

Article

“Very Misunderstood”: Self-Perceived Social Communication Experiences of Autistic Young Adults

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Abstract: Historically, society has labeled social communication differences in autistic individuals as disordered by comparing them to the social communication behaviors of the predominant non-autistic population. This study explores how autistic young adults view their social communication experiences and how their differences impact them when navigating social situations in predominantly non-autistic environments. This qualitative study utilized purposive sampling to recruit 15 autistic adults aged 18–28 in the United States. All participants were conversation-level speaking communicators and high school graduates. Each participant engaged in an individual semi-structured, conversational interview with the first author via Zoom video conferences between November 2019 and June 2020. The data analysis identified inductive themes through interpretive phenomenological analysis. Five major themes emerged from the data that captured the challenges of autistic adults: (a) “Communication definitely is a struggle at times”, (b) “if it’s a very comfortable situation, then it’s fine”, (c) my communication style has “been very misunderstood”, (d) “I have to learn people”, and (e) “we’re all human. Autistic too, we’re still human”. The participants’ experiences suggest that differences in their communication style and social behavior resulted in overwhelming feelings of uncertainty and marginalization as they put great effort into engaging with non-autistic individuals.

Keywords: social interaction; autism; neurodiversity; resilience; self-acceptance; self-awareness



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1. Introduction

The autism spectrum condition is identified as a neurologically-based developmental disorder that significantly impacts how a person experiences their environment. Autistic traits include but are not limited to, passionate interests, a preference for repetitive and familiar behaviors and routines, divergent reactions to internal and external sensory input, and a communication style that involves differences in social-emotional reciprocity and non-verbal behaviors [1]. Present in childhood, autistic characteristics contribute to pervasive challenges in social communication and interaction when engaging with the predominant non-autistic neurotype (or neurological development) [1–4].

Considering the complexities surrounding the social communication needs of autistic people, healthcare providers, and non-autistic individuals must value autistic voices [5,6], understand the social-cultural identity of neurodiversity [7], and self-reflect on the framework through which they view people with disabilities [8] to understand specific needs and provide meaningful support. A supportive network of healthcare providers and non-autistic individuals that meets both formal and informal needs enhances the quality of life for autistic individuals [9]. Given the diversity of skills and needs within the autistic community, a comprehensive range of support, which includes advocacy, collaboration, and

education on autistic perspectives and experiences, is likely to contribute to improved outcomes [10–12]. This paper explores how autistic young adults who are conversation-level, verbally-speaking communicators describe their social communication experiences and perspectives when engaging with others. This research aspires to explore the self-perceived relational experiences of autistic young adults through first-person narratives.

Historically, healthcare providers, particularly speech-language pathologists (SLPs), have utilized the medical model of disability as a framework to determine the need for client services [8]. This model of disability operates from an established standard of normalcy to identify deviant areas that require treatment for correction. In this framework, disability is rooted within individuals [13]; therefore, healthcare professionals can improve an individual's level of functioning by correcting the identified area(s) of deficit. Assessing, diagnosing, and treating communication disorders follow the medical model of disability by using established developmental norms of the predominant non-autistic neurotype as a comparative standard for identifying needs. It implies that the intervention provided to address an identified communication disorder will improve individuals' functional abilities, thereby reducing or eliminating the disability and enhancing their quality of life.

One of the defining characteristics of autism is divergent social communication skills [1]. Utilizing the medical model of disability to determine social communication support for autistic individuals contributes to a perception of inherent deficiency when comparing autistic individuals to the predominant non-autistic neurotype as the standard of normalcy. Categorizing autistic social communication differences as a deficit is associated with strategies of camouflaging (also referred to as "masking") to assimilate to society's social norms to connect with others [14], mental health concerns such as anxiety and depression [15], fear of rejection and judgment, and autistic burn out which causes severe mental, physical, or emotional exhaustion [16]. Furthermore, research has revealed camouflaging to be laborious to autistic individuals, challenging their identity and view of self and resulting in harmful effects on their mental health [17].

When impairment in intellectual and language skills is absent, there is a pervasive, stigmatizing perception that communication breakdown between autistic and non-autistic individuals is due to autistic challenges with identifying social cues [18], utilizing non-verbal language, and maintaining social reciprocity [19]. Autistic adults present with different social communication profiles [10], demonstrate less conversational reciprocity [20] and are often perceived as more awkward, less likable, and less attractive [21,22] when compared to non-autistic adults. Although non-autistic individuals aware of autistic characteristics view autistic adults more favorably when their diagnosis is disclosed or assumed [23], they more often form a negative first impression of autistic adults when compared to non-autistic counterparts [22].

