, four (13.33%) were in the South Atlantic region, three (10.00%) were in the West North Central region, three (10.00%) were in the Pacific region, two (6.67%) were in the East North Central region, one (3.33%) was in the Middle Atlantic region, and one (3.33%)

was in the United States (unspecified). Regarding professional settings, twelve (40.00%) participants reported working in a hospital, ten (33.33%) in a university, four (13.33%) in private practice, one (3.33%) in an academic health center, one (3.33%) in a community mental health center, one (3.33%) in a non-profit organization, and one (3.33%) in a non-profit clinic. With regards to sex and gender, only three of the thirty participants included in section one identified as male (10.00%), the remaining 27 (90.00%) identified as female, and all 30 (100.00%) identified as the same sex that they were assigned at birth. See Appendix C for charts depicting the demographic data for section one.

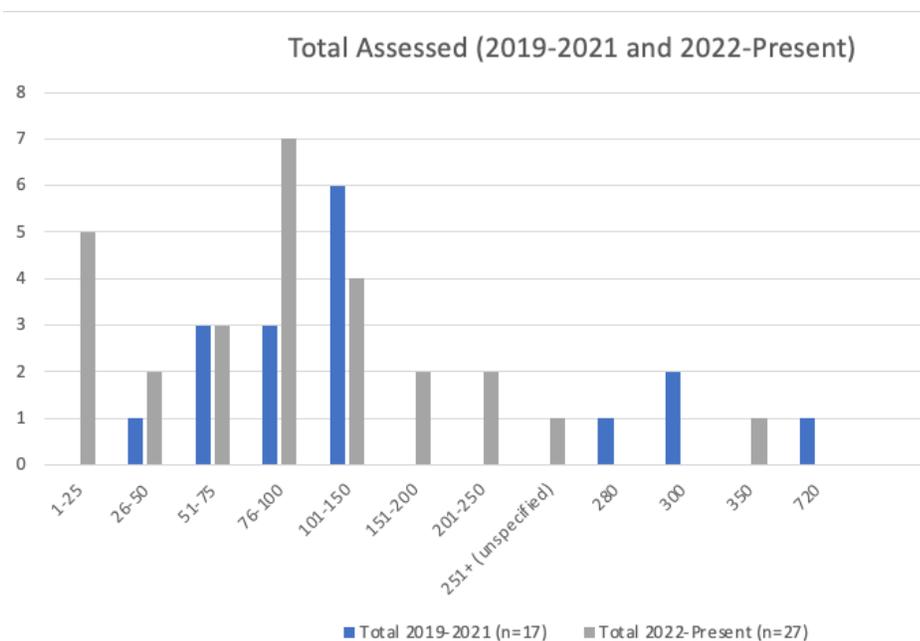
Descriptive Qualitative Analysis

2022 to Present Assessed

Total Assessed. For the 2022 to present period (n = 27) regarding all clients assessed for autism, five participants (18.52%) assessed 1-25 clients, two participants (7.41%) assessed 26-50 clients, three participants (11.11%) assessed 51-75 clients, seven participants (25.93%) assessed 76-100 clients, four participants (14.81%) assessed 101-150 participants, two participants (7.41%) assessed 151-200 clients, two participants (7.41%) assessed 201-250 clients, and two participants (7.41%) assessed 251+ clients. Participants who selected that they assessed over 250 clients were given a free response box asking for them to specify how many they assessed. One participant specified that they assessed 350 clients, and one participant did not specify exactly how many clients they assessed after they indicated that they assessed over 250 clients in the time period. Refer to Figure 3.

Figure 3

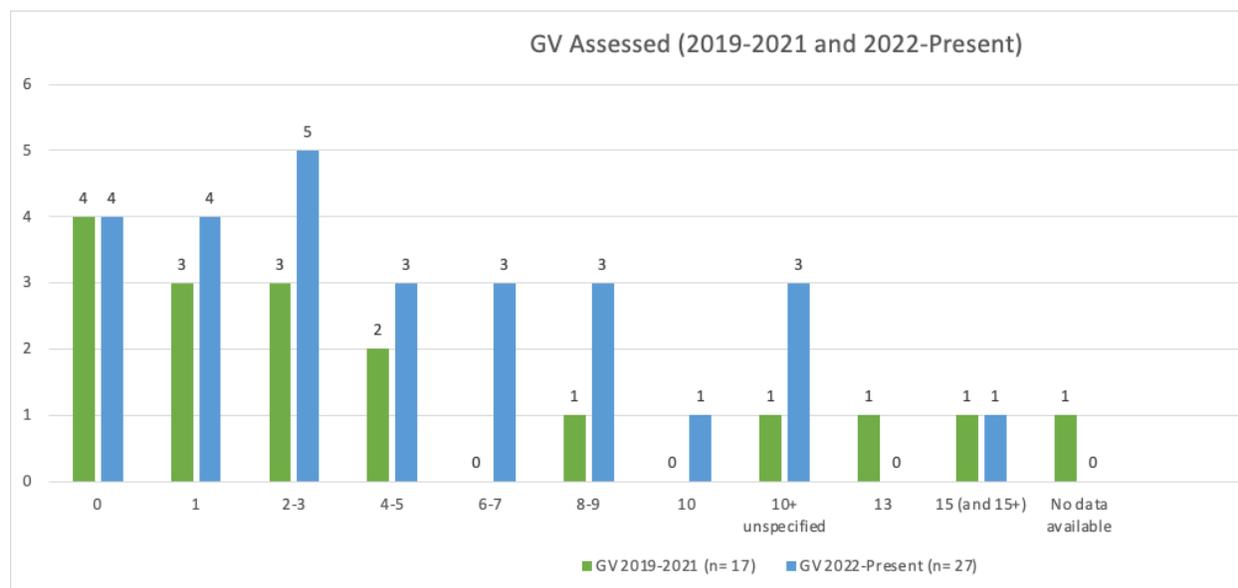
Total Assessed Across Two Time Periods: 2019-2021 and 2022-Present



GV Assessed. For the 2022 to present period (n = 27), four participants (14.81%) assessed 0 GV clients, four participants (14.81%) assessed 1 GV client, five participants (18.52%) assessed 2-3 clients, three participants (11.11%) assessed 4-5 GV clients, three participants (11.11%) assessed 6-7 GV clients, three participants (11.11%) assessed 8-9 GV clients, and five participants (18.52%) selected 10+ GV clients. Participants who selected that they assessed “10+” GV clients were given a free response box asking for them to specify how many they assessed. Of those that clicked 10+, one participant specified that they assessed 10 GV clients, one participant specified that they assessed 15+ GV clients, and three participants clicked 10+ but did not specify exactly how many GV clients they assessed after they indicated that they assessed over 10 GV clients in the time period. Refer to Figure 4.

