Autistic Women and Masking: The Road to Closing the Gender-Based Gap in Autism Spectrum Disorder Diagnoses

Autistic Women and Masking: The Road to Closing the Gender-Based Gap in Autism Spectrum Disorder Diagnoses

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Abstract

The current state of autism spectrum disorder diagnoses reflects a skew toward men which is due to a bias in the diagnostic criteria. The diagnostic criteria in the DSM-5 fail to properly assess for alternative-to-male expressions of the disorder; one specific factor that is not adequately addressed is masking. Masking pertains to an individual's ability to hide and adapt their autistic traits to appear more neuro-typical. Though any autistic person may have the ability to mask their autistic traits, recent research shows that more women than men possess this ability, and to a higher degree. Masking is not exclusive to adults; it is seen in autistic girls from a very young age.

The diagnostic criteria need to be amended to account for an expression of autism under the cover of masking. If we do not change the way we diagnose autism, and we keep the insensitive and biased current criteria, we will continue denying diagnosis to so many autistic women who deserve support and acknowledgement. The first step in this process is to gain a better understanding of masking, and the best way to do this is to ask autistic women themselves for their expertise, experience, and guidance. Self-report is necessary in this exploration. I recruited five autistic women through Instagram and then I conducted five semi-structured interviews with each of those women, separately. During the interviews I used an interview guide that consisted of 27 open-ended questions, all of which were aimed at gaining knowledge about the experience of autism and masking for each of these women. I found four themes in common across the

interviews: gradual realizations, routine yet forced masking, burnout and comfort-seeking, and advocacy for self.

Dedication

This study is dedicated to all the autistic women who have been failed by past and present researchers and diagnosticians. This is for the autistic women who were misdiagnosed, brushed off, told they weren't autistic enough, and not diagnosed until adulthood. I dedicate this paper to all the autistic women who were born autistic, have always been autistic, and always will be autistic. Lastly, I dedicate this paper to all the autistic women who are self-diagnosed, because getting a neuropsychological assessment is inaccessible, too expensive, or won't be offered to you because your presentation does not meet certain biased, white-male standards.

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Most graciously, I want to thank the five women who bravely shared some of the most vulnerable parts of themselves with me for this study. Each of the five women offered a unique perspective and they were all eager to share their experiences, knowledge and expertise when it comes to being an autistic woman. Each of these women agreed to participate without being offered any sort of compensation, they did it purely because they want change, and they wanted a chance to share their voices. My

gratitude for their willingness to participate cannot be understated. I truly couldn’t have done this without them.

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Chapter I.

Introduction

Recent research on autism spectrum disorder (ASD) highlights evidence that our current understanding of ASD is based on an expression of the disorder that fails to address women-centric autism characteristics (Tubío-Fungueiriño et al., 2020). There is one main aspect of ASD that is not adequately addressed in diagnosis or understanding of the disorder—masking (Tubío-Fungueiriño et al., 2020). Masking refers to one's ability to hide their symptoms and effectively blend in with society. Another word that is commonly used to refer to masking is camouflaging. Masking and camouflaging are essentially synonymous as they both reflect an ability to hide symptoms and subsequently, blend in; these two words are often used interchangeably.

Being diagnosed as early as possible is often the best-case scenario for individuals with ASD. It is important to note, though, that for underrepresented communities and BIPOC (Black, Indigenous, and People of Color) individuals, receiving a diagnosis can sometimes do more harm than good due to the stigmatization that still surrounds mental health disorders. However, for many people receiving a diagnosis can be helpful because it allows the individual to access support and accommodations that they may not receive without a diagnosis. The issue at hand is that autistic women can be difficult to diagnose because they often possess an enhanced ability to mask their symptoms, and the current criteria for diagnosis do not sufficiently take this into account (Suckle, 2020). Misdiagnosis and lack of diagnosis are prevalent among autistic women because there is not currently any attention placed on the likelihood of masking occurring more in autistic

women than men; the same holds for young girls versus boys, as masking is not exclusive to adults. The DSM-V briefly addresses the possibility of an autistic individual masking their symptoms at the very end of the diagnostic criteria (American Psychiatric Association, 2013), but this is clearly not enough, as the bias in diagnosis is still very much present with only one girl being diagnosed for every three boys (Loomes et al., 2017). Ultimately, more encompassing and accurate diagnostic criteria are needed for women, BIPOC individuals, and any other underrepresented communities. This paper will specifically address the need for revised criteria for women. To get there, we need to first understand the subjective experience of masking. However, there is one obvious and important issue: masking in and of itself is a hidden technique and is therefore, not something one can necessarily observe. Therefore, one means of studying masking is through asking the women themselves for their experience. Understanding the subjective experience of masking would provide insight into why and how these women are able to mask their symptoms and blend in. More than anything though, it would give these women who have been ignored for so long, a voice. Ultimately, if we want to get better at diagnosing autistic women we need to be able to identify signs and traits commonly experienced by masking autistic women, as well as the behaviors and feelings surrounding masking.

Autism Spectrum Disorder Background

Autism spectrum disorder (ASD) is a disorder marked by issues with social communication and restriction or repetition in various aspects of life (Sanchak & Thomas et al., 2016). In the past, there were several disorders that were distinct from ASD, yet

very similar in terms of symptomatology; some of those disorders were Asperger syndrome and autistic disorder (Sanchak & Thomas et al., 2016). Currently, ASD is a term which encompasses both aforementioned disorders (Sanchak & Thomas et al., 2016). Autism is a disorder that exists on a spectrum, meaning that people with the disorder can range in their levels of impairment and subsequent support needed (Masi et al., 2017). A main feature of ASD is that it is currently and always has been diagnosed more frequently in boys than in girls (Loomes et al., 2017). Loomes et al. (2017) found that the ratio of men to women diagnosed with ASD is about three to one.

The DSM-V and Masking

The current diagnostic criteria in the DSM-V for autism spectrum disorder include two main sections with three subsections in the first and four subsections in the latter. The first section addresses symptoms such as deficits in social communication, social-emotional reciprocity and relationship development and maintenance. The second section addresses restricted and repetitive behavior patterns, examples of this might be needing to do things the same way over and over again, and only enjoying talking about certain things. While masking is very briefly mentioned at the end of the criteria, there is no attention placed on the higher likelihood of masking affecting the presentation in women. The criteria do not offer any information on how masking may change the presentation of the disorder, even though it very clearly does. It is important for masking to be part of the criteria because masking changes the way that autism symptoms are exhibited and if masking is not taken into account, many people will not be diagnosed (Suckle et al., 2020). If diagnosticians are looking for the specific symptoms mentioned in the DSM-V, they will not always find those in autistic women who are masking. For

example, an autistic woman may only enjoy talking about very specific things, but she may mask this in social situations and talk about other things to fit in. If a clinician is looking for evidence of restricted interests in the example I just mentioned, they may not find strong evidence of it due to masking.

Previous Research on Masking

Loomes et al. (2017) found evidence for a diagnostic bias of the criteria for ASD toward a male presentation of the disorder. In other words, the diagnostic criteria for ASD are not sensitive enough to the way many women present their symptoms. The underlying symptoms of ASD may be similar independent of gender, the differentiating factor is that many women are excellent at masking their symptoms while many men do not have this ability to the same extent.

Suckle (2020) found that autistic women do exhibit a breadth of behaviors that do not look like the typical behaviors of an autistic individual; these behaviors are largely accounted for by the compensatory technique, masking, that many autistic women possess. Many autistic women report that masking requires an ability to analyze and systematize interactions to learn how to act more neuro-typically (Suckle, 2020). Though autism consists of complex and varied behavioral presentations across the board, Suckle (2020) acknowledged the importance of taking masking into account when it comes to women specifically because many autistic women do not overtly exhibit behaviors typically associated with ASD due to masking.

A principal distinction that Suckle (2020) makes is that it is not necessarily that autism at its core is different in women; it is that the way many women present ASD is

different because of masking. For example, many women do deal with deficits in social communication and interaction, and this is a symptom in common with many autistic men (Suckle 2020). The difference is that these women deal with social deficits internally but mask the symptom externally which effectively hides the symptom from observers (Suckle 2020). More research is needed to understand the subtleties of masking. There is a gap in the understanding of what this ability feels like, how conscious it is, and how much effort it takes. Without this knowledge, we cannot adequately determine if an individual is masking and what effect it has on the presentation of symptoms.

