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"I'm Excited to Have my Voice Heard": Understanding Autism Research Participation From the Perspective of Autistic Women, Non-Binary Adults, and Parents of Autistic Girls

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Abstract

The purpose of this qualitative study is to better understand how underrepresented gender groups within the autism community engage with autism research as participants. Using reflexive thematic analysis of semi-structured interviews with autistic women, autistic non-binary adults, and parents of autistic girls/women ($N = 41$), we identified themes that encompass motivations to participate in research, barriers to participation, and elements of a research study that facilitate or hinder the research experience. Some themes overlapped with previous research with different groups of community members. However, other themes surrounding representation in autism research and the importance of community in facilitating research participation were novel and particularly salient among members of these underrepresented gender groups. This study builds upon previous research aimed at understanding gender-specific research priorities to extend the field's understanding of research *participation* for these historically underrepresented groups. Themes from the current study can therefore improve the facilitation of future research partnerships with members of this community to achieve shared research goals moving forward.

Lay Abstract

Previous studies have asked autism community members (parents of young children, autistic adults, caregivers of adults) about their views towards autism research, and found that community members are motivated to participate in research that they think will be helpful to the community or themselves/their child. They also found that personal values play a large role in the decision to engage with a research study. To our knowledge, this study is the first to focus on *gender* while examining study participation. We interviewed groups that have historically been underrepresented in autism research: autistic women, autistic non-binary people, and parents of autistic girls. Our results were very similar to studies focused on other community members, but one new motivator to participate in autism research for these underrepresented groups was the idea of improving the representation of their gender in autism research. By focusing on groups that have been historically under-recruited as autism research participants, we were able to identify group-specific suggestions for how autism researchers can make the experiences of their participants more comfortable and fair.

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Since the turn of the century, the number of studies focused on autism has exponentially increased (Cervantes et al., 2021), resulting in remarkable strides in what is known about the condition. However, much of the early work in the field was rooted in misleading theories about autism, leading to the development of inhumane intervention approaches and widespread stigma towards autistic people (Evans, 2013; Silberman, 2015). For decades, community members have advocated against the harmful treatment of autistic people (Botha, 2021; Kapp, 2020; Silberman, 2015), some of which may have occurred during the research process itself. People with developmental disabilities, particularly those with co-occurring intellectual disability, have been reported to experience coercion in the consent process (Fisher, 2003), and be more likely to experience discomfort or pain during clinical trial procedures (Bellieni et al., 2012). Further, a recent review of autism intervention studies found that researchers rarely report adverse events that their participants may experience (Bottema-Beutel et al., 2021). Establishing a safe, mutually beneficial researcher-participant partnership is critical to yielding meaningful results from research. This study seeks to understand ways that this partnership can be fostered by qualitatively analyzing responses to questions regarding participation in research from autism community members who have been historically under-represented in autism research.

Previous work has established a baseline understanding of how autism community members engage with autism research as study participants. Autistic adults and family members reported less satisfaction with research engagement compared to clinicians and researchers, citing dehumanizing experiences, a lack of reciprocal communication, and not feeling valued or heard in their engagements with researchers (Pellicano et al., 2014). Other studies have identified factors that drive decisions to participate in autism research: Fletcher-Watson et al. (2019) surveyed European parents about early childhood research, and Haas et al. (2016) interviewed Australian adults and parents of adults on participation in adult-focused studies. Despite the focus on different lifespan periods, both studies converged on several findings: Participants valued alignment between the long-term goal of the study and their community values, as well as incorporating elements of *choice* into study participation. Additionally, these studies found that autism community members are motivated to participate in research for a range of reasons, including wanting to help the community and to learn more about autism or themselves/their child. These motivations align with the main motivations behind parents participating in genetic autism research (Lilley et al., 2024; Singh, 2015; Trottier et al., 2013).

This line of research has been extended to examine research participation in groups that have been historically under-represented. Since the conception of the field, autism research participants have overwhelmingly consisted of younger, white, male children (Fombonne, 2003; Maenner, 2023). In recent years, research funding agencies and working groups have encouraged researchers to recruit participants from underrepresented racial, ethnic, and sex/gender[1] groups (Interagency Autism Coordinating Committee, 2023; The National Institutes of Health, 2021). In line with guidance, researchers have identified facilitators and barriers that racially and ethnically diverse communities face in participating in autism research, providing cultural-specific recommendations (e.g. meeting families in community settings; Maye et al., 2022; Shaia et al., 2020; Zamora et al., 2016). Recent commentaries on autism community engagement have urged the importance of better understanding and including historically underrepresented sex and gender groups in research (Cascio et al., 2021; Taylor & DaWalt, 2020). However, to our knowledge, no prior study has examined factors affecting the ways in which underrepresented *gender* groups engage with and participate in autism research, and the specific barriers they may face.