Figure 4

GV Assessed Across Two Time Periods: 2019-2021 and 2022 to Present



2019 to 2021 Assessed

Total Assessed. For the 2019 to 2021 period (n = 17), regarding all clients, no participants reported assessing 1-25 clients. One participant (5.88%) assessed 26-50 clients, three participants (17.65%) assessed 51-75 clients, three participants (17.65%) assessed 76-100 clients, six participants (35.29%) assessed 101-150 clients, zero participants (0%) assessed 151-200 clients, zero participants (0%) assessed 201-250 clients, and four participants (23.52%) assessed 251+ clients. Participants who selected “251+” were given a free response box asking them to specify how many they assessed. One participant specified that they assessed 280 clients, two participants specified that they assessed 300 clients, and one participant specified that they assessed 720 clients. Refer to Figure 3.

GV Assessed. For the 2019 to 2021 period (n = 17), four participants (23.53%) did not assess any GV clients, and one participant (5.88%) reported “no data available.” Three participants (17.65%) assessed 1 GV client, three participants (17.65%) assessed 2-3 GV clients, two participants (11.76%) assessed 4-5 GV clients, no participants (0%) assessed 6-7 GV clients,

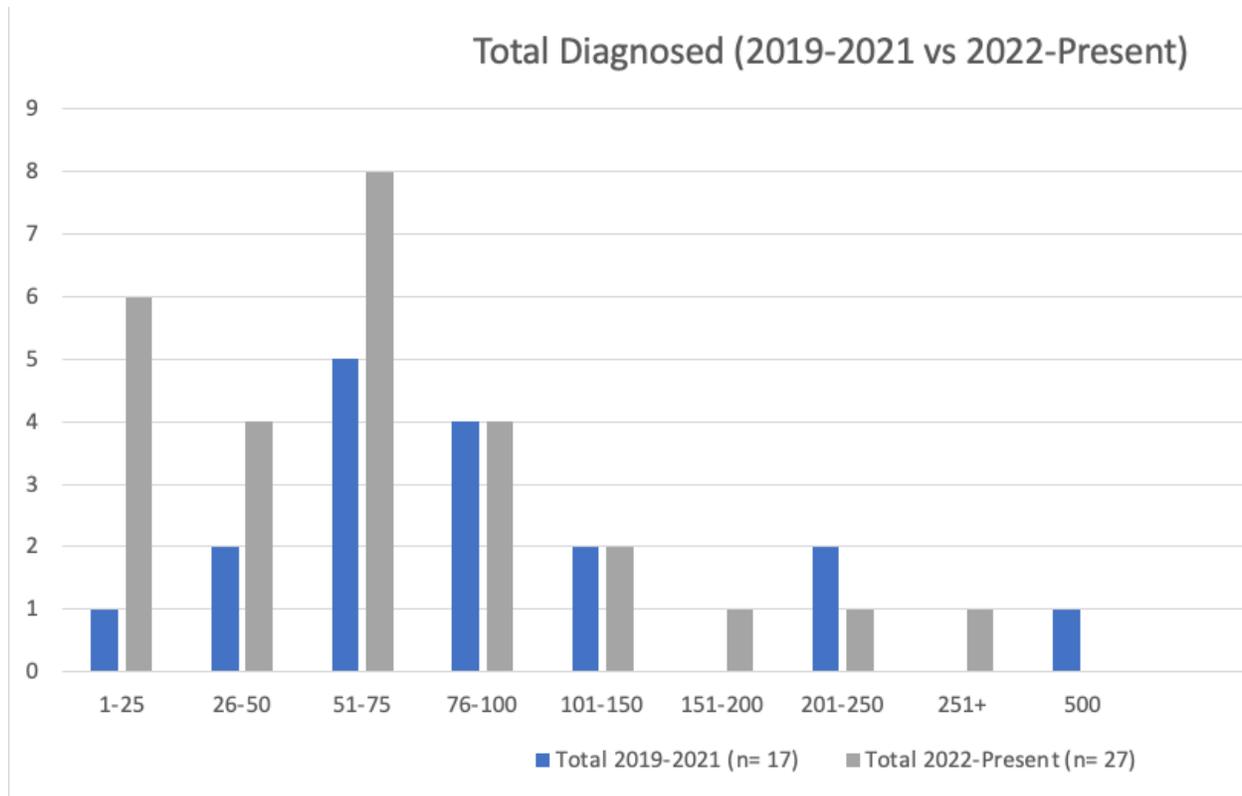
one participant (5.88%) assessed 8-9 clients, and three participants (17.65%) assessed 10+ GV clients. Participants who indicated that they assessed 10+ GV clients, were given a free response box asking for them to specify how many they assessed. One participant reported assessing 13 GV clients, one participant reported assessing 15 clients, and one participant did not specify exactly how many GV clients they assessed after they indicated that they assessed over 10 GV clients in the time period. Refer to Figure 4.

2022 to Present Diagnosed

Total Diagnosed. For the 2022 to present period ($n = 27$) regarding all clients, six participants (22.22%) diagnosed 1-25 clients, four participants (14.81%) diagnosed 26-50 clients, eight participants (29.63%) diagnosed 51-75 clients, four participants (14.81%) diagnosed 76-100 clients, two participants (7.41%) diagnosed 101-150 clients, one participant (3.70%) diagnosed 151-200 clients, one participant (3.70%) diagnosed 201-250 clients, and one participant (3.70%) diagnosed 250+ clients. Participants who indicated that they assessed over 250 clients by clicking “251+” were given a free response box asking for them to specify how many they assessed. One participant clicked 251+ but did not specify how many total individuals they diagnosed. Refer to Figure 5.