In many cases, receiving an autism diagnosis initially requires a "gatekeeper", or a person who notices neuro-divergent behaviors and can then inform someone who can get the individual at hand support (Whitlock et al., 2020). This concept of gatekeepers is important in the discussion of women and masking since many women do not display the classic and man-centric symptoms of autism. Because many autistic women do not exhibit a typical autistic behavioral presentation (according to the white male stereotype), the people who could have been gatekeepers do not always end up notifying anyone because they do not notice anything overtly different about the individual (Whitlock et al., 2020). For example, if a young girl has autism but does not display the classic symptoms that a teacher would normally look for, then the teacher cannot act as the gatekeeper and this can impact the timeliness and likelihood of the girl getting diagnosed (Whitlock et al., 2020). Simply not being a boy makes it less likely that one will get an autism diagnosis due to the current criteria (Whitlock et al., 2020).

Whitlock et al. (2020) tested whether educators demonstrated a bias in identifying autistic behaviors in girls and boys. They used vignettes and tested gender stereotyping

where they presented boys and girls with identical autism symptoms and assessed whether there was a bias accounted for by gender in educators' ratings of autism likelihood. Whitlock et al. (2020) did in fact find a gender-stereotyping bias in that educators were more likely to rate boys as autistic as opposed to girls, regardless of phenotypic expression. Whitlock et al. (2020) found that regardless of presentation of autistic traits, girls were less likely to be rated as autistic, supporting the idea that there is a bias against autistic girls. In summary, Whitlock et al. (2020) found that educators were less sensitive to autism in girls in general and exhibited a bias against the women-centric autism phenotype. This study substantiates the need for attention brought to researching non-typical autism expressions.

In addition to the many differences that have been found in the externalized symptoms of ASD among genders, there is evidence of neuro-anatomical differences as well. I want to include a disclaimer that the discussions of gender and sex are not synonymous, for example, autistic female and autistic woman do not necessarily mean the same thing. A person may identify as an autistic woman, but not female, and therefore this is something that should also be taken into consideration in research. Cauvet et al. (2018) set out to assess whether the brains of twins with autism were different based on sex. Before any brain scans took place, researchers assessed autism trait severity using the Social Responsiveness Scale-2 (SRS-2) and the Autism Diagnostic Observation Schedule-2 (ADOS-2). After these assessments, the researchers conducted structural MRI imaging to assess whether there were brain differences among the twins based on autism trait severity. Cauvet et al. (2018) found that higher autism trait severity was associated with decreases in the volume of cortical areas and reduced surface area of the temporal

and frontal lobe in female twin pairs, but not in male twin pairs. The main takeaway from the study was that for similar clinical severity and increases in autistic traits, female MRI images displayed distinct and higher degrees of brain alterations when compared to males (Cauvet et al., 2018). This information lends support to the idea that females possess a protective mechanism—masking—that hides autism symptoms. This means that for a woman to have diagnostically detectable symptoms, her symptoms must be so severe as to be partnered with increased brain alterations that are not necessary for diagnosis in men.

Wood-Downie et al. (2020) studied several aspects of masking or camouflaging as the researchers in this study refer to it, in children with high levels of autistic traits, with an autism diagnosis, and without a diagnosis. The researchers decided to include children without a diagnosis because they wanted to account for the children who mask their symptoms. Wood-Downie et al. (2020) wanted to measure social reciprocity in these children to measure the children's drive to exhibit turn-taking behavior and hence, measure their desire and ability to mask. Social reciprocity is associated with masking because children with high autistic traits in regards to sociality often deal with social difficulties; an ability to demonstrate social reciprocity means the child would likely be masking their social difficulties. To assess social reciprocity, the researchers used the Interactive Drawing Task (IDT) where the participant and researcher would take turns creating a drawing together. A potential issue here is that the child was paired with a researcher who was much older than them, and therefore the child may have been acting in ways that were different than they would normally behave with a peer of similar age.

Wood-Downie et al. (2020) did in fact find higher rates of social reciprocity in girls when compared to boys. This heightened social reciprocity demonstrates an enhanced ability to mask symptoms in autistic girls (Wood-Downie et al., 2020). Wood-Downie et al. (2020) surmise that this may be a key reason for the late or absent diagnosis of ASD for many women. This is an issue because, as mentioned previously, getting a diagnosis also means being exposed to help and support that one would not have access to without a diagnosis.

Masking can also result in a plethora of very serious issues. Masking often leads to the person being confused and lost in terms of their true identity or personality (Bargiela et al., 2016). It can leave girls feeling anxious, depressed, lost, low in self-esteem, and can even result in self injury and suicidal thoughts (Tubío-Fungueiriño et al., 2020). Furthermore, masking can lead to the person prioritizing other people's needs before one's own and therefore, being left with one's own needs unmet (Bargiela et al., 2016). Masking can also result in the individual being manipulated and abused by other people (Bargiela et al., 2016). Because of their ability to mask, autistic women and girls tend to internalize these negative outcomes and report having less symptoms than men and boys (Tubío-Fungueiriño et al., 2020).

Bargiela et al. (2016) studied masking in their study; however, they noted that the topic needs to be researched more extensively. They assert that the topic specifically needs research when it comes to self-report to better understand behavior that is oftentimes hidden from the outside observer's perspective. The value of self-report is that it allows the researcher to gain an understanding of what might normally be an unobservable thought or behavior. In this case, many aspects of masking behavior are

hidden since masking is literally the hiding of certain symptoms and subsequent blending into neuro-typical constructs of behavior. Because masking in and of itself is an unobservable and undetectable behavior, we need self-report to study it. Though self-report can include bias, there are ways to mitigate this using techniques that aim to capture the true experience of the person being interviewed.

Experiences of Autistic Women: What We Know and Need to Learn

Though there is a wealth of research yet to be conducted in relation to understanding the experiences of autistic women, we do have some literature exploring the topic. Bargiela et al. (2016) interviewed fourteen women who had been diagnosed with autism to assess how being a woman influenced experiences of being diagnosed. They also researched how late-diagnosed women adapt to the challenges they face in being autistic. In these interviews, Bargiela et al. (2016) found that masking was widespread but not something that every woman did. For the women that did mask, they described their experience as learning to use more appropriate and accepted social skills. Bargiela et al. (2016) stated that from their analysis it appeared that the women learned these skills through things such as watching their peers, reading novels, and trying things out in social interactions. However, some women spoke of an unconscious element to masking where they mimicked without much conscious awareness or effort. Bargiela et al. (2016) asked questions that briefly delved into how women learn to mask and what the consequences are, but they did not address the actual process of masking. The goal of the present study is to take what Bargiela et al. (2016) did and further it through in depth exploration of the masking process itself. By asking the women these questions, we will develop a better sense of commonalities in behaviors and feelings experienced by autistic

women who mask. In understanding the common behaviors and feelings, we can gain insight into what may be some potential flags that an individual is masking their autism symptoms. This means that we will be able to identify autistic women despite masking.

Research Goals

The aim of the present study is to explore the features of autistic masking that take place behind the scenes via interviews and using qualitative research methodology. If we can find out more about the experience of masking, then we can identify some potential behaviors or symptoms that co-occur with masking.

To date, no studies have assessed the subjective experiences of masking with the intention to understand the actual processes and reasons for the behavior. This study will provide insight into the feelings and behaviors surrounding masking so that in the future, it will be easier to assess whether masking is occurring and help practitioners to support autistic women more effectively.

Interview Questions and Pie Chart

I conducted five semi-structured interviews to obtain the data used in this research. I developed interview questions with specific intent to be open-ended and non-leading. I collected data on eight main categories: warming up, experiences of masking, awareness of own masking, emotional effects of masking, reasons for masking, situations where they don't mask, diagnosis, and advice or suggestions. I created a pie chart based on one initially created by “the.autisticats”, that I found on Reddit. I used this pie chart to assess the degree to which the participants masked on an average day.