Social communication and interaction involve verbal and non-verbal language to engage with others and meet interpersonal or behavioral goals [24]. It is a bi-directional exchange between individuals; therefore, its success should not be dependent solely on the behavior of one of the individuals involved. The 'double empathy problem' (DEP) indicates a lack of congruence between autistic and non-autistic neurotypes on the outlook, attitudes, and values toward social communication and interaction during engagement and navigation of social situations [25]. An equal misunderstanding of social exchanges causes a disconnect between the two groups' expression and interpretation of the messages exchanged [25,26]. Research has found that social communication disjuncture is a bi-directional problem between autistic and non-autistic neurotypes [18,25,27]. However, people often perceive it as a communication breakdown caused by skill deficiencies in autistic neurotypes. Such negative perceptions can lead to social penalties, reduced interaction, and limited social opportunities for autistic individuals [22]. People often view social communication differences in autistic individuals as deficits that require correction without placing any responsibility on non-autistic individuals to adjust. This viewpoint contributes to the underestimation of skills, which further stigmatizes and dehumanizes autistic individuals [7,28].

Judy Singer introduced the concept of neurodiversity in the 1990s. She asserted that the variation seen in human neurodevelopment should be accepted at every level of its diversity without categorizing one as superior or more desirable than another [29]. The structural and functional development of the human brain does not follow a single path [13]; therefore, assigning a standard of normal to a particular path of neurodevelopmental behaviors as the gold standard for comparison purposes is deemed problematic. Neurodiversity is also a social justice movement [29,30]. Embraced by individuals with neurological conditions that do not match the dominant neurotype (e.g., autism, attention-deficit/hyperactivity disorder (ADHD), dyslexia, etc.) and supporters of its paradigm, it proclaims everyone, regardless of their neurotype, is entitled to be treated with dignity and valued in their authenticity [13]. Neurodiversity encourages radical acceptance of autism, embraces the unique experiences of autistic individuals, and empowers their identity. However, embracing autistic differences does not suggest the rejection of support services. Advocates for neurodiversity view the autistic experience as a “natural variation and a disability” [30] (p. 272). This viewpoint emphasizes acceptance through changes in social systems and expectations, fostering respect for autistic individuals, and providing support services that promote adaptive functioning without the elimination of “unusual but harmless behaviors” [31] (p. 60) common to autism.

Developing meaningful social communication support that empowers autistic individuals to feel free to be “themselves” while considering the environmental, societal, and individual-level needs is pivotal for healthcare providers and non-autistic individuals who interact with autistic adults. Person-centered practice, which values patient needs and seeks to understand patient experiences [32], and compassion must be at the foundation of engagement. Non-autistic individuals and healthcare providers should seek to understand the challenges that autistic adults perceive about their social communication skills and need to implement supportive strategies rooted in acknowledging the humanity in autistic people. This research study asks, “What self-perceived challenges related to social communication and interaction do autistic young adults experience?” Its results aim to facilitate greater sensitivity and acceptance of autistic social communication and provide insight to non-autistic individuals and healthcare professionals necessary to develop effective support strategies.

2. Materials and Methods

This study is part of a larger research project on the perspectives of social communication and interaction experiences of young adults on the autism spectrum. It is a phenomenological qualitative design [33] and utilizes an interpretive phenomenological analysis [34] to explore the personal reflections of social communication challenges experienced by the participants. Ethical approval was granted from the Loma Linda University Adventist Health Sciences Center (LLUAHSC) Institutional Review Board (IRB# 5190319). After reading the written informed consent and being given the opportunity to ask questions, participants gave verbal consent to participate to the first author.

2.1. Participants

Purposive sampling was utilized to ensure specific qualities were reached [35]. Fifteen autistic adults aged 18 to 28 ($M = 23.4$, $SD = 3.38$) who resided in the United States participated in this study. Nine participants self-identified as Caucasian/White, with the remainder distributed equally among African-American/Black, Hispanic/Latino, and Biracial/Multiracial. At the time of the interview, all participants were high school graduates, and nine were either undergraduate or graduate students. Of the participants in higher education, five had overlapping part-time employment. Table 1 presents additional characteristics.