In childhood, it is estimated that four males are diagnosed with autism for every female (Maenner et al., 2023). Children assigned female at birth are consistently diagnosed later in childhood compared to their male counterparts (Dillon et al., 2021; Harrop et al., 2021, 2024; McCormick et al., 2020), or are not diagnosed until adolescence or adulthood (Harrop et al., 2024; Lai & Baron-Cohen, 2015; Russell et al., 2022). Although autistic women are more equally represented in adult-based research (Rutherford et al., 2016), autistic females make up 17% of overall autism research participants, with even less representation in intervention studies (Watkins et al., 2014). While some of this under-representation may be explained by childhood diagnostic ratios, there is also evidence that gold-standard diagnostic tools used in autism research may systematically exclude autistic females from study eligibility (D'Mello et al., 2022). Autistic females, many of whom are socialized as girls, are known to have different lived experiences with autism throughout their lifespan, such as different interests, social relationships, and mental health risks (Allely, 2019; McFayden et al., 2023). These differences underscore the need to include females in research, and they may account for or be affected by the under-recruitment of this group in autism research.

The autistic population is also known to significantly overlap with the transgender and gender-diverse (TGD) population, with TGD people receiving autism diagnoses at an estimated rate 6 to 10 times higher than cisgender people (Heylens et al., 2018; Kallitsounaki & Williams, 2023; Warrier et al., 2020). TGD autistic people are multiply minoritized by these intersecting identities, experiencing compounding effects of discrimination, depression, and anxiety (Strang et al., 2021). Similar to cisgender women and girls, TGD people experience significant disparities in diagnostic timing and are also underrepresented as research participants (McQuaid et al., 2024; Strang et al., 2020). Cascio et al. (2021) noted that not considering the *gender* of research participants, in addition to their assigned sex at birth, can lead to an uncomfortable research experience. This was reflected in two recent studies that found that research priorities varied by gender identity (Grove et al., 2024; Putnam et al., 2023). The current study explores whether these differences in priorities may also be reflected in engagement and experiences with research studies.

The purpose of this qualitative study is to better understand study participation from the perspective of three underrepresented gender groups within autism research: autistic women, autistic non-binary adults, and parents of autistic girls and women. Using semi-structured interviews and reflexive thematic analysis, we sought to understand what motivates and facilitates community participation in autism research and to identify barriers to research participation. We focused on the perspective of both autistic adults (women and non-binary) and parents of autistic people, as the biggest sex/gender disparity in research is seen in early childhood, when parents play a larger role in their child's study participation, usually facilitating their enrollment in studies.

Methods

Positionality Statement

Our study team consists of a mix of autistic and non-autistic researchers, some of whom have personal experiences as research participants, as autism researchers, with late- or undiagnosed autism, and with gender diversity. Interviews were conducted by one of two graduate-level cisgender women in their mid-twenties, who disclosed any details of such identities or shared experiences with participants at their discretion. Data analysis was conducted by the lead author (who was also an interviewer) and by a transgender, undiagnosed autistic woman who was hired to work on the analysis portion of this project to gain research experience and to provide both lived and professional expertise on the intersection of gender and autism.

Qualitative Research Paradigm

The authors and research team approached the current qualitative research study using an interpretivist paradigm (Willis, 2007). By adopting this paradigm, we aligned with the qualitative research assumptions that knowledge borne from this work is constructed by the experiences and values of both our participants and the research team. Our team ascribes to the neurodiversity framework, which does not equate neurocognitive or behavioral differences with deficits and aims for understanding and acceptance of different neurotypes, such as autism (Chapman, 2020; Rosqvist et al., 2020). Many of our participants also expressed this perspective. We, therefore, acknowledge that the intersection of these values alongside shared gender and neurotype identities between participants and researchers in this study informed the way we constructed and interpreted the data.