As mentioned previously, I collected the data with intention to assess eight

different categories. I developed a total of 27 questions, all of which were open-ended and non-leading. The interview guide can be found in Appendix 1. The "warming up" section was meant to create rapport between the participant and myself. I wanted to ease into the tougher questions by asking some simpler and lighter questions to start. I also wanted to learn some baseline information about the participant to help set the scene for the upcoming questions. I developed the "experiences of masking" section to figure out how conscious masking was for the participant. I wanted to see if and how the participant would answer the question—would they be able to easily come up with a situation that involved masking; or would the participant not be able to think of an answer, meaning they did not knowingly mask or perhaps did not mask at all? For the "awareness of own masking" section, I asked these questions in effort to learn about how aware the participant was of her own masking. I wanted to know if the participant actively thought about masking, or if it was something more subconscious and less mechanical. I formed the "emotional effects of masking" section to assess the emotional impact masking had on the participant, if any at all. The purpose of this section was to find out if there were any commonalities experienced by the participants after masking had occurred. I developed the "reasons for masking" section to figure out what the motivation behind masking was, and if it felt like something the participant had to do or if it was more so something the participant wanted to do. I created the "situations where they don't mask" category because I wanted to find out if the participants could distinguish between their masking self and their non-masking self. I also was interested in how, and if, comfortability impacted masking at all. I preceded the diagnosis section with a disclaimer stating that the following questions would be personal, and if the participant did not want

to disclose the information, they were not at all obligated. In this section I asked if the participant had been professionally diagnosed with ASD, and what that journey was like for them if they had been diagnosed. I chose not to ask for proof of diagnosis in this study because that seemed overbearing, like it could lead to negative rapport, and it could invalidate participants who might have been self-diagnosed. However, I felt it was important to know whether the participant was professionally diagnosed since this study is largely about the difficulties experiences by many autistic women when it comes to getting the correct diagnosis. In the last section, "advice or suggestions", I asked the participant's if they had any questions, advice, or suggestions to include in the study for future research or clinicians. This was an invaluable aspect of the interview where the women were given space to voice their opinions, hopes and even anger about the current state of support and diagnoses for autistic women.

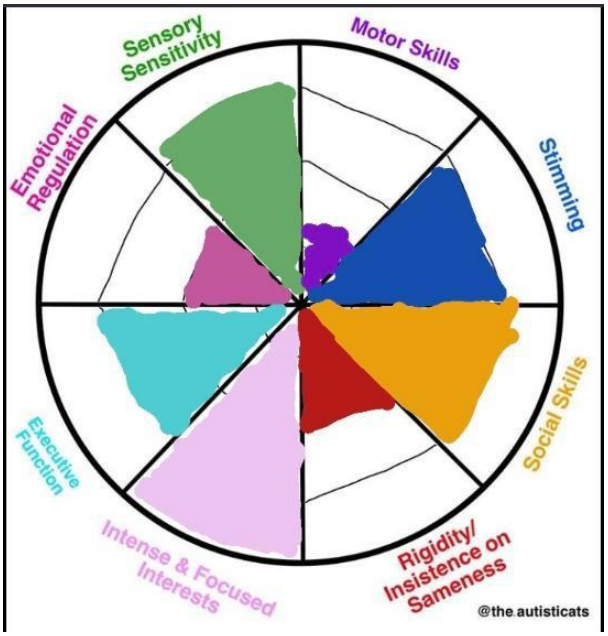
Although ASD is thought of as existing on a spectrum, this idea becomes harmful when the spectrum is pictured as linear. Recently, more and more autistic individuals are speaking out about how and why this idea of autism as a linear spectrum is not beneficial and in some instances, detrimental to the autistic community. Autism being represented on a linear scale implies that some people have more autistic traits, and some people have less; this leads to what are notoriously known as functioning labels. Functioning labels represent where an autistic individual would exist on the linear spectrum. For example, if someone had low autistic traits, they would be considered high functioning, and someone who had more autistic traits would be low functioning. The problem with this is that traits are not always experienced in the same degree by the same person. For example, an autistic individual may experience some autism traits very strongly, while experiencing

others mildly or not at all. For this reason, people cannot be classified as high or low functioning because this invalidates the truth of their experience.

To rectify this issue of the linear spectrum, many people have come up with their own variations of the spectrum that are more inclusive and validating. An example of this would be a version created by "the.autisticats" that looks as follows:

Figure 1. The Autism Spectrum

A pie chart depicting various Autistic Traits from @the.autisticats



In this example there are eight different triangular segments that denote different aspects of commonly experienced autism traits. The triangular segments are also divided into fragments which act as levels for the degree of experience of a certain trait. Fragments closer to the center represent low degree of experience, fragments toward the outside of

the triangle represent high degrees of experience. Therefore, figure 1 demonstrates that the individual experienced high degrees of “Intense & Focused Interests” and only mildly experienced “Rigidity/Insistence on Sameness”. This type of chart depicting the autism spectrum allows for flexibility in degree of experience for all traits, it does not box an individual into a category of being all one thing, or all another.

I designed a chart that focused on traits that seemed particularly relevant to the phenomenon of masking, that chart can be found in Appendix 2, along with the instructions that were provided to complete it. I came up with eight different traits that are commonly associated with masking, based on my own research. I asked participants to fill the chart out before the interview so I had a little bit of background before meeting them.

Chapter II.

Methodology

Participants

A total of five women were recruited for participation in this study. These women were all aged between 18 and 30 years. I selected this age range because I wanted to include women who were close enough to childhood to have clear memories of beginning to mask, and I also wanted them to be as close to the age they were diagnosed so they could remember that experience as well as possible. These women were recruited for participation in this study after approval of the Harvard Committee on the Use of Human Subjects. Several inclusion criteria were used in the recruitment of participants: (1) individual must identify as a woman, (2) individual must be between the ages of 18 and 30 years, (3) individual must be able to communicate verbally in English. Individuals who were not verbal or could not effectively verbally communicate were excluded from this study.

Recently, there have been many women who have come out publicly on social media speaking about their struggles with autism and receiving a diagnosis. Recruitment included reaching out to autistic women on Instagram who had content related to autism knowledge and awareness on their page. The recruitment message included the following points: who I am, what my thesis is about, who I am recruiting, the inclusion criteria, a disclaimer about readers of the study potentially finding out they are autistic though their participation in the study, that the study would take approximately one hour, and I asked them to let me know if they would like more information or were interested in potentially participating. I assessed the account for the following criteria: that the person seemed to

identify as a woman, the person was outwardly identifying as autistic, and that the person had some sort of information demonstrating their ability to communicate in English. Several women responded and were willing and even excited about participating. I sent these women consent forms to look over via email, once they signed and sent them back to me, we scheduled interviews over Zoom. After I scheduled each interview, I sent out the pie chart for the participant to complete and send back to me at least one day before the interview. As soon as I recruited and finished conducting all five interviews, I ended the recruitment process.

Measures

This is an exploratory study involving semi-structured interviews using open-ended questions. I explored eight main categories using 27 questions in total. I used semi-structured interviews because I was prepared to follow the participants' responses and remain flexible to give the participant freedom to flow in directions that felt comfortable. The interviews ranged from around 30 minutes to two hours long. The length of interview was based on how much the individual felt comfortable sharing and how much detail they wanted to give in their responses. Some women were also limited in the amount of time they could give me due to having busy schedules.

Procedure

I recruited participants via messaging on Instagram to explain the nature of the study and ask if the person would like to participate. I provided necessary disclaimers to make sure that the individual was aware that the interview would explore topics pertaining to experiences of being autistic. The interviews all took place online using

Zoom. No interview lasted longer than two hours. I started each interview by introducing myself and I made sure the participant felt comfortable and knew they could terminate the Interview at any time. I also made it clear that they could refrain from answering any question that they did not want to answer. After this, I asked if the participant had any questions, if they did, I answered, if they didn't, I moved onto the first section using the Interview Guide (appendix 1). After the participant answered each question, I tried not to react but to instead ask a follow up question using the guide. There were no time gaps between questions, each question was followed by a response by the participant which was followed by another question from me.