Table 1. Demographic Table of Participants.

		Participant (<i>n</i> = 15)
Gender	Female	10
	Male	4
	Gender Fluid	1
Ethnicity	African-American	2
	Biracial (African-American and White)	1
	Caucasian/White	9
	Hispanic/Latino	2
	Multiracial (Louisiana Creole)	1
Age	18–21	6
	22–25	4
	26–29	5
Age Learned of Diagnosis	12 years and under	2
	13–20 years	7
	21 years and older	6
Geographic Location	West (California, Washington, Arizona)	6
	Midwest (Indiana, Michigan, Wisconsin)	3
	South (Georgia, Kentucky, Virginia, Texas)	5
	East (New York)	1
Highest Level of Education Completed	High School	8
	Bachelor’s Degree	6
	Master’s Degree	1
Higher Education Status	Full-Time Graduate Student	2
	Part-Time Graduate Student	1
	Full-Time Undergraduate Student	5
	Part-Time Undergraduate Student	1
	Not Enrolled	6
Support Services	Counseling	9
	Speech-Language Therapy (not related to SC/I skills)	4
	Academic Support/Resource Specialist Program	4
	Social Communication Skills	3
	Occupational Therapy	1
	Emotional Support Animal	1
Employment Status	Full-Time Employment	1
	Part-Time Employment	6
	Unpaid Internship	1
	Unemployed—Actively Looking	2
	Unemployed—Not Actively Looking	4
Residential Status	Live with Parents	7
	Live in College Dorms	2
	Live with Self-Chosen Roommate	4
	Live with Significant Other	2
Relationship Status	Serious Relationship w/Non-Autistic Adult	5
	Serious Relationship w/Autistic Adult	2
	Not Currently in a Relationship	3
	Never Dated	5
Identity Language Preference	Autistic Adult	4
	Adult with Autism	3
	No Preference	8

Inclusion criteria were autistic adults between 18 and 29 years old who reported a clinical diagnosis of autism. The levels of support, as defined by the DSM-5 [1], were not reported by the participants, and proof of an autism diagnosis was not required to participate. However, all participants received a general high school diploma and were conversation-level speaking communicators. Ten of the participants learned of their

diagnosis after completing high school, four of the participants learned of their diagnosis after the age of 5, and one of the participants learned of their diagnosis before the age of 5. Exclusion criteria included factors that may have impacted social communication skills, such as hearing and visual impairment, intellectual disability, or the diagnosis of an emotional disturbance other than anxiety and depression. Recruitment was conducted via online advertisements on social networking sites and by sending email invitations to autistic adult support community organizations and Offices of Disability Services (or equivalent) of various community college and university campuses.

2.2. Procedures

A semi-structured interview was utilized (See Table 2). The first author, a licensed, neurodivergent, non-autistic SLP, developed the interview questions. Information gathered from the review of the current literature and informal, anecdotal knowledge of working with autistic adolescents influenced the interview questions. The topics included the participants' perception of their autism on general living experiences to assist with establishing rapport and gaining background history, as well as how they viewed their social communication and interaction engagement with others. After developing the questionnaire, the first author met with an autistic adult, who was used as a consultant and was outside the sample's target age range, to discuss the study's aims. The interview questions were emailed to the consultant to check for sensitivity, language, and suitability for the study's intended purpose [36]. Upon receiving feedback, the first author made mild adjustments to the questionnaire to improve the clarity of the language used.

Table 2. Semi-structured interview questions.

1. How old are you?
2. What do you identify as your gender?
3. What is your ethnicity?
4. What city and state do you live in?
5. What high school did you attend? Was it a public or private school? Did you receive a high school diploma? What year did you graduate?
6. Tell me about yourself.
7. What identifying language do you prefer?
8. How do you feel your life is impacted by your autism?
9. When did you learn about your diagnosis? What was your reaction to it?
10. Thinking about your life since you graduated from high school,
a. How do you define your personal strengths?
b. Tell me about areas of your life that you find challenging.
11. Tell me about your personal strengths in your conversational skills.
12. Tell me about your challenges with your conversational skills.
a. How have your conversational skills changed since you graduated from high school?
13. Tell me about your personal strengths when interacting with others.
14. Please share about your challenges with interacting with others.
a. How have your interaction skills with others changed since you graduated from high school?