Figure 5

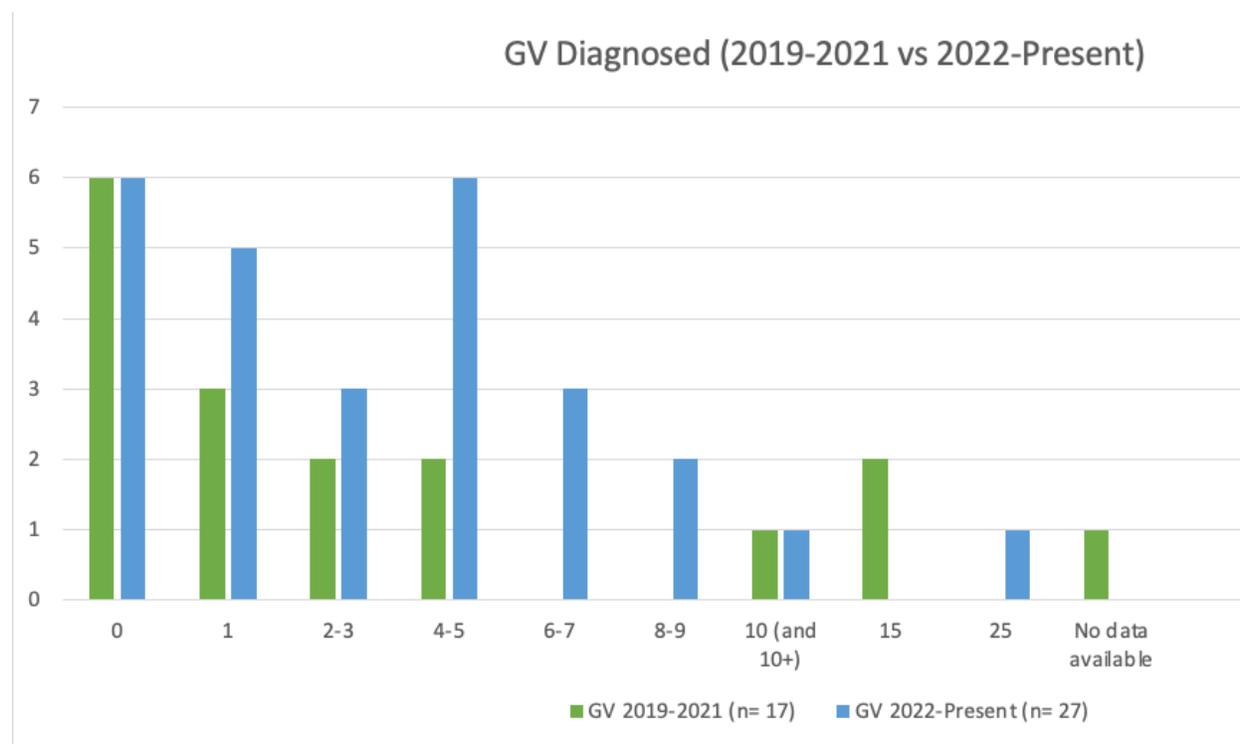
Total Diagnosed Across Two Time Periods: 2019-2021 and 2022-Present



GV Diagnosed. For the 2022 to present period (n = 27), six participants (22.22%) diagnosed 0 GV clients, five participants (18.52%) diagnosed 1 GV client, three participants (11.11%) diagnosed 2-3 clients, six participants (22.22%) diagnosed 4-5 GV clients, three participants (11.11%) diagnosed 6-7 GV clients, two participants (7.41%) diagnosed 8-9 GV clients, and two participants (7.40%) diagnosed 10+ GV clients. Participants who indicated that they diagnosed 10+ clients were given a free response box asking for them to specify how many they assessed. One participant specified that they diagnosed 25 GV clients, and one participant did not specify any further. Refer to Figure 6.

Figure 6

GV Diagnosed Across Two Time Periods: 2019-2021 and 2022-Present



2019 to 2021 Diagnosed

Total Diagnosed. For the 2019 to 2021 period (n = 17) regarding all clients, one participant (5.88%) diagnosed 1-25 clients, two participants (11.76%) diagnosed 26-50 clients, five participants (29.41%) diagnosed 51-75 clients, four participants (23.53%) diagnosed 76-100 clients, two participants (11.76%) diagnosed 101-150 clients, no participants (0%) diagnosed 151-200 clients, two participants (11.76%) diagnosed 201-250 clients, and one participant (5.88%) diagnosed 251+ clients during this time period. Specifically, the one participant who indicated diagnosing 251+ clients reported diagnosing 500 clients during this period. Refer to Figure 5.

GV Diagnosed. For the 2019 to 2021 period (n = 17), six participants (35.29%) diagnosed 0 GV clients, three participants (17.65%) diagnosed 1 GV client, two participants (11.76%) diagnosed 2-3 clients, two participants (11.76%) diagnosed 4-5 GV clients, no participants diagnosed 6-7 or 8-9 GV clients, and four participants (23.53%) reported diagnosing 10+ GV clients. For participants who endorsed assessing “10+”, one participant specified that they diagnosed 10 GV clients, two specified that they diagnosed 15 GV clients, and one participant reported having “no data available”. Refer to Figure 6.

Qualitative Analysis of Section Four Comments

Section four provided participants with an opportunity to complete an open-ended comment, and six participants provided input. Using qualitative methodology to group and analyze the comments (Boyatzis, 1998; Hobson et al., 2022), three common themes emerged: “age,” “data,” and “community”. Specifically, the keywords yielded three groups that provided comments about client age, data collection, or external impacts on GV client numbers.