Data Analysis Plan

I qualitatively analyzed the data by combining an abductive approach, which involves predetermined themes, with an inductive approach to allow for new themes to surface (Charmaz, 2006). I used this combination because there were already some predetermined categories that the data fell into, which lends to an abductive approach, but at the same time I wanted to maintain an open-mind so that I would not miss any potential themes that I may not have been expecting, which is why I wanted to include an inductive approach as well. Three out of five of the interviews were coded line-by-line, and the other two were thematically coded using the themes that were found from the line-by-line coding of the first three. I decided to only code three of the interviews line by line because this approach can be quite time consuming, and I was working on a deadline. However, I felt three was enough to give me an expansive sense of the data and the themes that were surfacing. Once the data were coded, I searched for any other potential themes that may have presented. I ended with

the following themes: gradual realizations, routine yet forced masking, burnout and comfort-seeking, and advocacy for self.

Chapter III.

Results and Discussion

In the initial analysis of the data, I uncovered many similarities across the interviews—the women spoke of a multitude of common experiences and feelings associated with autism and masking. I narrowed the commonalities down to four main themes, as I mentioned previously: gradual realizations, routine yet forced masking, burnout and comfort-seeking, and advocacy for self. Throughout all of the interviews, the aforementioned themes were notable.

Gradual Realizations

The first theme that I uncovered was gradual realizations. Under this theme, I listed the sub themes of being different in childhood, learning to mask as a child, and researching normal. Across the interviews, the gradual realizations tended to be embarrassing, stressful, or upsetting. I want to make it clear that these were not positive moments for these women; these were moments where young girls realized that they were not going to be able to fit in unless they adapted themselves to fit into society's standards. These were incredibly attune children who realized they couldn't be themselves if they were supposed to be like everyone else.'

Two of the five participants spoke about experiences growing up in a household that was not particularly accepting of their autistic traits. Participant one made reference to her mother during childhood saying, "my mom used to yell at me a lot… I know she didn't understand…she just kind of like basically forced it out of me over time." In this quote, participant one is talking about how she used self-stimulation, or stimming, as a

child. She said that she would shake her leg a lot or stim with her hands. Her mother would notice and yell at her, leading her to stop this behavior or alter it to be more acceptable. For participant one, being reprimanded by mother was a catalyst for masking. From a young age, participant one realized that if her mother noticed these things about her, other people probably did as well. Similar to participant one, participant three grew up with a mother who did not understand her needs: "I grew up in a household that wasn't very friendly to my needs, unfortunately." As she was talking about her mother, she stated "and she would…chastise me or punish me for acting certain ways, throwing what she deemed to be tantrums, that were actually meltdowns. So I think that's where my masking started."

Some of the participants also shared a common experience of being hyper-aware of how they present and what others thought about them. Participant one mentioned that as a teenager she would frequently be "thinking about what other people are thinking, like, are they noticing my hands are they judging like my hand movements." Participant four also spoke about her experiences of realizing she was different as a child: "When I hit about middle school, people kind of started realizing that I was a bit different…I wouldn't play during recess. I would sit against the fence and like read a book or something… my interests were always like outside of the norm." From a very young age, participant five also recalled specific memories of being pointed out as weird or different and making adjustments to present herself in a more acceptable way. She mentioned that she didn't necessarily realize it as a child, but looking back she recognizes a lot of things that she did that may have been deemed weird or different. An example she gave was:

> I remember like in second grade during recess, I always like crawled around on the floor and picked up everyone's pencils that had fallen out of

> their desk instead of like, wanting to play. Like, that's weird… okay, like, in fourth grade, like I had this one friend and we would always hang out under this one table during recess… I always followed her [referring to this fifth grader she knew] around at recess and like, I didn't play with the other kids.

She mentioned that at this point she isn't sure if she was actually masking, but she recalls that middle school is when she definitely started masking. She remembered wanting to "try to like fit in with other kids but like, I wasn't good at it." She would try "Talking about things that they [kids she wanted to be friends with] like to talk about. And trying to dress the way that other people like to dress and just doing what other people were doing. It's just a copying." She also remembered a specific moment when she was five or six years old:

> I remember like, even in like, first grade, um, like someone would comment like, I don't like when you swing your arms when you walk…then I like started, you know, trying to make sure I don't do that when I'm walking. So like I don't know, I feel like as early as like five or six years old. Like if someone like commented something like you're moving weird…like someone thought I was so sad because I was like looking at the ground while I was walking. And I was like, I was fine. I was like content and happy but they thought I was like looking down at the ground…someone would comment on like me doing something weird like that. And I would try to stop doing it like that.

She recalled moments from as young as five or six years old where people pointed things out to her, that up until then, she hadn't noticed. And from those points on, she adapted those parts of herself to appear less different. Participant two had a somewhat unique experience of being involved in pageants from the young age of 13. She mentioned that she "always felt like a social outcast, kind of an outlier black sheep. I've always known I was different in indescribable ways." She noted that pageantry was where she really learned how to modify these different things about her to appear more typical. She said, "it was an easy way for me to adapt the parts of myself that were maybe odd or unique."

Participant two made reference to an aspect of the pageants that was particularly tricky for her: eye contact. She explained that:

> Eye contact was actually something that they were kind of trying to drill home like when you give an interview…because eye contact can be distracting and uncomfortable for me, I've learned to like look at up here [pointed up between her eyes], you know, in between someone's eyes, or you know, look at their mouth.

She taught herself compensatory techniques to make up for her inabilities. Participant one spoke about her unfortunate experiences being bullied as a child: "I was bullied a lot…I would be called a poser when trying to like mimic other people and like fit in…just weird and different. Those lovely things." These moments made her feel like she was different, weird and unacceptable.

Two of the five participants spoke about doing their own research about behavior and social norms. Participant two mentioned that:

> [She] always loved psychology and trying to understand people and behaviors. And just like the generalization of how society functions. Learning those social graces, especially through pageant kind of helped me have like a rulebook, which was easy to refer back to and to kind of switch on.

Participant two was taught exactly how to perform in a socially acceptable way through her pageant participation. She also supplemented this with her own research into human behavior and social norms. Participant three similarly stated:

> As I got older, I began to become aware of my social awkwardness. And as I was more aware of it, and realized the differences between myself and my peers, I would begin to research once the Internet became available to me… I studied body language very intensely because I was trying to understand… simple things like how to know if someone likes me, and like how to know if somebody thinks I'm funny. And then I would study what the body language of that was, and if somehow someone's body language didn't match up to that, it would become very confusing and I would get mixed signals quite a bit.

Participant three believes she is socially awkward, and this is typically a hallmark of autism spectrum disorder. However, I feel it is important to note how taken aback I was when participant three mentioned this during the interview. I didn't find her awkward at all, in fact I found her to be one of the most articulate, well-spoken, and easy-to-talk-with people I have ever met. Later in the interview, I found out that she did know that people typically saw her as "bubbly, outgoing, friendly, very people pleasing." She stated "I'm sort of at your service, like almost a customer service persona, like I used to associate my mask with working in a retail environment." When she mentioned this, it clicked for me…I was talking to her mask.

Participant four said that teachers did send her for evaluations as a child, "but it was always like, she's got depression, she's got anxiety. They never once went toward autism." So even though participant four was picked out and noticed as being different, nobody ever considered that she was autistic. Participant four didn't explicitly mention beginning to mask from being pointed out as different, but she did mention that she realized and could see that other people viewed her in that way. Later in the interview, she talked about her masking in the current day, but she did not address if it pertained to her in childhood.

Routine Yet Forced Masking

The second theme I discovered was routine yet forced masking. Throughout the interviews, I found that the women talked about masking as if it was something automatic and not under conscious control, while simultaneously feeling unnatural and forced. It seemed that across all of the interviews, the general theme was that the women learned to

mask as children and at this point in life, it was something that just happened automatically.

Most of the participants shared the experience of masking feeling like something that is on without conscious control, but still something that feels unnatural. I asked participant one what masking felt like for her, she stated, “I don't really think about it. I think it just kind of happens subconsciously now.” When I asked participant two about masking, she also stated, “I pretty much mask all the time. In public definitely during I mean, even during this interview 100%.” I also asked participant two if she could explain what masking felt like internally for her, she explained it as:

> Pretty much like it's like a background app. It's always running. It may not be what my brain is focused on in the moment like, during my response right now, it's, it's in the back of my mind, like, what is my face doing? How am I presenting myself? How's my tone of voice? What do I look like? Like all of that is still going on as I'm trying to respond. So it’s definitely always there. But it's not always at the forefront of my mind, depending on whether or not I'm responding or listening.