The first author conducted individual interviews between November 2019 and June 2020 using Zoom video conferencing. The duration of interviews ranged from 95 to 198 min ($M = 138.4$, $S.D. = 29.26$). Interviews were presented in an informal, conversational format. The questions were open-ended and worded to prevent leading the participants toward a specific type of response. The focus of the questions balanced strengths and

challenges to capture the whole experience of the participants' social communication. Some questions were modified or omitted when participants naturally answered them in their responses to other questions. Follow-up questions were asked to expand on all responses related to their thoughts, feelings, and experiences with social communication and to gain further information when the participants made unfamiliar, unique, or ambiguous statements. Additionally, the researcher asked clarification questions and rephrased the participants' statements to confirm the interpretation of the message and ensure their intent was understood [37]. All participants received a \$75 e-gift card incentive upon completion of the interview.

2.3. Data Analysis

Transcripts of each interview were thoroughly reviewed three times: one by artificial intelligence, one by a research assistant, and one by the first author to ensure the accuracy of the data. After each recorded interview, the audio recordings were uploaded into Otter.ai, an artificial intelligence voice transcription program [38]. The transcription was de-identified and printed out for a secondary review. A research assistant listened to the audio of each interview while reading the printed-out transcriptions. Edits were made to correct errors made by the artificial intelligence transcription program. Upon completion of the secondary review, the first author completed a third review of the audio and corrected transcripts to correct any misinterpretations that may have occurred during the initial and secondary review.

Data analysis occurred in Dedoose, a web-based application that organizes and analyzes qualitative and mixed-methods research data [39]. Each line of every interview was read multiple times and coded using an inductive thematic approach [40] to capture an understanding of individual perspectives. Responses directly related to the interview questions or indirectly associated with the thoughts, feelings, experiences, and perceptions about their social communication and interaction were selected and coded. Once the codes were determined, they were categorized, examined for redundancy, and reviewed for relevance to the research question. Additionally, each selected excerpt was examined for the appropriateness of its assigned codes. Subsequently, the aggregated data were condensed and organized into primary themes based on the commonalities of codes related to the research question [41]. Analytic memos were written after each coding session and aggregated data reviews were to reflect on the content and reduce researcher biases. To achieve validity, peer debriefing with the first and second authors occurred throughout the coding, data analysis, and data interpretation period. Member checking involved asking follow-up questions during the interviews to ensure an understanding of the participant's intent. The participant's responses were compared to the existing literature to interpret the data and draw conclusions. Synthesized Member Checking (SMC) was utilized to verify and validate the analyzed data [42]. The research team emailed participants the analysis of their collective interviews, organized by codes and themes, along with corresponding supportive excerpts. They asked participants to review the information to determine if it aligned with their views and to provide comments if they disagreed or wanted to add more details. Of the 15 participants, 6 were provided feedback. The team reviewed the feedback and made adjustments to ensure this study accurately represented the participants. Finally, an autistic consultant reviewed the manuscript to give input on the sensitivity of language use and the concepts discussed from an autistic perspective.

3. Findings

Five themes emerged from examining the participants' interviews, utilizing an interpretive phenomenological analysis. The themes represent a description of the participants' self-perceived social communication challenges (Figure 1). The findings share verbatim excerpts that vividly capture the participants' responses, reflecting common perspectives aggregated across various encounters and settings.