The first theme of “age” was composed of comments from participants 26 and 18. Participant number 26 said, “[m]ost of my gender variant clients are in the age range of 13 to 30 years.” Participant number 18 commented, “[W]hile I see children up to age 18 years, the majority of my new evaluations are in children under 5 years of age, often with significant language and cognitive delays.”

The second theme of “data” came from participants 30 and 16, who both commented on the difficulty they faced completing the form because they did not have the data accessible. Participant number 30 commented, “I wish I had hard data about the questions you asked, however, my personal tracking system is not that detailed. It is a good reminder that I should not only track the quantity of assessed and diagnosed, but also of gender factors and other factors.

That might be a good recommendation for clinicians as it will help future stud[ies].” Participant number 16 said “It's so hard to remember!”

The third theme of “community” came from Participant number 15, who mentioned the external impacts on GV client numbers. They reported, “We are definitely seeing an increase in the number of kids/teens identifying as gender diverse, perhaps because our community is generally pretty accepting, and also because we are getting better at openly asking and looking.”

Quantitative Analysis

Two quantitative methods were employed to determine if the percentile of the participants' assessments of GV individuals out of the total assessed was greater than the reported percentile of GV individuals in the broader population. The estimated number of GV individuals is based on the data from the UCLA Williams Institute, the Pew Research Center, and Ipsos (Brown, 2022; Herman et al., 2022; Ipsos, 2021), which reported between 1% to 1.6% of the population both in the US and abroad identify as GV. In the quantitative analysis, each participant’s results were compared to 1.6% to determine if they assessed a greater percentage of GV individuals than is representative of the population. 1.6% was used to determine significance because it is the highest percentile of GV representation in the current literature. Using the largest percentile prevents underestimating the GV population and finding a false overrepresentation of GV individuals presenting for an autism assessment. If more than 1.6% of the patients a participant assessed for autism were GV, that signified a greater number of GV patients in an autism setting than representative of the broader population.

Quantitative Analysis Attempt One: Range Percentages Calculations

Using the lowest possible value for the percentage of total people being assessed that were GV, a conclusion can be drawn regarding the percentage of GV individuals reported by

participants in the autism assessment setting and if it is greater than the estimated number of GV individuals. For the 2019-2021 period, 6 of the 17 participants (35.3%) reported that a minimum above 1.6% of the people they assessed for autism were GV. The numbers are higher for 2022-present period: 19 of the 27 participants (70.4%) reported that a minimum above 1.6% of the people they assessed for autism were GV. See Figure 7 for individual results.

Figure 7

The Percentage of People Assessed for Autism Who are GV for Both Time Periods and Range

Percentages

Participant Number	January 1, 2022 to present: Number Assessed	January 1, 2022 to present: GV Number Assessed	January 1, 2022 to present: GV Percentage Assessed for Autism*	January 1, 2019 to December 31, 2021: Number Assessed	January 1, 2019 to December 31, 2021: GV Number Assessed	January 1, 2019 to December 31, 2021: GV Percentage Assessed for Autism*
1	76-100	2-3	2.0%—3.9%	-	-	-
2	101-150	8-9	5.3%—8.9%	-	-	-
3	76-100	10+	10.0%—13.2%	76-100	4-5	4.0%—6.6%
5	1-25	1	4.0%—100%	51-75	1	1.3%—2.0%
6	76-100	2-3	2.0%—3.9%	101-150	1	1.0%—0.7%
7	76-100	1	1.3%—1.0%	0	0	-
8	1-25	0	0%	-	-	-
9	151-200	8-9	4.0%—6.0%	101-150	2-3	1.3%—3.0%
10	1-25	8-9	32.0%—100%	-	-	-
12	1-25	1	4.0%—100%	26-50	0	0%
13	101-150	4-5	2.7%—5.0%	300	2-3	0.7%—1.0%
14	76-100	4-5	4.0%—6.6%	-	-	-
15	76-100	6-7	6.0%—9.2%	76-100	2-3	2.0%—3.9%
16	101-150	2-3	1.3%—3.0%	300	4-5	1.3%—1.7%
17	1-25	6-7	24.0%—100%	-	-	-
18	350	1	0.2%	720	0	0%
19	26-50	6-7	12.0%—26.9%	101-150	15	10%—14.9%
20	201-250	0	0%	280	0	0%
21	51-75	15+	20.0%—29.4%	51-75	15	20.0%—29.4%
23	26-50	0	0%	101-150	1	0.7%—1.0%
24	76-100	10	13.2%—10%	101-150	8-9	5.3%—8.9%
25	251+	10+	4.0%	-	-	-
26	151-200	10+	5.0%—6.6%	76-100	10+	10.0%—13.2%
27	201-250	2-3	0.8%—1.5%	-	-	-
28	51-75	0	0%	51-75	0	0%
29	51-75	2-3	3.9%—4.0%	-	-	-
30	101-150	4-5	3.3%—4.0%	101-150	No data available	-

Note. Data is reported by individual participants. For individuals who did not specify after clicking 10+ or 251+, a value of 10 or 251, respectively, was used for their recalculations. Data in the columns with an asterisk (*) were calculated using the methodology shown in Figure 1.

Quantitative Analysis Attempt Two: Range Average Calculations

Percent of Assessed That Were GV. If the average is taken, instead of only using the lower end of the range, for 2019-2021 data, 41.18% of participants (n=7) reported that more than 1.6% of the patients they assessed were GV (and one reported exactly 1.6%). For 2022-present, 70.37% (n=19) of the participants reported that more than 1.6% of the patients they assessed were GV.

Percentage Diagnosed

Using the averages of each of the ranges for the 2019-2021 period (n=17), about 94% (n=16) of participants diagnosed at least 50% of their total assessments with autism, while about 67% of participants (n=8) diagnosed at least 50% of their GV assessments with autism. Further, about 12% of participants (n=2) diagnosed 100% of their total assessments, but about 42% of participants (n=5) diagnosed 100% of their GV assessments. For the 2022-present period (n=27), about 96% of participants (n=26) diagnosed at least 50% of their total assessments, while about 74% (n=17) of participants diagnosed at least 50% of their GV assessments. Further, of the participants (n=17), about 33% (n=9) diagnosed 100% of their total assessments, while about 52% (n=12) diagnosed 100% of their GV assessments.