I thought her analogy of masking being like a background app was really interesting, it’s something that may be on but not necessarily the main point of focus. Participant five works as a speech-language pathologist, so lots of our conversation revolved around her work and how autism and masking affect her work, if at all. She said that she sometimes had to consciously think about masking when she was speaking with parents, because at times she could be quite blunt in her responses. However, she described masking as something that “kind of just like turns on automatically…like, sometimes I think like…how do I say this like, in a nice way, or like something like, Oh, they're like having small talk with me. Like, what should I say?” She spoke about how she had been masking since childhood: “It’s something I have done a lot. Some things I don't really have to consciously think about too much”; because she had been masking for so long, a lot of it

felt automatic to her. Despite the automaticity, masking still required some active effort for this participant. It seems that masking is something that is therefore, available to the person but requires effort to actually be used. Masking is subconsciously on for these participants, but actually using it is a choice that depends on the situation and the person's levels of energy at the moment.

I asked the participants about specific times when they recall masking. Participant one spoke about being in the grocery store and she said:

> I do mask most of the time in the public. If like I start to slip out of that, then my husband is usually there and I'll like cling to him or like my stimming. I've gotten really good at like, making my stims less noticeable to other people because of being told like most of my life to stop stimming.

I thought the comment she made about starting "to slip out of that" was interesting because this implies that even though it is automatic for her, it is not necessarily easy to do for extended periods or when she is already tired, for example. During my interview with participant three, we talked about a recent experience she had when neighbors began congregating around her yard at a time when she wasn't expecting so much social interaction. She said:

> I become aware of the masking I think like a couple of minutes into masking…so it's not a conscious choice…I remember almost stiffening up just as I saw the first person walking up to us. And then there was a lot of other stimulation. My dog was outside with me. And then that neighbor brought their dogs outside and then suddenly neighbors were bringing their children outside. And I remember with each person that came out, I almost felt like I became more like I felt like I had to get smaller like I had to take up less space. Like I had to be out of the way I wanted less people to notice me and directly engage with me. So whereas I was sitting outside with my best friend and talking and having a good time, prior to that, suddenly I was not talking and like staring at people and making eye contact and not really being able to focus on what they were saying. Because I was so focused on making eye contact point your body towards them, so they feel like you're listening and respecting them. Like just all of those little things. And it wasn't until I was already surrounded by all these

> people that I realized, Oh, I'm masking really hard right now. All of these people don't know that I'm autistic.

Participant three explained that she was masking in this situation without even realizing it. She was hiding her feelings and her autistic traits, but this did not happen without her awareness and effort of trying to behave in a socially appropriate manner. Although participant three did not immediately realize she was masking, implying its automaticity, this did not mean that it was not effortful. She also mentioned that masking is like "trying really hard to keep up with responding in the appropriate way"; however, once she realizes she is masking "It usually sort of spirals into shutting down because I don't want to be masking but it's also hard for me to voluntarily stop."

Participant four mentioned something slightly different from the other women when I asked her about masking and socializing, she spoke about a sort of "checklist" that she used in some of her conversations. She said:

> I'll like, go through like a checklist in my head like, Okay, did you ask them where they're from? Did you remember to ask them about like, do they have pets? Like what area they live in? It's almost like, like, I've got like separate lists for each like topic that I kind of go through my head.

She also stated that she pulls

> From different people that, you know, I feel like do well, socially, like what would they say in the situation? You know, I'm always like reflecting like, in each scenario, like, pulling from like different personalities that are within like, my, like family group or something like that. So I'm like, hyper aware of like, how my face looks, inflection in my voice, like, it's like I have to be very like on the entire time.

The feeling of having to be "on" when socializing seemed similar to the sentiment expressed by the other participants. It seems that the mask is available without conscious awareness, but the process of using the mask is effortful and requires attention.

Burnout and Comfort Seeking

The third theme I found was burnout and comfort seeking. Burnout refers to feelings of mental and physical exhaustion after using an extensive amount of effort for a certain task, and in this specific example, that task is masking. All five of the participants felt some degree of burnout after masking and they all used comfort-seeking behaviors to quell these feelings.

I asked the participants how it feels if they have to participate in social situations. Participant one talked about going to the grocery store and how just being in social situations for a short period of time can be really tiring and difficult for her. She explained that "honestly, just going out and being in public around other people is very exhausting. Like, I'll have to come home and just kind of relax for the rest of the day…socially it is exhausting." It is clear that social situations are not comfortable for this participant and involve extensive efforts to mask. Participant four is a hairdresser, and she explained that parts of her job can be stressful due to the social nature of it. I asked her what it was like for her to socialize with clients all day and she said:

> At like some point my words become like stilted and then I feel like I kind of come across like, not incompetent but maybe a little bit or even my fine motor skills [become] a lot clumsier, it's hard for me to like, talk. And then it takes like several hours after I get out of work to be able to kind of regain those skills again.

She described a sort of physical deterioration that occurs as she approaches a burnout point. Participant five works as a speech-language pathologist and she works with children and their parents during work. I asked her how she typically feels after a day of work and she said:

> I have to take my after-work break…I usually am somewhat tired and if I don't take my work break then like, if we like go to do something and I didn't get a chance to take a break then like I'm gonna have like, a lot

> harder time with like, sensory input and like, a lot harder time with just like handling things. Um, then if I like am able to take a break…It's not necessarily a break for like physical break, but like a mental break…I'd say the biggest thing is like the sensory stuff…I might have a meltdown if I don't get to take a break and like there's too much sensory stuff or like just things that are different than usual. Then like, I might not really like handle it very well and like start to kind of like, have a meltdown. But I feel like we've like figured out how to like, avoid that happening by letting me take a break when I need to and stuff like that. Or like if I tell my husband No, actually. I can't do this right now. And he like understands instead of trying to like push me to do something.

I asked participant five what a meltdown would be like for her, she said:

> I'm crying and feeling like everything is bad. Like, hard to be able to get on and like I have to go to a very calm place like do nothing for a little bit…I think it would look like a tantrum but like not have the same like not the same causes a tantrum or end goal is a tantrum but looks like a tantrum.

Being pushed to do things that are not comfortable or having to do things without taking a break after work seem to be triggers for highly emotional and upsetting meltdowns for this participant. Participant four stated that after a long day of work she felt

> Like I'm able to like form you know, like pretty coherent like thoughts, but it's like the connection between my mouth and my brain are like off by that point. And then I also feel like extremely like clumsy as well. Like, running into things and like, almost feels like my body feels like a little drunk or something, you know…it just feels like all that interaction just completely takes it out of me.

Participant four described that she experiences physical impacts from having to mask all day at work. I asked participant three to refer back to the situation she was talking about with her neighbors. I asked her what she felt like after that situation had occurred, she said it feels

> Super tense in my body…I call it my foggy brain. Where like, I just feel like after masking, it's just hard for me to unmask once I've begun to mask and oftentimes that transition either leads into an almost meltdown or like a dwindling ability to focus or regulate my emotions… Usually, it becomes harder for me to express any real thoughts or feelings because I kind of almost separate myself from my emotions…I'm not able to

> process those emotions the way that works best for me. So I often feel that soreness, the brain fog and it typically goes away within a couple of hours if I'm not forced to mask for an extended period of time. But then sometimes, like with the situation with the neighbors, for example, I was masking around the neighbors, and then coming back into my own home right away. I tried to unmask and then it came off to my husband and my friend as rude and almost confrontational because it was like a very sudden switch from polite bubbly smiley, to I don't want to do that anymore. I'm very tired. And yeah, it manifests in very, like angry presenting ways.

I asked her if she could explain this in more detail:

> Once I realize I'm masking it usually sort of spirals into shutting down because I don't want to be masking but it's also hard for me to voluntarily stop…I usually refer to the shutdowns as almost disassociating, I space out very often, it becomes hard for me to focus on anything that's happening around me. So a lot of times from the outside it probably looks like me quietly listening and nodding a lot and the nodding or like, like twisting of my hands or fingers becomes like my stim because I've developed that as a socially appropriate stim. So like, it looks, I feel like this sounds horrible, but it looks like active listening, like I've read a lot about active listening, and I go Uh huh. Yeah, that's great. Uh huh. But inside my head, I'm not retaining that information. And I'm not able to recall that information very well.