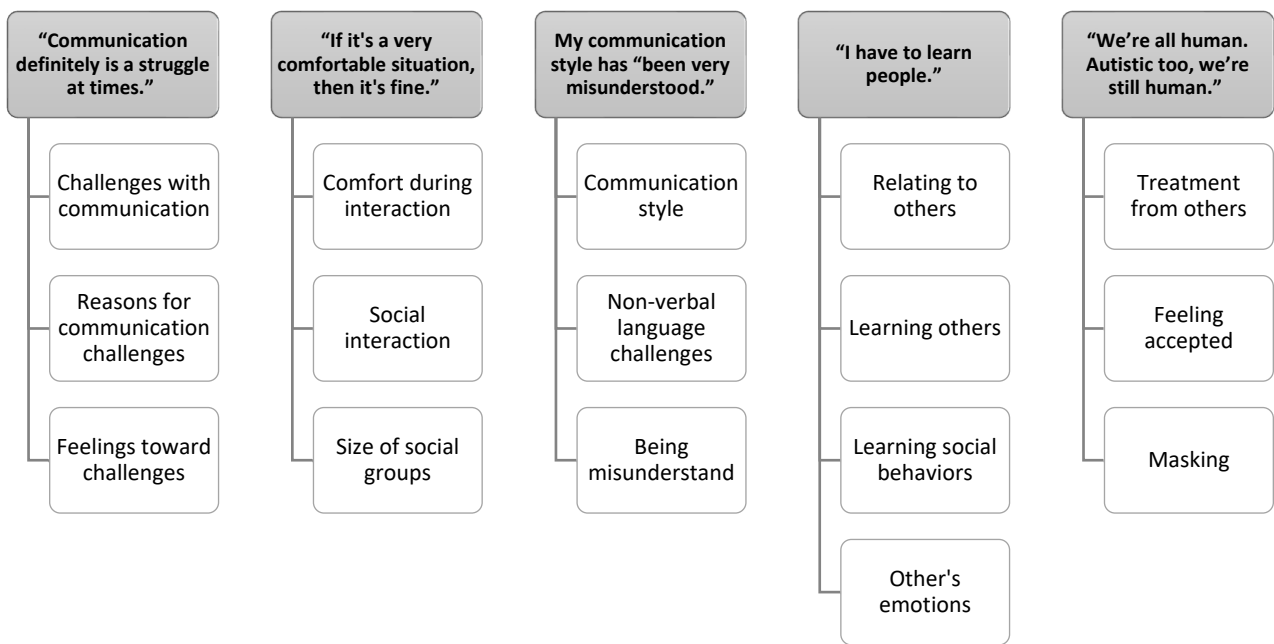


Figure 1. Thematic Map. **Note:** This figure illustrates the 16 codes derived from the interviews, which were organized into five overarching themes to highlight key patterns and relationships in the analysis.

3.1. Theme 1: "Communication Definitely Is a Struggle at Times"

Initiating interactions was one of the most challenging aspects of conversational exchange. Some participants were apprehensive due to fears of rejection, and others reported diffidence in knowing what to say beyond the initial greeting. Uncertainty with language use contributed to challenges with (a) expanding their conversational input beyond their original idea, (b) transitioning topics to keep the conversation going, or (c) attending to topics of discussion that did not include their interests. One 24-year-old female shared,

It's like when I walk into a room with a bunch of [people] when at a social gathering. Like, I look at that one person, I want to talk to so badly. I just feel awkward, you know, or I don't know what to say or like, how to approach them. So, I kind of just keep looking at that person . . . like, once I, like, get out of that barrier, which I think most people have, then I'll start, but then it'll be like a two-second, like, it'll be like a five-second conversation. I'll say, 'Hey, how's it going?' And then that's basically how far it'll go. (P10)

Primary reasons for communication breakdown during conversations were an overlap of communication partners speaking quickly or concurrently in group conversations, competing sensory stimulation from the environment (e.g., noises, lights, etc.), or focusing on a specific aspect of the conversation. Simultaneous processing of spoken and non-spoken information during conversations was challenging. Participants were either unaware of or misread their communication partner's body language and facial expressions, contributing to difficulties following conversations and misinterpreting others' emotions. One 26-year-old female stated,

Keeping up with multiple streams of conversation, or even if it's one conversation, but with, you know, multiple people talking, even if it's not all at once, even if it's just one person sharing. Like I get very focused on what someone is saying. And then yeah, three people later, I'm still kind of like thinking about this thing, and I'm trying to like, move on. But I'm trying to process. Like what were they saying? And like, what's all the contexts? And do I understand it? And did I miss

something? And what was their body language? And it's just like, the questions are so long that by the time I get to what I want to say or trying to contribute, it's like, oh no, I'm sorry, I missed, I missed the boat. (P3)

Many participants reported feeling incapable, incompetent, or overwhelmed during communication breakdowns. Ruminative thoughts of self-criticism or self-blame persisted after moments of communication breakdown. They analyzed their interactions repeatedly to determine what they did wrong. Some participants reported angst about other's negative perceptions, particularly if their conversation partner was aware of their difficulties with following conversations or if they made an error when communicating with unfamiliar partners or groups of people. A 26-year-old female explained,