This study's data collection and analysis procedure also align with the interpretivist paradigm, such that we used semi-structured interviews to capture the experiences and impressions of autistic participants and a reflexive thematic analysis approach (Braun & Clarke, 2022), which involved the authors and research team actively considering their roles and how their personal and professional backgrounds informed the analysis.

Participants

Participants were recruited through a local autism research registry, targeted social media posts, and an online research participation website. Participants were recruited for a larger mixed-methods study focused on gendered experiences and perceptions of autism research (see Putnam et al., 2023 for details). Participants were eligible to participate in the larger study if they lived in the United States and either reported that they had a clinical autism diagnosis or that they were actively in the process of seeking a diagnosis. Our team chose not to exclude autistic people who did not yet have a formal diagnosis but who were seeking one due to the challenges and barriers that adults, women, and TGD people experience during this process (Langmann et al., 2017; McQuaid et al., 2024; Navot et al., 2017). Participants in the larger study completed an online survey, which included forms related to demographics and answering questions about autism research priorities (see Putnam et al., 2023 for details). Participation in the survey portion of the study was not limited to autistic women and non-binary people or to parents of girls or women, however, only individuals from these groups were invited to participate in a follow-up interview.

Participants self-reported their gender (woman, non-binary, or otherwise specified) or their child's gender. Participants ($N = 41$) were comprised of 21 autistic women, 10 non-binary autistic adults, and 10 parents (all mothers) of autistic girls or women. Three autistic adults were also parents to an autistic child. Autistic adults ranged from 22 to 70 years old ($M_{\text{age}} = 34$, $SD_{\text{age}} = 11.43$). Daughters of parent participants ranged from 9 to 23 years old ($M_{\text{age}} = 18.4$,

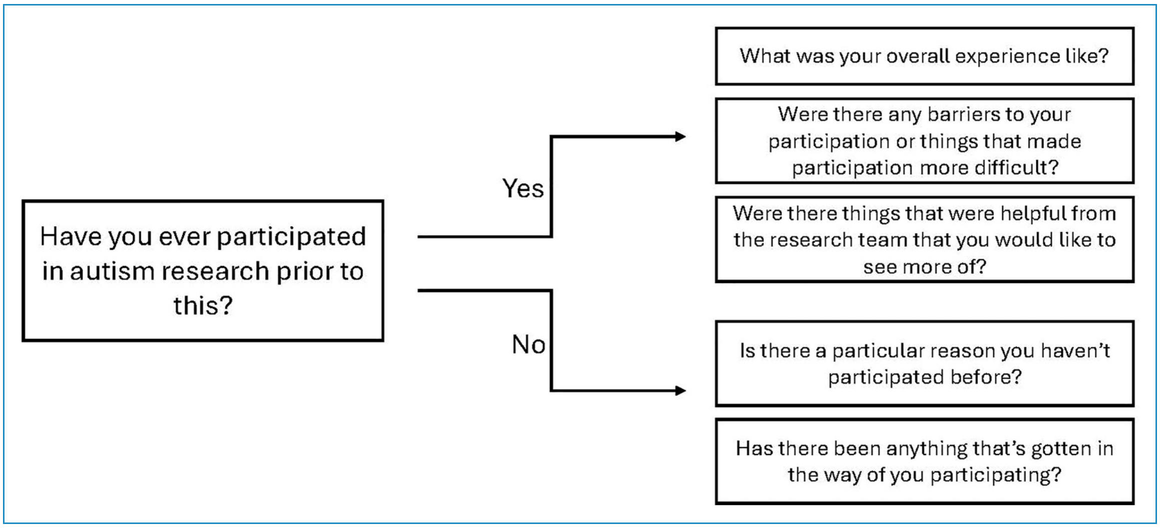

Figure 1. Semi-structured Interview Questions.

$SD_{age} = 4.17$). Age of diagnosis ranged from 3 to 67 years old ($M_{age} = 27.11$, $SD_{age} = 15.72$) for autistic adults and from 2 to 21 years old ($M_{age} = 8.78$, $SD_{age} = 5.95$) for daughters. Five autistic adults and one daughter (from the parent group) were actively seeking a diagnosis at the time of their interview. The majority of the sample was White ($n = 27$ autistic adults, $n = 9$ parents), and the sample represented a variety of annual household incomes in the following ranges: Less than \$20k ($n = 10$ adults), \$20–40k ($n = 7$ adults, 1 parent), \$40–60k ($n = 5$ adults, 2 parents), \$60–90k ($n = 6$ adults, 2 parents), and more than \$90k ($n = 3$ adults, 5 parents). Self-reported co-occurring conditions included ADHD ($n = 13$), anxiety ($n = 25$), bipolar disorder ($n = 5$), depression ($n = 22$), intellectual disability ($n = 1$), developmental delay ($n = 1$), sensory processing disorder ($n = 1$), and other genetic and physical conditions ($n = 1$).