I asked what is usually looks like when she starts getting too overwhelmed, she said:

> Usually it spirals into things like pacing in circles and counting my steps, and like trying to almost regain control of my environment by doing as many repetitive things as I can. And then if that doesn't work, then it can spiral again back into things like hitting my head repetitively. Usually, there's plenty of crying involved. I don't have control over the volume of my voice when I'm in a meltdown so people can think that I'm yelling or screaming at them and that's, that's just the only way I can communicate. It just comes out that way.

It is important to distinguish between a meltdown and a shutdown, and both of these can vary from person to person. Based on these interviews, my understanding is that a shutdown is more reserved and a bottling up of emotions, while meltdowns can be louder and sometimes more aggressive. Both of these are responses to having to mask for too long, and each autistic person's "too long" can vary. Participant three said:

> If I'm in a place of comfort like my home around people I'm comfortable with, then it becomes more of an outburst of that anger and those emotions and sometimes it'll lead me to, to breaking things I still sometimes break things if I'm say like sitting at a table sometimes I'll like, like, I'm stimming and flailing my arms and I'll hit something off the table. But if I'm in public, it usually winds up spiraling more into a shutdown scenario, where I bottle it up, and I just try, I elope if I can like I just try and get out of the situation as quickly as possible. And then find a place of comfort like if, for instance, if it starts to happen in a grocery store, which is fairly often then retreating to my car is the quickest way for me to unwind and let myself do things like get my squishy stim toys out or like rock back and forth and I feel comfortable in that space to do those things.

It seems that all of the participant's experienced some form of meltdowns, but the way they experience them are not necessarily the same.

Participant two told me about how she functions on a daily basis and the things that stress her out, she said "I'm capable of doing just about anything, you know, an allistic person could do. But there are days where that fluctuates based on a lot of variables that are uncontrollable. And on those days I look the part but on the inside, it's turmoil." She also made an interesting analogy:

> Trying to care for myself after caring for my house, my daughter, and my relationships. That's a hard thing to find time and energy for and you know, just basically knowing that my default state, like full tank of capability is equivalent to like an allistic's [allistic meaning someone without a disability] quarter tank…And that's a hard realization to come to, to know my limitations.

I asked the participants how they dealt with the difficult emotions they experienced when it came to burnout. Participant two replied:

> I don't show my emotions outward when I'm in a masking state which is usually publicly. I'll come home and the meltdown will happen at home. But publicly I kind of have the privilege of being able to reserve those emotions for later on. On the internal side of things, it is just massive depression. Like I'm just trying to keep everything bottled up. I'm trying to regulate my emotion. I'm still hyper fixated on how is my face appearing? I don't want to offend other people or upset other people in the process of me trying to amp down my nervous system response. But yeah, it's just a lot of pressure to try and keep that that lid on until I get home basically.

She explained that for her, masking means partly hiding all of those distressing emotions and waiting until she is home to let them out in the form of a meltdown. I asked her what it would look like when she got home and could let herself release the mask, she said:

> Usually I try and separate myself…sometimes it's crying. Sometimes it's just I need to listen to music or read or just like watch a show to kind of take my mind off of the intensity of what I'm feeling…But a lot of times it's very emotional, and these are often mistaken as like, tantrums because they look very emotionally aggressive.

Participant two mentioned to me that she was masking the whole time during the interview, so I asked how she would likely feel after the interview would end and she said:

> Pure exhaustion would be the best way to describe it. It's like, not just like, Oh, I'm tired. I need to take a nap. It's like full body. Like the system just cannot function to the degree it needs so like simple tasks become more difficult for me because I've exerted so much energy. I'm performing basically. And so it often comes across as full body exhaustion. And sometimes there's some emotional dysregulation with that as well. Because I've been concealing so much, again, kind of keeping that lid on what's going on internally through that, that I can I can become dysregulated in that and I need alone time to reset that system.

She revealed that the interview would put her into a state of pure exhaustion. I feel it is important to note that during the interview this participant did not present at all as tired or distressed in any way. She was extremely composed, well-spoken and articulate. I would not have ever guessed that all of those things were happening for her internally…another reminder of how equipped she is at using her mask. When I asked participant three what helps her deal with her feelings of burnout she said:

> It’s usually really simple things-jumping around, rocking back and forth, those sorts of things…usually while listening to music, I call it like, I'm a terrible dancer, but I call it my dancing. Because listening to music and being able to reconnect with that sometimes, when I was younger, it was poetry and reading a lot more. But now it's turned a little bit more into music, but just being able to hear other people's expression of emotion and being able to sort of almost embrace that and like bring it into myself

> gives me a sense of like validation, I guess. Like yes, I'm feeling confused right now. Other people also feel confused at times. Yes, I'm feeling frustrated and angry. Other people also feel that way. It's not just because I'm autistic. And it's not just because I was masking, other people get these surges of emotion. And so like listening to some sort of creative or, or sometimes audiobooks, usually helps me get back into that place where I can find my own emotions again.

I asked the participants what or who brings them comfort and what helps when burnout is occurring. Participant two said, “Definitely my daughter and my husband. Those are the people that I think could see me at my worst and still love me and still are here with me.” She mentioned that something that helps her to feel the most comfortable around them is that she is pretty sure her daughter is also autistic, and her husband is also neuro diverse. She said:

> Being a neuro diverse family, we operate a lot differently. We have different values, I think, different expectations or even just more relaxed views of certain things as a family. So I think that really bodes well to be unmasked in those ways…and just kind of experience life in a more simplistic way. And so I think it removes the pressure to, to have to perform or to have to be something that any of us aren't, we just kind of exist as we are and support each other to the best of our ability.

I asked participant four what would be helpful to her when she is experiencing these feelings of burnout, she replied, “Usually like sitting in my car for like up to like 30 minutes before like, leaving the parking lot or like I'll drive home without any music on. When I get home, I usually like take like a hot bath and like keep the lights pretty dim.” She explained that minimizing sensory input was really helpful to her in those moments. I also asked her who makes her feel the most comfortable, and she said her mom, who is also autistic—“I would say my mom, probably. Just like being at her house, just you know, us two. She's also autistic. We're pretty much like the same person almost. So it just feels more natural.” When I asked participant one who makes her the most comfortable, she talked about her husband: “He’s a rock of comfort for me, like just

touching him sometimes really leaning on his shoulders enough to like, deescalate my body. So I mean, just having that really helps." Participant one said that her husband was a safe and comforting person for her. She mentioned that her husband is neurodivergent as well, which is helpful because it provides a sense of "Familiarity, having someone that struggles with a lot of the same things that I do and has those same sensory issues that they have to deal with." I also asked participant three who makes her feel the most comfortable, she referred to two of her best friends, one of which is autistic. She told me about her friendship with her autistic best friend:

> We kind of were on this diagnosis journey together. And found out that oh, there is probably a reason why we've always felt most comfortable around each other. So also, when other people identify themselves as autistic, I tend to be able to relax a little bit more because I know there'll be a lot more understanding about my inability to make eye contact or there'll be more understanding about my stims or there'll be more understanding about you know, my facial expressions not always being so pleasant.

She also told me about her relationship with her other best friend:

> It's nice to have someone like my best friend around who is able to either remember those things for me to remind me later, or to be like, hey, are you like I can tell that you're not really into it? Let's get you out of a situation or, like, let me find some way to comfort you. So that way you can refocus in this situation.

At this point, it was a running theme across all the participants that masking leads to feelings of burnout which are expressed through shutdowns or meltdowns. Furthermore, having a comfort person is helpful and in all of these cases, that comfort person was also either autistic or neuro divergent in some way.