Discussion

The aims of this study were to determine if GV individuals are presenting for an autism diagnosis at a higher rate relative to the total population, if GV individuals are being diagnosed with autism at a higher rate than the total population being assessed relative to their intake rate, and to determine future recommendations for the developing field. Both qualitative and quantitative analyses were done to analyze the participant data and the comparable rates of intake versus diagnosis of GV versus total clients both within and across time periods. The qualitative data was broken up into two sections: a descriptive qualitative analysis of section two and section three results, and a qualitative analysis of the section four comments.

Descriptive Qualitative Analysis Discussion

There are a few key results from the descriptive qualitative analysis that highlight the need for further research in the field.

Number of GV Individuals Seeking Autism Assessment Increasing

The first is that compared to the 2019-2021 data, the 2022-present data had more or an equal number of individuals who reported assessing GV clients in each of the provided ranges. Similarly, the 2022-present data had more individuals who reported diagnosing GV clients in each of the provided ranges than 2019-2021. Both assessment and diagnosis rates of GV individuals increased or remained stagnant in all ranges for the 2022-present period relative to the 2019-2021 period. This indicates that the number of GV individuals seeking an assessment and receiving a diagnosis is increasing.

The data from the 2019-2021 period shows that over half of the participants assessed over 100 total clients, and over half of the participants assessed at least 2 GV participants. The 2022-present period data reports that over half of the participants assessed over 75 total clients, and over half of the participants assessed at least 4 GV clients. The median total assessed for 2022-present is lower than 2019-2021, but the median GV assessed is higher. This further indicates the increasing number of GV individuals seeking an autism assessment.

GV Assessments per Area

The Mountain region (Arizona, Colorado, Idaho, New Mexico, Montana, Utah, Nevada, Wyoming) had the largest number of participants (n=9), followed by the West South-Central region (Arkansas, Louisiana, Oklahoma, Texas) (n=5). It is notable that the states that are represented by these regions, with the exception of Colorado, New Mexico, Nevada, and Wyoming, have all passed a law or policy that bans gender-affirming health care (as of

September 15th, 2023) (Human Right's Campaign, 2023). These bans may limit the number of GV individuals who outwardly identify as GV, which may affect participant's reported numbers. Considering that nearly half of the participants (14 out of 30) are from these regions, it is worth noting this potential variable.

Qualitative Analysis of Comments Discussion

The three themes that emerged from the comments, age, data collection, and external impact on GV client numbers, yielded insights related to each category. The "age" comments emphasized the importance of considering the age ranges that clinicians assess when determining prevalence rates. Participant 26, who primarily assessed clients aged 13-30, reported the highest number of GV individuals diagnosed for 2022-present and is tied for the highest number of GV individuals diagnosed for 2019-2021. On the other end of the spectrum, participant 18 reported assessing and diagnosing only one GV individual across both time periods despite reporting that they assessed 350 individuals in the 2022-present period and 720 individuals in the 2019-2021 period. This participant said that most new evaluations are for individuals under age five. Therefore, the comments emphasized both ends of the spectrum – assessing older clients yields higher rates of GV clients, and assessing younger clients yields low rates of GV clients.

The other two categories yielded suggestions for future research. The "data collection" comments highlighted the importance of clinicians keeping track of the data regarding gender for their clients to assist in future research. Participant 30 was the only one to report "No data available," and they recommended that clinicians keep track of gender factors when tracking assessments and diagnoses. The "community" section shows external impact, exhibiting the relevance of location and social atmosphere when determining the locations where GV-specific

research and methods are needed. The participant stated that they are seeing an increase in GV clients and theorized that it may be due to their community being accepting of GV individuals.

Quantitative Analysis Discussion

The novel quantitative analysis is used to provide statistical support for the results from the qualitative analysis sections. The quantitative data analyses results are consistent with the hypothesis that clinicians are seeing an overrepresentation of GV individuals compared to their frequency in the population. Additionally, the data shows that the percentage of GV individuals being diagnosed with autism relative to their intake rate is increasing over time.

Across the two time periods, using the low end of the range percentages, the percentage of participants who reported that at minimum 1.6% of the participants they assessed were GV increased. For the 2019-2021 period, 35.3% of the participants reported that more than 1.6% of the clients they assessed were GV, and for the 2022-present period, 70.4% of the participants reported that more than 1.6% of the clients they assessed were GV. This is a notable increase, implying that the percentage of GV individuals who are seeking an autism assessment is increasing.

The same analysis was done but using averages of the ranges, so the true number may be marginally higher or lower than the reported value. In the 2019-2021 period, 41.18% experienced an overrepresentation. In the 2022-present period, 70.37% experienced an overrepresentation; a noteworthy increase compared to the 2019-2021 period. This data is important for two reasons: it shows a high level of overrepresentation, and that the frequency of overrepresentation increases over time.

The range averages were additionally used to calculate how many participants reported diagnosing 50% and 100% of their clients. For both the 2019-2021 period and the 2022-present

period, there was a higher percentage of participants that diagnosed 50% of their total clients than diagnosed 50% of their GV clients, but a higher percentage of participants diagnosed 100% of their GV clients than their total clients. The percentage of participants that diagnosed both 50% and 100% of their GV clients was higher in 2022-present compared to 2019-2021. Given the inconsistency in participant numbers between the time periods, and the novel analysis method, the authors are unable to conclusively say that GV individuals are being diagnosed at a higher rate than the total population relative to their intake rate. However, the increase in the percentage of participants that diagnosed both 50% and 100% of their GV clients is indicative that a greater number of GV individuals are being diagnosed with autism relative to their intake rate.