Procedure

The research protocol for this study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill (Protocol #20–2624). All participants provided written or verbal informed consent (depending on the interview format) and were compensated with a \$20 Amazon gift card. All interviews were conducted between June to November 2021. Participants were sent interview questions in advance and could choose from a variety of interview formats (Zoom interview with or without video, Zoom chat feature, email correspondence, phone). As fraudulent participation has become more common in remote-participation studies (Pellicano et al., 2024), our team took steps to balance our accommodating interview setting with the preservation of data integrity. Interviewers asked suspected fraudulent interviewees (i.e. individuals posing as autism community members to receive the monetary compensation) additional questions to determine the sincerity of their responses, cross-checking their answers with their previous survey responses. Three interviews were terminated and excluded from analysis because of suspected fraud.

The semi-structured interviews were scheduled for 30 min but ranged from 20 to 60 min. Participants were offered the opportunity to have a support person help them with the interview: Outside of one mother/daughter pair who interviewed together, interviews were conducted one-on-one between a research team member and a participant. While the majority of discussions were focused on perspectives towards the broader field of autism research (see Supplemental materials for full interview protocol), all interviews began with a discussion on the participants' personal experience participating in or being involved with autism research studies (Figure 1). Important to our protocol and analysis is the continuous, underlying theme of *gender*. These interviews took place in the context of a gender-focused study, in which gender representation in autism research was discussed in the informed consent process and throughout the interview. As such, although the interview questions that were relevant to the current study aims do not directly focus on gender, they were asked within the context of a gender-focused interview.

Data Analysis

Audio recordings of the interviews were transcribed verbatim and analyzed using Braun and Clarke's (2022) method for reflexive thematic analysis with inductive coding. That is, we did not enter the coding process with any predetermined themes or codes and rather developed our codebook based on patterns we observed in the transcripts. Although questions on the topic of research participation were always asked at the beginning of the interview, transcripts from the entire interview were coded and any other discussion about the participant's personal experience engaging with researchers that occurred later in the interview were included. All transcripts were double-coded using Dedoose software (SocioCultural Research Consultants, LLC, 2024). The codebook was developed through an iterative process during which the coding team met weekly to reach a consensus on the final codes. After initial coding was complete, OCP and GE reviewed all coded excerpts to identify those that directly related to our research questions about participation (as opposed to other questions targeted in the interview). This process was done with consultation from SC. After our final codebook was determined, both authors re-read and applied memos to all exported excerpts for a given code. Sometimes this involved revisiting an original transcript to check the context of an excerpt. OCP reviewed all memos and proposed a preliminary set of themes based on similar memos across multiple participants. These themes were finalized and discussed in multiple meetings with GE and SC.

Given that this was a reflexive thematic analysis, we did not aim to reach data saturation and instead aimed for *information power* (Malterud et al., 2020), which considers the different factors that would influence the number of participants and perspectives needed to understand experiences for these community members. Further, we derived codes and themes by exploring patterns of meaning rather than quantifying the frequency of specific themes, which aligns with the recommendations outlined in Braun and Clarke (2022). When reporting these patterns, we use descriptors such as 'some', 'many', and 'several' to indicate the relative frequency and prominence of a response.

Results

Autistic women, nonbinary adults and parents of autistic girls reported a number of motivations and barriers to participation in autism research, some of which are blended into identified facilitators of participation. These resulted in five main themes:

The Importance of Gender Representation

Throughout the interviews, nearly all participants mentioned the lack of female or gender-diverse representation in autism research: "A lot of them [studies] are male centered, you know? There's nothing that talks about females. What is different in autistic females?" (P6, parent, daughter age 17). Some commented on how the lack of evidence-based information on autistic females affected their lives. For example, multiple mothers shared that preparing for puberty was made more difficult because of a lack of information about supporting their daughters through menstruation. Others attributed their or their daughter's delayed autism diagnosis to the lack of information on autism in females: "Girls often present differently than boys, just like the services seem more geared towards boys than girls" (P62, parent, daughter age 22). Frustration at this lack of representation and subsequent knowledge was therefore a primary motivator for many to participate in research:

> It's really important to me because, like, females have been sort of excluded from this research for so long…we know that it presents differently in women or females, and there's so little research into that that like the diagnostic criteria just sucks (P24, non-binary, age 25).