Advocacy for Self

The next theme I found was that all but one of the women had to advocate for themselves when it came to getting the correct diagnosis. Participant one said, “I had gone my entire life like struggling with mental health because of having a bipolar diagnosis that didn't fit right.” She was misdiagnosed as bipolar and had to seek out another diagnosis herself because she often felt “mental health doesn't work because this isn't working for me, but it wasn't what I needed. So it wasn't that it didn't work. It was just that I was misdiagnosed.” She was not diagnosed as autistic until she was an adult and actively sought her diagnosis out. Similar to participant one, participant two also had to seek out and advocate for herself to get the correct diagnosis. She said:

> I started taking the autism and indicator tests online, some of them unofficial and some of them, like official ones that they use in the diagnostic process, just to kind of gauge my baseline. And every one of them was saying yes, seek a diagnosis if possible. And then that's when I just like…researched articles, started following people on social media, YouTube and blog and, and all sorts of testimonials. And that's when like, self-identification, and I was self ID or self-diagnosed for a period of time. And that's actually when I came out on Facebook to friends and family which was a terrifying step because I didn't have this diagnosis yet.

She mentioned self-diagnosis here, and this is a growing phenomenon due to the difficulty autistic women face in getting the correct diagnosis. Similar to participant one, participant three was also misdiagnosed: “I was misdiagnosed before I was diagnosed with autism. I was diagnosed with OCD and panic disorder.” To actually get the correct diagnosis, participant three had to advocate for herself and similar to participant two, she was self-diagnosed for some time:

> Realizing I was autistic is very separate from my formal diagnosis because I embraced it and believed it for about 18 months to two years before I was diagnosed and I started treating myself and demanding accommodation as an autistic person before my formal diagnosis and leading up to it I remember feeling and I I'm very aware of how

> inappropriate this may sound, but um, I remember feeling a lot of anger around stereotypically presenting autistic people, because I remember feeling as though like I deal with that. So why can't you and I remember feeling a lot of frustration constantly about like, well, I have to clean up after this incontinence issue but, but like who's, who's cleaning up after me? No one because I was hiding it.

Participant three revealed a very vulnerable sentiment in the previous statement, and although she felt it could be taken as inappropriate, she explained that she felt angry toward stereotypically presenting autistic people because they received support and acknowledgment that she couldn't get just because she was so good at hiding her autistic traits. She said:

> Once I realized I was autistic, and started seeking out accommodations, I realized very quickly that without a formal diagnosis, people weren't respecting my declaration of being autistic, people weren't really believing me. I did a lot of research before I came out as autistic…And it was mentioned to me in passing by a counselor and I thought who me? Of course not like that doesn't make any sense. I'm so outgoing and I'm so you know, I'm so great with everyone, that can't possibly be me. And it wasn't until I came across TikToks actually by an influencer named Paige Layle. Yeah, and she I came across her TikToks while doing research, because for me research about any given diagnosis has always looked more like getting information from the people who have it. Rather than looking at the medical side or the you know, non-autistic view of it. I wanted to know how people who were autistic felt and I came across her TikToks about how autism presents differently in women or in females in general. And I remember being like feeling very personally attacked, and I was like, wow, this is crazy. And when she started talking about masking, that was the first time I had ever questioned that it wasn't normal for me to have to researched body language. It wasn't normal for me to have to look up how do I know if someone likes me? How do I know if you know? Those things do obviously occur occasionally with neurotypical people, especially throughout adolescence, but even as an adult, I was like, how do I act in an interview with like, I would, you know, constantly obsess over those things, and I always felt like I performed best when I mimicked what I was told worked. And so it was a lot of research. And then I finally came out as autistic leading up to my diagnosis.

Similar to participants two and three, participant five was also self-diagnosed prior to receiving an evaluation. She told me she wasn't officially diagnosed until 2020, and I asked her what that journey was like for her:

> At that point, like I pretty much already was self-diagnosed and like figured it out and like, by then like I was looking at like, oh, autism is different in females…And like at my old job, I worked with a lot of autistic kids too, I was at one of the two elementary schools in the district that had autistic support classrooms. So I worked with like all those kids and like those five classes like I had seen a lot of other autistic kids. So like that kind of like just being around them like kind of helped me like figure it out even more so like, Oh, I like I definitely like I know that you're like a six year old but like I relate to these kinds of experiences you're having. So I pretty much already knew that I was autistic going into it. Um, the evaluation and like I even like, prepared like, all sorts of like, here's a list of everything I remember from my childhood that like all the things I remember are things that I used to do or things that like I do like my autistic students, like they do them. And like I remember I used to all these different kinds of things like all these like went through all these different lists say I found online of how to zoom in females specifically and like, highlighted all the ways that pertain to me and like write about examples of how these pertain to me and like a cross off the ones that these things don't pertain to me I'm really I went in like super prepared, which was probably like a red flag for autism in and of itself of like, how much I was like, how much research I had done on it. Because I was like hyper fixated on like learning about autism then.".

As she mentioned, she was very prepared and did a lot of research prior to seeking out her diagnosis. She had to advocate for herself, if she didn't, she may have never gotten the diagnosis that she deserves.

Participant four had a slightly different experience when it came to diagnosis than the other four women. She explained to me that she hadn't actually been diagnosed as autistic until a month before our interview. I asked her what that process was like for her, she responded that she initially sought out a diagnosis for social anxiety, but then her "Psychiatrists' supervisor, who was a woman, asked me if I had ever looked into autism and women and so I did some research and it was like, pretty much me." Participant four

had the unlikely experience of autism being brought up to her as a possibility by a psychiatrist. Participant three did briefly mention that a counselor brought up the potential of autism. However participant three's journey still required a lot of research and self-diagnosis. The difference between participant three and four is that a counselor cannot give a diagnosis, but a psychiatrist can. Therefore, when the counselor mentioned autism to participant three, she had to do a lot of research and seek out a diagnosis herself. When the psychiatrist mentioned autism to participant four, she was already where she needed to be to get a diagnosis. I asked participant four if she thought she was diagnosed earlier or later compared to other women, she said "Honestly, I think maybe a bit earlier. I hear a lot of people don't get diagnosed till they're like in their 30s." I asked her why she thought she was able to be diagnosed earlier and she said "We have military health care. So I had the opportunity to go and it wasn't like a financial burden for us." She brought up a really important point, which is that regardless of self-advocacy, research and firm belief, some women simply cannot get the diagnosis because of inaccessibility or the financial cost.

Chapter IV.

Conclusion

Suggestions from the Women

One suggestion for future research is to actually involve autistic women in the process of fixing the current biased diagnostic tools. Participant two said:

> There is so much of our experience that is out of touch because we're being spoken over, we're not being heard. We're not being considered in the process of research or diagnostics, support systems just the whole system is just so flawed and it has to be not just revamped, but uprooted and just replaced…We don't know what autism looks like beyond because we've had such a narrow control group of white male children…There is massive amount of untapped potential for understanding beyond what we've only known to be a child presentation based on a white boy, we need to have this research done based on our standards, not the standards of society.

Participant four said "Interviewing an autistic person, that's really the best way to get the information is like actively talking to the community." Participant five said "I feel like maybe just having autistic people help to develop whatever kind of assessment is used… I'm glad that you're taking the time to ask the actual people."

Another suggestion is to better train clinicians to identify how autism may look if the person is masking. Participant two said:

> This is a huge one for training medical professionals in identifying these masking traits, what to look for, and everyone from like nurses, doctors, psychologists and therapists, like, especially therapists, because that's where we're at we are in therapy, searching for answers, years and getting burnt out, trying to figure out what's wrong with us when we're just we're being treated with these neuro typical expectations that can't be applied to an autistic mind or body.

Participant three said:

> My advice to future psychologists and specialists in autism would be to be a little bit more open minded about the physical presentation of how you look at people. I think as a society in general, we need to be less convinced by the things we see and more open to listening to how others are actually feeling…I had therapists who would even tell me like, oh, well, you can't be autistic because I have an autistic client who doesn't even know how to smile and you smile fine. And things like that. I got a lot of, Oh, are you sure you're autistic? Or well, maybe you should prepare yourself for not being autistic. And it almost felt like gaslighting. Like I knew they didn't get the emotional experience that I was going through in my mind and I knew what I had experienced my whole life and having people tell me that my feedback about my own personal life and my own brain was irrelevant, because somebody else had, no offense, a degree in it…The autism industry definitely has a lot of work to do in just understanding that people's feelings and what's going on in someone's brain is not always how there presenting to the world.