Limitations

A major problem this study faced was the low response rate. With only 34 initial participants and a minimum of 17 participants being included in every section of the study, it is difficult to generalize the findings that GV is more prevalent in individuals being assessed for and diagnosed with autism than it is in the broader population or conclude that GV individuals are diagnosed at a higher rate than the total population. A second major limitation of this study was the response options being ranges instead of individual numbers. This prohibited traditional quantitative analysis. While range options were selected to make it easier for participants to report data, it made analysis difficult and quantitative attempts novel. The third limitation of the study was the broad location options provided to the participants. The location options were chosen based on how the US census groups states to increase participant privacy, but this did not allow for state-specific or county-specific analysis of need. Location based analysis was an originally intended method of analysis when the study was conceived, but prioritizing participant privacy was deemed more important for this study.

Recommendations for Future Research

To conclusively determine if there is an over-representation of GV in individuals seeking an autism diagnosis/being diagnosed with autism and a high co-occurrence rate, there are three steps that need to be taken. The first is procuring a larger sample. The IDEA listserv had approximately 500 people at the time of the study, but only 34 were willing to click on the link and complete the consent form. Ways to increase the response rate are contacting individual clinicians and offering compensation. Both would decrease the anonymity of the participants but would potentially increase the response rate.

The second improvement that can be made is not using ranges for the data collection. This would enable the variables to be compared more accurately. For this to be possible, clinicians (future participants) must implement a more thorough record-keeping system that includes gender presentation and identity as a recorded variable. A simple addition to clinicians' records would allow quantifiable research studies to be conducted. This would be more secure for the privacy of the patients than chart studies and more time efficient for both future researchers and clinicians.

The third step for the future is narrowing the location ranges. In order to determine what regions of the country are seeing the highest number of GV individuals seeking an autism diagnosis, it is critical to obtain narrower geographic region data. Location-specific and community-specific research needs to be done to determine which locations/communities require more GV-specific resources.

A major overarching goal of this study was to prove that there is a significant population that is both GV and seeking an autism assessment to provide validity for future studies to investigate how GV individuals are being assessed for autism. The data presented does indicate

that the frequency with which GV individuals are being assessed for autism is increasing. This, along with the multiple analyses presented, is indicative that further research is worthwhile.

Conclusion

Both the qualitative analyses and the supplemental quantitative analysis indicated that there is an increase in GV individuals presenting for an autism assessment across time periods, there is a sizeable GV population seeking an autism assessment, and there are multiple steps that clinicians and researchers need to take in the future to properly assess the needs of the GV population seeking an autism assessment. The analyses showed an increase in GV clients from the 2019-2021 period to the 2022-present period. That fact, along with the descriptive qualitative analysis showing that a significant number of participants assessed GV clients, indicates that there is a substantial need for further research. The analyses and our experience developing the survey revealed several steps that clinicians and researchers can take to move GV and autism cooccurrence research forward.

Appendix A: The Survey

Section One:

Section One: Basic Demographic Information

What is your current age? _____

Biological sex (assigned at birth) Female
 Male
 Intersex
 Prefer not to say

What is your preferred gender? Female
 Male
 Intersex
 Nonbinary
 Transgender
 Other
 Prefer not to say

Where do you primarily work? University
 Private Practice
 Hospital
 School Setting (primary, intermediate, or secondary)
 Other

If "other", please state the setting in which you primarily work. _____

Do you work in the United States (50 states) or abroad (including US territories)? United States
 Abroad

What region of the United States do you work in? New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
 Middle Atlantic (New Jersey, New York, Pennsylvania)
 East North Central (Indiana, Illinois, Michigan, Ohio, Wisconsin)
 West North Central (Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota)
 South Atlantic (Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia)
 East South Central (Alabama, Kentucky, Mississippi, Tennessee)
 West South Central (Arkansas, Louisiana, Oklahoma, Texas)
 Mountain (Arizona, Colorado, Idaho, New Mexico, Montana, Utah, Nevada, Wyoming)
 Pacific (Alaska, California, Hawaii, Oregon, Washington)

Please select the continent on which you work. Africa
 Antarctica
 Asia
 Australia/Oceania
 Europe
 North America (excluding the United States)
 South America

Job Title Psychologist
 Neuropsychologist
 Developmental pediatrician
 Neurologist
 Psychiatrist
 Other MD
 Other

If "Other MD", what is your job title? _____

If "Other", what is your job title? _____

Do you conduct autism assessments and provide a diagnosis according to DSM-5-TR or ICD-11? Yes
 No

Do you work as a part of a team to assess autism? Yes
 No

Please note: Only have one team member complete this survey as we do not want to account for individual clients more than one time.

Section Two:

Section 2: January 1, 2022, to Present
 This section asks for information about patients that you saw for an autism assessment from January 1, 2022, to present.

Please provide your best estimate, responses do not need to be exact.

Gender variance is an umbrella term used to describe an individual whose gender expression, behavior, and/or identity is outside of the norms according to societal expectations for their sex assigned at birth, including gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance. Please provide data for individuals whose behavior and expression falls outside of the gender binary AND have self-identified as gender variant/their guardian has identified them as an individual whose behavior and expression falls outside of the gender binary.

Have you worked at your current job since January 1, 2022, or earlier? Yes No

****Regarding ALL clients****
 Birth to 5 years old
 6 to 12 years old
 13 to 18 years old
 Adults (18+)
 (Mark ALL that Apply)

****Regarding ALL clients****
 From January 1, 2022, to present, please select the approximate (best estimate) NUMBER of individuals you ASSESSED for autism.
 0
 1-25
 26-50
 51-75
 76-100
 101-150
 151-200
 201-250
 251+
 No data available

If 251+: From January 1, 2022, to present, what is the approximate (best estimate) NUMBER of individuals you ASSESSED for autism? _____

****Regarding ALL clients****
 From January 1, 2022, to present, of those you assessed for autism, select the approximate (best estimate) NUMBER of individual that ended up with a DIAGNOSIS of autism.
 0
 1-25
 26-50
 51-75
 76-100
 101-150
 151-200
 201-250
 251+
 No data available

If 251+: From January 1, 2022, to present, what is the approximate (best estimate) NUMBER of individuals you DIAGNOSED with autism? _____