One autistic non-binary adult felt positive about participating in research because they felt they were improving research representation: "You're going to find a whole lot of women and non-binary people who want our voices heard and who will be happy to jump in and participate" (P31, non-binary, age 40).

Many participants felt a sense of exclusion and disconnect from autism research, particularly if they had not participated in an autism research study prior to the current study. In addition to not seeing themselves reflected in past research, some felt that ongoing research was not "for" them, as many enrollment opportunities they encountered were only aimed at recruiting parents of young children, "All the emails I get from [autism registry] are for parents of children with autism…it seems like there's a lack of resources for adults with autism" (P39, woman, age 25), or those with a formal diagnosis of autism, "A lot of studies will say that a prerequisite to participating is that you have a formal diagnosis and so that excludes those of us that don't" (P23, non-binary, age 36).

The Role of Community in Research Engagement

A majority of the participants' experiences engaging with research seemed to be facilitated through *community*. Many participants described specifically seeking out and pursuing studies that had a focus on autistic females or gender-diverse people. Several autistic women and multiple parents shared that they had not previously participated in autism research not from a lack of interest, but from not encountering any opportunities that they were eligible for or not knowing how or where to find out about research opportunities. The majority of these participants had learned of the current study through gender-specific social media pages, groups, and listservs, or from acquaintances who had participated. For many, these online communities were trusted, relevant spaces in their lives and were thus a positive facilitator of research engagement opportunities.

For some, community itself was also a motivator to seek out and engage with research opportunities. Multiple mothers and autistic adults described past experiences with research-facilitated support groups, although gender-specific groups seemed difficult to come by. One mother described one such group for autistic girls that had been ultimately canceled due to low enrollment. Several participants expressed a desire to engage more with research that involved community members. For example, one non-binary adult spoke about trusting research projects more when they were led by autistic people, and one parent felt that autism research driven by autistic adults would be beneficial for her daughter: “The people she can learn from the most are other autistic adults and how they deal with day-to-day struggles…that’s what I hope she could learn from research” (P62, parent, daughter age 22).

Science for Science’s Sake: Needing to Trust Researchers

Many participants were motivated to contribute to research simply because they felt that a particular topic, autism research as a whole, or science in general, was exciting or important to get involved with:

> I participated in it because it sounded interesting at first and they were trying to see if there was a biological or genetic component to why certain disorders co-occur with autism…and that’s what I was interested in. But then I found out that they were actually focused on finding a way to diagnose autism prenatally and prevent autism. I didn’t really want to participate in eugenics. (P19, woman, age 34)

Despite scientific interest, a mistrust of researchers was a barrier to participation for some who had concerns that their data would be used to try to preempt or prevent autism, or to otherwise harm autistic people through attempts at “cures”: “I fear the way some of the research may be able to be used” (P50, parent, daughter age 15). Because of this concern, some autistic women and non-binary adults shared that they tend to consider the purpose of an autism research study before they opt to participate: “I tend to ask the question of how could this information be practically used? Or you know, why would we want to know this information?” (P38, woman, age 27). Sometimes, the misalignment of a study’s goals with their own values stopped them from participating in certain studies: “I looked into a few opportunities prior to this, and they were perfectly accessible for me, but the thing that kept me from participating was that I questioned their motives and the overall goals of their study” (P29, non-binary, age 40).

Participants in the current study were motivated to contribute to research that aligned with their personal interests or values and amplified their voices/experiences, suggesting that considering community priorities may be a key to a study’s success, particularly when conducting research focused on underrepresented groups.

Bi-directional Research Relationship

For many, feeling like a respected partner in research was a key facilitator of whether or not participants in the current study had experienced positive past research experiences. Many participants spoke of the time and effort they had dedicated to research and the ways that researchers did, or did not, make them feel like their partnership was valued. Some autistic women and non-binary adults mentioned that they sought out, or only participated in, studies that offered monetary compensation: “It shows value for our time…having some sort of compensation shows appreciation and not just like a raffle for the potential of it” (P31, non-binary, age 40). Some parents were motivated to participate in research that provided services for their daughter, and one autistic mother spoke about viewing research participation as a potential resource for herself and her child. Multiple parents expressed wanting to participate in studies in order to receive guidance or resources from autism experts:

> I’m hoping to get her more involved with studies like this because…she was only diagnosed two years ago. So for us, it’s kind of overwhelming. There’s, you know, no place to go to figure it out…tell me where to go so I can learn (P6, parent, daughter age 17).