But there definitely is still sometimes with some people if I'm really trying to like look extra not autistic really, and I'm really trying to like mask and really trying to like get away with it. Then I'll, I'll tend to not ask those questions [of clarification when I don't understand] because I'm afraid it's going to like be some kind of like tell. And then they're going to know like, Oh, she's, she's not getting it, like something is wrong with her and she's stupid or something. (P3)

3.2. Theme 2: "If It's a Very Comfortable Situation, Then It's Fine"

Comfort level was a significant factor in the social communication experiences of the participants. When participants felt their voice was heard and respected by an individual or within a topic or setting, they felt confident, competent, and perceived strength during interactions. This resulted in authentic interactions that allowed them to engage with others without masking behaviors. One 18-year-old female shared,

If I like get to know someone really well, I'm just really like myself with them. I don't really hold back. I just do a lot of really weird stuff. And um, yeah, I'm very comfortable with people who I know very well. (P6)

However, they typically needed multiple communication interactions over time before their comfort level increased. A 24-year-old female expressed her experience building relationships with colleagues at work by stating, "So, it's like, it's like a slow development. But eventually, once the trust builds, it becomes like a really good, open relationship and open conversations where I'm able to just talk without like worrying about what I'm saying." (P15). This sentiment was also shared in strength-based, empowering language by a 24-year-old male who reported, "I think my strengths are definitely, just like when I'm interested in somebody, you know, I can, like the conversation, the conversation can flow pretty long. And I see myself do that, and that's a big accomplishment." (P12).

Conversely, uncomfortable social situations, such as (a) interacting with new, unfamiliar people or casual acquaintances, (b) communicating in groups of three or more, or (c) communicating in environments that provoked sensory overload, induced challenges in navigating social experiences. Participant six shared, "It takes a lot for me to become comfortable with someone. Like I'm really good talking to like my boyfriend and obviously my family members, but other people I just, I simply cannot speak to them." Their discomfort impacted their ability to engage in tasks of interest, such as talking to strangers, making new friends, performing effectively during a job interview, socially interacting with co-workers, or asking others on a date. During moments when they conquered their discomfort, they perceived their performance to have decreased efficiency. A 24-year-old gender-fluid individual shared,

Having to talk to somebody I'm not comfortable with, I have a tendency to be very, very quiet. And it's almost impossible for me to be louder than that. So, I have a lot of trouble where people literally can't hear me a lot of the time. (P11)

They were also less likely to advocate for their needs, such as asking questions for clarification during a miscommunication or using alternate modes of communication

(i.e., writing or texting) to supplement their verbal challenges during communication breakdown.

3.3. Theme 3: My Communication Style Has “Been Very Misunderstood”

Differences in the behavior and values of autistic communication presented challenges with connecting with others, particularly with non-autistic individuals who did not know or understand them. Small talk did not have the same value or utility for the participants. Some participants found it challenging due to difficulties sustaining conversations or formulating their thoughts into words. Conversely, many participants reported being competent in using small talk; however, they expressed aversion to it, as they did not consider it a natural experience. They found it futile to have conversational interactions unless it was applied to meet their needs, learn information, or discuss topics of interest. One 28-year-old female reported,

“I think when it comes to small talk, like I hate it, I don’t like doing it. And I just have like memorized multiple small talk scripts in order to get through that, because it is necessary in a lot of places and spaces”. (P4)

Their social behavior differences, often misunderstood by non-autistic individuals, included listening intently or approaching a group in a discussion without contributing a comment. A 26-year-old female shared,

I like, I almost default to too much active listening sometimes because I just get so caught up with what people are saying and I forget I’m supposed to interact with them. Aside from listening, I forget that I’m supposed to like, reciprocate, and also say things. (P3)

Limited variability with non-verbal expression and discrepancies between the expression of their non-verbal language and their emotions also contributed to being misunderstood. One 28-year-old expressed, “For sure, like, it’ll seem like I’m just very spaced out and aloof, even though I am acutely aware of everything that’s going on around me all the time” (P14), and a 21-year-old female shared,

I just think that my own body language usually isn’t great in terms of expressing what I’m actually feeling or talking about. Sometimes [they] like can’t read my body language in what I’m saying . . . and it ends up being a miscommunication in terms of I look, or sound in [their] eyes, angry or what some emotion right? And I wasn’t actually feeling that. (P7)

Additionally, their direct communication style and disinterest in contributing to an unstimulating topic or in moments when they did not have a meaningful contribution were perceived as rude by non-autistic individuals.