****Regarding GENDER VARIANT clients****
 From January 1, 2022, to present, of those that you ASSESSED for autism, please select the approximate (best estimate) NUMBER of individuals that identified as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance.
 0
 1
 2-3
 4-5
 6-7
 8-9
 10+
 No data available

****Regarding GENDER VARIANT clients****
 If 10+: From January 1, 2022, to present, of those that you ASSESSED for autism, approximately (best estimate) what is the NUMBER of individuals that identified as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance? _____

****Regarding GENDER VARIANT clients****
 From January 1, 2022, to present, of those you assessed for autism, please select the approximate (best estimate) NUMBER of individuals that ended up with a DIAGNOSIS of autism who identified themselves as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance.
 0
 1
 2-3
 4-5
 6-7
 8-9
 10+
 No data available

****Regarding GENDER VARIANT clients****
 If 10+: From January 1, 2022, to present, of those you assessed for autism, approximately (best estimate) what is the NUMBER of individuals that ended up with a DIAGNOSIS of autism who identified themselves as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance. _____

Section Three:

Section 3: January 1, 2019, to December 31, 2021 (3 years) This section asks for information about patients that you saw for an autism assessment from January 1, 2019 to December 31, 2021 (3 years).

Gender variance is an umbrella term used to describe an individual whose gender expression, behavior, and/or identity is outside of the norms according to societal expectations for their sex assigned at birth, including gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance. Please provide data for individuals whose behavior and expression falls outside of the gender binary AND have self identified as gender variant/their guardian has identified them as an individual whose behavior and expression falls outside of the gender binary.

Did you work at your current job doing autism assessments between January 1, 2019, and December 31, 2021? Yes No

****Regarding ALL clients****

Birth to 5 years old
 6 to 12 years old
 13 to 18 years old
 Adults (18+)
 (Mark ALL that Apply)

****Regarding ALL clients****

From January 1, 2019, to December 31, 2021, please select the approximate (best estimate) NUMBER of individuals you ASSESSED for autism.

0
 1-25
 26-50
 51-75
 76-100
 101-150
 151-200
 201-250
 251+
 No data available

****Regarding ALL clients****

If 251+: From January 1, 2019, to December 31, 2021, what is the approximate (best estimate) NUMBER of individuals you ASSESSED for autism?

****Regarding ALL clients****

From January 1, 2019, to December 31, 2021, of those you assessed for autism, select the approximate (best estimate) NUMBER of individuals that ended up with a DIAGNOSIS of autism.

0
 1-25
 26-50
 51-75
 76-100
 101-150
 151-200
 201-250
 251+
 No data available

****Regarding ALL clients****

If 251+: From January 1, 2019, to December 31, 2021, what is the approximate (best estimate) NUMBER of individuals you assessed and gave a DIAGNOSIS of autism?

****Regarding GENDER VARIANT clients****

From January 1, 2019, to December 31, 2021, of those that you ASSESSED for autism, please select the approximate (best estimate) NUMBER of individuals that identified as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance.

0
 1
 2-3
 4-5
 6-7
 8-9
 10+
 No data available

****Regarding GENDER VARIANT clients****

If 10+: From January 1, 2019, to December 31, 2021, of those that you ASSESSED for autism, approximately (best estimate) what is the NUMBER of individuals that identified as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance?

****Regarding GENDER VARIANT clients****

From January 1, 2019, to December 31, 2021, of those you assessed for autism, select the approximate (best estimate) NUMBER of individuals that ended up with a DIAGNOSIS of autism who identified themselves as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance.

0
 1
 2-3
 4-5
 6-7
 8-9
 10+
 No data available

****Regarding GENDER VARIANT clients****

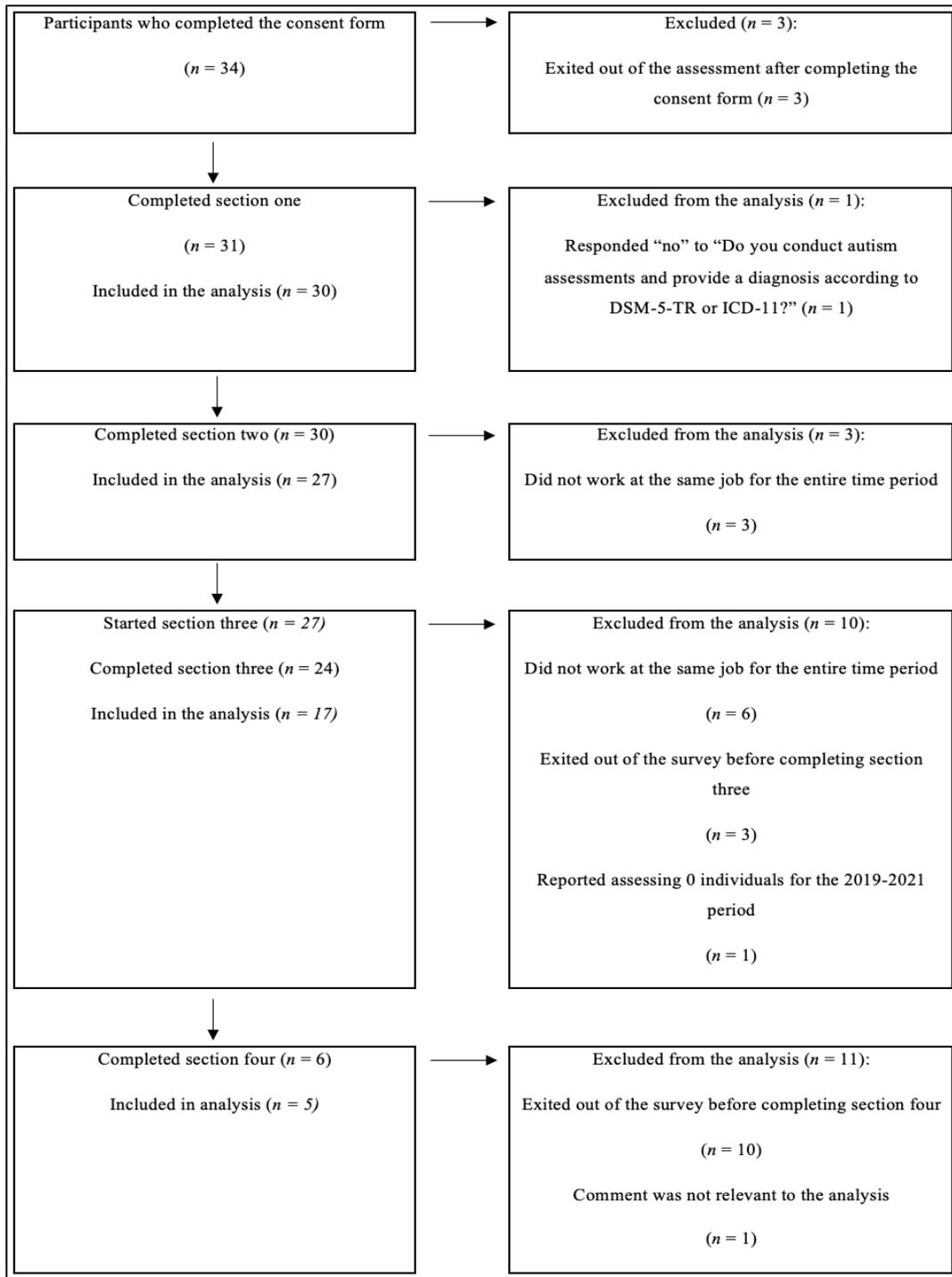
If 10+: From January 1, 2019, to December 31, 2021, of those you assessed for autism, approximately (best estimate) what is the NUMBER of individuals that ended up with a DIAGNOSIS of autism who identified themselves as gender non-conforming, transgender, nonbinary, genderqueer, or as having gender variance?