Many participants sought compensation in the form of information, particularly given the lack thereof surrounding autistic females. Several parents, including one autistic mother, were eager to participate in clinical or genetic studies that offered personalized information about their daughter. However, some encountered cases where they had been promised personalized feedback or study results, but never heard back from researchers after the study concluded. As this information was a primary motivator of study engagement, it left these participants feeling discarded and undervalued.

Some participants shared that their engagement with studies was made easier when they felt that researchers respected and valued their identity. For some, this looked like their gender identity being acknowledged, as multiple non-binary adults spoke of settings where they were misgendered or forced to pick from “man” or “woman” options. For others, particularly autistic adults, feeling that their lived experience with autism was respected and considered by researchers was important:

> I just think it’s incredibly critical for autistic voices to be heard. We know what we want and need, and if someone is looking for the best way to help us, it’s not going to be found in a board room full of allistics. It’s going to be found by talking to autistic people and listening to what we say. (P29, non-binary, age 30)

Multiple women and non-binary adults shared that they were interested in being involved with autism research and felt that community involvement was beneficial to everyone as well as necessary to produce quality research: “I mean you need different perspectives to be able to solve complex problems…we’ve got things we can bring to the table if you’d let us” (P17, woman, age 33).

Communication is Key

Communication *throughout* the study process was also identified as a key determinant of satisfaction with research engagement. Multiple participants described ways that participation in studies would be easier and more feasible for them through increased accessibility, which often meant improved communication from the research team. For example, offering information in advance and allowing for multiple forms of communication are frequently recommended ways of improving accessibility for autistic people (Cascio et al., 2021; Nicolaidis et al., 2019), but were reported to be the exception rather than the norm by our participants. Some shared that when researchers did make accommodations for them, they felt more respected and valued as research partners: “Any study that insists on video or telephone contact would be a no-go. I just don’t communicate well that way, so it was helpful that this [current] study gave me the option to participate in writing instead” (P15, woman, age 52).

Some participants shared positive experiences of communication with researchers, such as being given a designated contact or receiving regular updates and advance information. Others had experiences of poor communication that left them unhappy with their participation or stopped them from participating altogether. For example, one woman had difficulty enrolling in a study due to vague instructions, “I was told, you know, just send an email to this email address, but it didn’t say what to include” (P28, woman, age 39). Others reported having difficulty responding to questions from non-autistic researchers: “Very often, questions are too vague to be able to answer correctly or precisely. I feel that especially if you’re asking autistic people questions, you should make sure your questions are not at all general or you won’t get accurate answers” (P15, woman, age 52). Another woman described a stressful laboratory visit after study staff did not communicate the expectations or logistics of their participation: “I was not given the questions in advance or allowed to articulate myself in writing, which has always been my strong preference and rarely if ever, been accommodated” (P8, woman, age 28).

Discussion

The goal of this study was to understand how underrepresented gender groups (autistic women, autistic non-binary people, and parents of autistic girls) within the autism community engage with research as participants. Some identified themes overlapped with those of previous studies examining community views toward broader autism research participation (Fletcher-Watson et al., 2019; Haas et al., 2016; Lilley et al., 2024), suggestive of common values and needs across community members. However, a number of themes put forth by our participants, and the considerations for researchers associated with them, stemmed from lived experience as a gender minority in this field and broader society. Consideration of these themes may be particularly important when conducting research with gender minority autistic people, who experience multiple marginalized and underrepresented identities.

Critical to the advancement of research that includes autistic females and people across the gender spectrum, was the theme of representation. Given the historic male bias in autism diagnoses, the majority of information regarding autism stems from research with mostly male samples. When sex/gender has been considered, this is often reduced to a binary conceptualization of gender (male/female, man/woman, boy/girl), leading to the experiences of those with autism whose identities fall outside these identities potentially being overlooked.