Participant one said:

> The biggest thing that I think is that there is a lot of stigma still around that autism is a boys condition. That it has to present in this particular way. And I think that men present a lot differently than women do, and I think because of that, that's why a lot of women go misdiagnosed or undiagnosed because they're basing it off of these very common traits that aren't necessarily seen in women… I hope that researchers and psychiatrist in the future don't say that it is over diagnosed. They just realize that more people have these differences in their brains than they realized before.

My Suggestions

Overall, the women had many ideas and suggestions for future research. They were more than willing and ready to talk about the suggestions they had. It is extremely important that autistic women are involved in future endeavors of autism research. It simply does not make sense to not involve them when there are so many autistic women who have ideas, knowledge and experience that a non-autistic person could not have.

I also suggest we do more qualitative research with BIPOC individuals, as well as other underrepresented groups of people. We also need to research how autism may present differently in people with different gender and sexual orientations.

More than anything, I suggest we start listening to people when they speak up about their experiences. Autistic women have been speaking about this issue in diagnosis for quite some time, we just have not been listening.

Limitations

A potential limitation of this study is that I recruited women who already had some sort of advocacy for autism on their Instagram accounts; these women may be particularly interested in autism awareness and therefore, be more well-versed on the topic compared to other women who are not publicly advocates. The reason I did this, however, is because I needed proof that the women I recruited were able to verbally communicate their experiences and opinions on the topic, and so I needed women who demonstrated that on their social media account. Furthermore, I do not feel that this limitation makes their experiences or opinions less important or valuable, it is just something worth noting.

Another limitation is the small sample size; however, my options were to recruit a larger sample size and have less in depth analysis, or a smaller sample size with more in depth analysis. I opted for the latter option as I felt it was more important to have quality of interview over quantity.

Future Research

More research is absolutely needed on this issue. I believe we need more qualitative research with autistic women themselves. Ultimately, I think the diagnostic criteria need to be reformed and this means more in-depth exploration of how autistic

women present differently and how we can assess autism in this population with sensitive enough criteria.

I believe the literature is really lacking in qualitative research specifically, and that is because a lot of what we need to gain understanding about is not quantitatively measurable. Though there can be some issues and bias with self-report, I do believe it's value in terms of this issue has been understated and underused. We cannot simply ignore the things we cannot see. We need to still research these things—experience is no less important than the things that we can measure quantitatively.

More research is also needed in other underrepresented populations; we need research amongst genders, races, different cultural backgrounds—all of these factors may influence the way autism presents. It is ignorant to believe that a disorder would look exactly the same across differences as big as gender, race, culture, etc. In many contexts, society expects different things from people of different genders, races, and backgrounds. And while I am not saying that is necessarily right, it is simply a fact and that needs to be accounted for when it comes to diagnosis. When a person knows what society expects from them, it can be difficult not to conform. More than being difficult, for some people it may be unsafe to not conform. When conformity is paramount, we must know that it will impact the presentation of any disorder.

Concluding Remarks

All of the women I recruited for this study were extremely willing to participate, wanting to share their voices and experiences, and wanting change. There is a clear bias in the diagnostic criteria for assessing and diagnosing autism spectrum disorder. This is not to say that men are not affected by the bias as well, the point is that anyone who

possesses an enhanced ability to mask their symptoms, will be affected. However, research does show that it tends to be more women than men who have this increased ability, and this is why so many autistic women are falling through the cracks and not getting the correct or any diagnosis at all.

It is detrimental to a person's well-being to be misdiagnosed or not diagnosed when they do in fact have a disability. Autism can present like an iceberg in people who mask their symptoms highly, you may barely see any of their struggle externally, but you have no idea what is happening internally. Autistic women deserve better assessments, they deserve better diagnosticians, and they deserve people who will advocate for them as much as they have had to advocate for themselves. From these interviews, we have a more clear picture of how autistic women experience masking—we know that for all of these women there were moments in time where they realized they were different and would need to hide or compensate to blend in, we know that masking is something they learned to do and has eventually come to feel automatic while still being forced, we know that they all experience some form of burnout from masking and require a lot of recuperation time afterwards, and we know that for most of them, getting a diagnosis required a lot of self-advocacy and effort. Furthermore, every one of these women were diagnosed in adulthood, and several of them were misdiagnosed. They had to do their own research and seek out a diagnosis and essentially, prove to diagnosticians that they were autistic.

Diagnosis should not involve a person needing to prove anything, diagnosticians should have criteria that are sensitive enough to detect disorders without a person needing to provide extensive reasoning and evidence that they deserve the title. A person

shouldn’t have to fight for their diagnosis, it’s theirs. Whether you call them autistic or deprive them of the diagnosis, they are autistic, they always have been autistic and they always will be autistic—the difference is a matter of being able to get the support and guidance that comes with a diagnosis or having to take the journey alone. We need better ways of assessing, diagnosing, and supporting autistic women, they told you themselves.

Appendix 1.

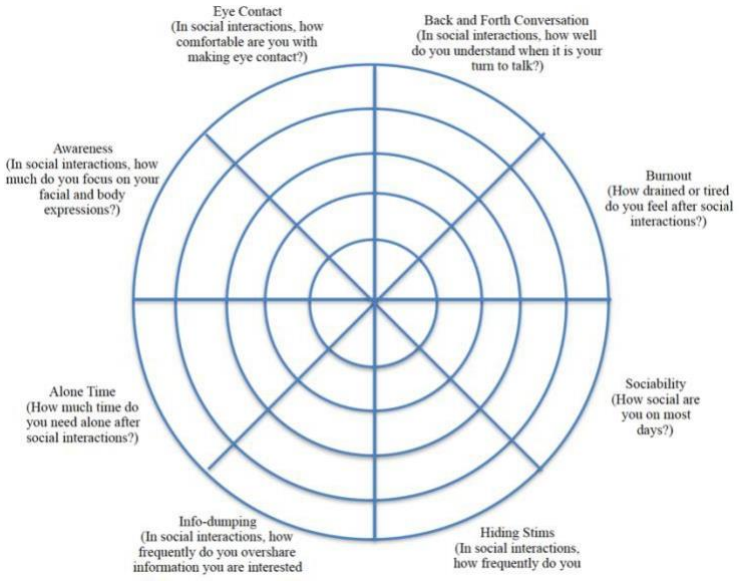
Interview Guide

What I want to explore	Actual questions
Warming up	I'd like to start by having you tell me a little bit about yourself… What kinds of things do you like to do? What do you currently do for work/school? Describe a typical work or study day for you. What are the most social aspects of your day? What parts of your day stress you out?
Experiences of masking	Can you describe a situation where you know that you are masking?
Awareness of own masking	During (insert situation), how frequently are you thinking about your own masking? Can you walk me through what some of your thoughts might be like during (insert situation)?
Emotional effects of masking	How do you feel after (insert situation)? Is there anything you feel you need after (insert situation)? How would you feel if you had to engage in (insert situation) for an extended period of time?
Reasons for masking	How do you think other people view you during (insert situation)? Do you feel comfortable during (insert situation)?

Situations where they don’t mask	When and with whom do you feel the most comfortable? What about (insert answer from previous question) makes you feel the most comfortable? How much do you knowingly mask when you are (insert answer from when and with whom)?
Diagnosis	Have you been professionally diagnosed with autism? If no: Would you consider trying to get professionally diagnosed? If yes: What was that experience like for you? What led to you getting your diagnosis? Do you think you were diagnosed early or late compared to other women with autism? Why do you think you got diagnosed earlier/later?
Advice or suggestions	What advice or suggestions do you have for future researchers to help autistic women? Is there anything else you would like to tell me? Is there anything you would like to ask me? Thank you so much for your participation in this study!

Appendix 2.

Masking Pie Chart



"This chart represents some traits that autistic people may experience during and after masking in social interactions. There are eight triangular segments, and each of those represents the blurb of writing above it. Within each triangle are five segments. You can fill each segment out using the "drawing" tool in Microsoft Word. Segments in the center rep-resents little experience of the trait, segments toward the outside of the circle represent frequent experience. An example is if I filled out only the center-most segment for alone time, this would mean I only need a little bit of alone time after interactions. However, If I filled out all of the segments for alone time, this would mean I need a lot of alone time after inter-actions. This chart will likely take around 10-15 minutes to complete. It is okay if it is not neatly filled out."

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