Section Four:

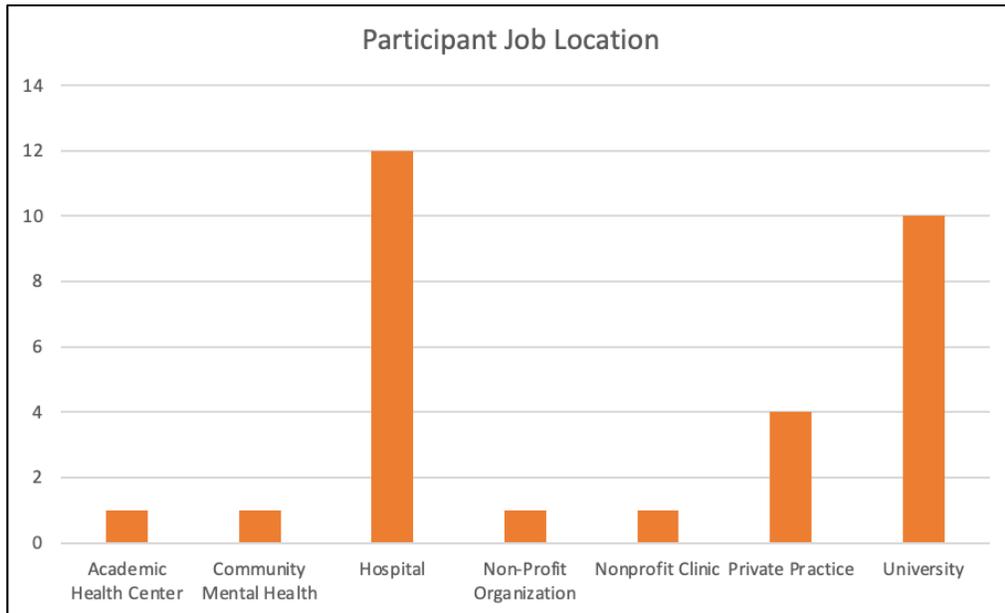
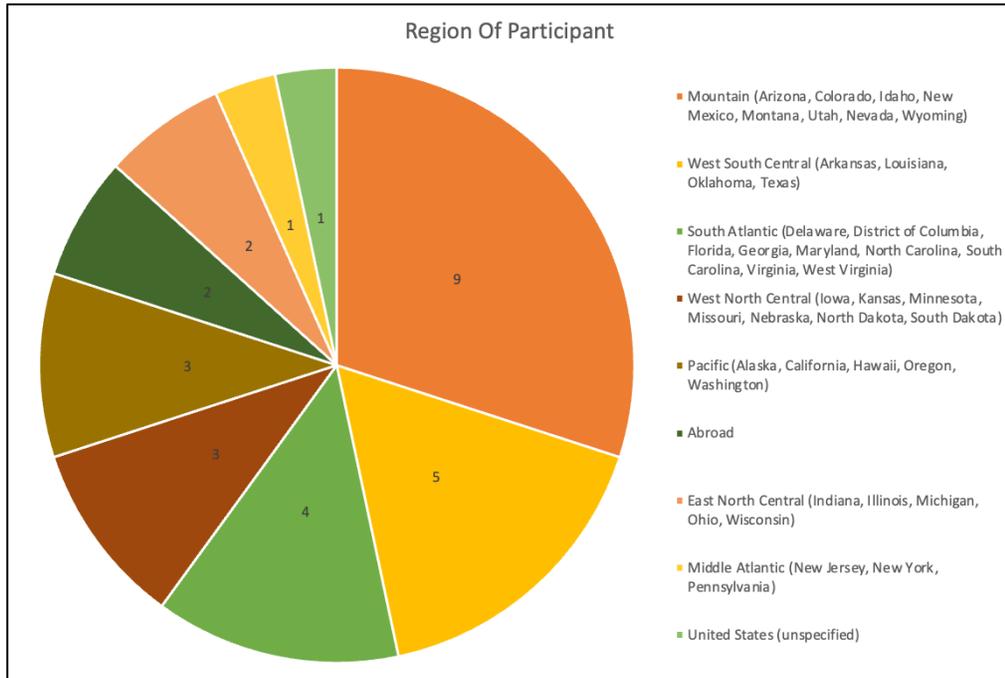
Thank you!

Please provide any additional comments:

Appendix B: Participant Flow Chart



Appendix C: Section One Data



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