Some participants had been excluded from participating in previous studies due to their age or diagnostic status. A recent study found evidence of a “leaky” recruitment-to-research pipeline for autistic females, who were disproportionately excluded from autism research criteria (D’Mello et al., 2022), suggesting that even those with a prior clinical diagnosis have been historically excluded from research studies due to *gold standard* inclusion criteria. The narratives provided by our participants illustrate this problem and the barriers it places between community members and research engagement. This result adds support to research frameworks adopting a more gender-equitable lens to study inclusion criteria (Lai et al., 2022), making research studies more inclusive of autistic girls, women, and gender-diverse people who may not neatly fit into, potentially, male-centric diagnostic and inclusion criteria.

Multiple participants in the current study expressed frustration at the idea that existing knowledge of autism may not apply to them and that relevant aspects of their experiences with autism have been overlooked. Recent studies have identified unique research priorities and needs put forth by autistic women and gender-diverse people, such as improved understanding and support for autistic girls (Grove et al., 2024; Putnam et al., 2023). The current study extends this work to demonstrate how these research priorities translate to engagement in the research process: Parents of autistic girls discussed participating in research studies to gain knowledge or expertise specific to their daughter—underscoring the importance of bi-directional communication but also the fact that the majority of information (lay and scientific) stems from research with mostly male samples. Participants also illustrated how the lack of these gender-specific lines of research impacted their lives, and this motivated them to contribute to research to improve these circumstances.

Previous studies have evaluated the engagement of specific historically underrepresented groups in autism research, such as Black American families (Shaia et al., 2020) and parents of minimally speaking autistic children (Asbury et al., 2024). Participants in these studies wanted to advance the understanding of autism in their specific community, and the current study extends this common motivator of participation to gender-minoritized groups. With this specific community value in mind, future groups who seek to extend their research findings across sex and gender groups may be successful in explicitly stating this goal to potential participants. This, among other themes found in the current study, underscores the importance of *transparency* in the research process. Many participants felt hesitancy and mistrust towards the bulk of autism research, and some avoided participating in studies where the objective of the research was unclear. Concerns about research intent did not appear to be expressed by parents in earlier studies on autism research participation (e.g. Singh, 2015; Trottier et al., 2013), but have emerged in recent studies (Asbury et al., 2024; Lilley et al., 2024) and by the autism community in online narratives (Chapman, 2020), highlighting the critical need for researchers to take steps to establish trust and transparency with the community in their work. This may be particularly important for multiply minoritized groups, such as autistic non-binary people, who are at an increased risk of discrimination in medical environments (Strang et al., 2018), and who may not feel safe engaging with research teams unless that safety is made clear.

One facilitator of trust and a stronger researcher–participant relationship highlighted in the current study was research that was led by or included members of the autism community. Some autistic women and non-binary adults in the current study expressed a desire to get involved with research themselves, wanting to bring their specific lived experience with gender and autism to research teams. Community-based participatory research (CBPR), in which community members co-create a study with researchers (see Chen et al., 2024 for a review), has become more common in recent years and was encouraged by participants in our study: Parents and autistic adults alike felt that autistic representation on a study team facilitated their trust in a research project and improved their overall experience as participants. Communication with research teams was a common facilitator of either a good or bad experience as a research participant, with clear, consistent communication making community members feel like valued research partners, and a lack thereof leaving them feeling discarded and distressed, mirroring findings from other studies (den Houting et al., 2020; Pellicano et al., 2014). Following field-wide guidelines for implementing good communication practices and other CBPR principles can better facilitate engagement with community partners (Nicolaidis et al., 2019)

Community was a key facilitator of research engagement for community members in the current study, in multiple senses. Previous studies on research engagement have found that autistic adults and family members alike place value in research improving the lives of the autism community at large (Fletcher-Watson et al., 2019; Haas et al., 2016; Lilley et al., 2024), with this being a driving factor for some to participate in research. Participants in the current study shared this value but expressed particularly strong ties to local and global communities of autistic girls, women, and non-binary people. Several participants sought engagement in research not only to help this community, but to *foster* community through research participation itself, either through CBPR or through participating in research that involved social groups and peer interaction with autistic girls. The importance of community has been emphasized in previous studies focused on autistic girls and women (Grove et al., 2024; Kelly et al., 2024), many of whom have found unique support in online gender-specific communities (Bargiela et al., 2016). Several participants in the current study shared that they had found the current study's recruitment materials through such online groups, thus illustrating the role that these smaller communities can play in supporting research engagement for underrepresented populations.

Strengths and Limitations of the Current Study

To our knowledge, this study is the first to contribute to the field's understanding of community perspectives on participation in autism research from a gendered lens. However, it comes with important limitations. Since the current study itself is an autism research study, we must acknowledge the risk of selection bias, as themes are extracted from community members who *did* participate in our study. As such, we weren't able to capture the views of those who experience barriers to participating in studies like ours or those who have other reasons for not participating. For example, some prospective participants may not have been able to complete our preliminary survey or may not have trusted our research team. Our team did not verify the diagnoses of those who reported having an autism diagnosis, and we left the interpretation of what it means to be "actively seeking a diagnosis" to the prospective participants. This vague wording may have led some prospective participants to self-disqualify.

Throughout the study process, we reflected on the fact that, at the onset of the current study, our team did not take some of the steps that our participants later discussed as being important to them. For example, although we sent our interview questions in advance to all participants, we did not pilot test the questions with community members, making them difficult to answer for some participants.

Because our sampling strategy was focused solely on gender identity, we did not recruit for the equitable representation of other intersecting identities (i.e., race, ethnicity, primary mode of communication). Results from the current study may be viewed in conjunction with others that have focused on other groups within the autism community that have been historically marginalized in research, such as a report from Asbury et al. (2024) on the perspectives of parents of nonspeaking children on research participation. Future studies may also seek to explore the role that intersecting marginalized identities (e.g. race and gender) may play in individual engagement with research.

Conclusion

Although recent research has highlighted the unique priorities that autistic women, non-binary people, and parents of autistic girls have for the direction of autism research (Grove et al., 2024; Putnam et al., 2023), this study is the first to our knowledge to examine how these priorities influence community participation in autism research. Understanding the ways in which historically underrepresented autism community members participate in research is important to establishing trust and producing quality research that reflects the diverse experiences of this population. Using reflexive thematic analysis of semi-structured interviews, we identified elements of research that motivate or hinder participation from these groups, as well as key areas that researchers can focus on to better facilitate the experiences of their participants. Understanding the value of transparency, role of community, and the motivation for representation from autistic girls, women, and non-binary people can support future research partnerships to advance shared goals that will specially improve the lives of these underdiagnosed and underserved groups.

Author Note

The list of affiliated institutions reflects author affiliation at the time of their work on this project. Since the completion of this project, GE is now affiliated with the College of Arts and Sciences at University of North Carolina at Greensboro and Madison Swisher is now affiliated with the Western Psychology Center for Autism and Developmental Disorders, University of Pittsburgh Medical Center.

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Statements and Declarations

Ethical Considerations

The research protocol for this study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill (Protocol #20-2624).

Informed Consent

All participants provided written consent to be contacted for the interview portion of the larger study, which the current article is based on. All participants were sent a written copy of the interview consent form in advance for their review. Participants who completed the interview over the phone or through a video call verbally consented to participate, while participants who completed the interview through Zoom chat or email correspondence provided written consent to participate. In all interview formats, the interviewer discussed the protocol and consent information with the participant prior to obtaining consent, offering time for reading and asking questions about the process.

Author Contributions/CRediT

Orla C. Putnam and Clare Harrop conceptualized the project idea. Orla C. Putnam, Madison Swisher, and Clare Harrop managed and designed the larger study. Orla C. Putnam managed recruitment of participants with supervision and assistance from Madison Swisher and Clare Harrop. Orla C. Putnam and Madison Swisher completed the interviews. Orla C. Putnam and Genessa Eddy conducted the thematic analysis with supervision and consultation from Shannon Crowley LaPoint. Orla C. Putnam wrote the original draft with contributions from Shannon Crowley LaPoint and Clare Harrop. All authors reviewed and approved of the final manuscript.

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Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability

To protect participant privacy, original interview transcripts are not available to the public. The interview protocol is available in Supplemental materials. Additional research materials related to recruitment or analysis are available upon request.

Supplemental Material

Supplemental material for this article is available online.

Note

1. In this article, we focus on the social construct of *gender*, referring to the behaviors, attitudes, and feelings associated with genders such as men, women, girls, boys, and more. Gender is inextricably linked with sex, which refers to the biological characteristics of males, females, and intersex people. However, the two are distinct. For example, some participants in the current study with non-binary *gender* identities refer to themselves by the *female* sex.

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