The participants were aware of how their communication differences affected their connections with non-autistic individuals. Although one participant shared no interest in making new friends or engaging with others outside of her current relationships, participants felt misjudged or rejected by others and desired relationships with greater depth than they experienced. One 24-year-old stated, “I do think it limits the amount of connections that I’m able to form with people because I don’t communicate in a way that they see as acceptable or that they accept as normal” (P11).

Conversely, connecting with other neurodivergent individuals, either in-person or online, presented fewer challenges. Participants mutually understood that non-autistic communication expectations were not the gold standard, and they embraced each other’s unique personalities. One 28-year-old female said,

I like to make friends with weird people. Because I’m weird. And so, a lot of the time when I meet weird, socially awkward people, like I’m forgiving of their weird social awkwardness. And they’re forgiving of mine. We get along really well. (P4)

3.4. Theme 4: "I Have to Learn People"

The participants put substantial effort into relating to others and developing new relationships. They observed others in-person, on social media, or via characters from entertainment programs to learn social behaviors. The participants scrutinized behaviors to absorb the social responses and reactions of others in various social situations. They reproduced learned behaviors in social situations to yield the desired reactions they had observed. One 28-year-old female shared, "My social skills were still not great, but I watch T.V. and just watched other characters and characters who seem to be like, funny or likable, and I just would like go to school and act like that" (P9). However, this strategy was inconsistently effective. Some participants revealed that although they chose certain behaviors to imitate, they did not fully understand their meaning or the reason contributing to the other person's reaction, as exemplified in P10's comment,

I've just kind of faked my way through a lot of social interactions. I didn't know what I did that made it good. Basically, it would either go good or go bad and either way I didn't know what I did to do it.

Most participants grasped non-autistic social behaviors from self-directed exploration. Reading self-help books, searching the internet, reviewing videos and posts on social media, memorizing scripts, or enrolling in interpersonal communication courses were strategies used to understand the social behaviors of the predominant neurotype and learn how to navigate social situations.

Overall, the participants did not apply a set of social communication skills across various people or social situations. The participants learned each of their communication partners' personalities and social behaviors. They adjusted their interactions based on the observations of those characteristics over time. This strategy was laborious, comprising multiple trials and correcting ineffective behaviors, impacting their ability to establish relationships. One 24-year-old female reported,

That's why I don't have a lot of friends because it takes a lot to learn how to interact with a specific person. So, once I've gotten one down, it's like I don't have the energy to keep learning other people. (P10)

Difficulty discerning the sincerity of other's statements also contributed to challenges relating to others. Incongruence between verbal and non-verbal language productions and failure to attend to the non-verbal language of others led to uncertainty in how to process messages. A 26-year-old male stated,

If I could listen to what someone says without looking at their face, I can go, I could build a response just based off their, what they're saying. But having to add in facial expression with what they are saying when they don't always match up, really confused me. Someone could be crying, and they could say "I'm okay." It's like uhh, I don't know where to go here. (P5)

Finally, difficulty understanding and reacting to the emotions of others was challenging. While many reported sensing differences in the emotional states of others and felt empathy toward them, the participants often misinterpreted other's feelings, the cause of their emotional reaction, and could not ascertain how to support their emotional needs without direct guidance.

3.5. Theme 5: "We're All Human. Autistic Too, We're Still Human"

The participants felt that non-autistic individuals were not sensitive to the complications of their social experiences. Some felt rejected or discriminated against in various situations and settings by people who did not respect their differences. Participants experienced being ignored by classmates in college courses, not being invited to social events at work, being wrongfully terminated for not socializing, and being verbally and physically bullied. At home, they reported being excluded from interactions with roommates. Feeling a lack of support caused frustration during moments of struggle when they were uncertain

about how to ask for help or did not receive assistance. P10, a 24-year-old female, reported, “When we become confused, and we can’t do something, a lot of it just becomes anger and resentment because we need help and people aren’t helping us.” Another female participant, who had difficulty maintaining employment positions due to social communication challenges, shared,

Just feeling like I just can’t, I can’t face these people anymore. They don’t like me. I can’t figure them out, like people are like some of the worst things about the world. It’s just too much like, it just be too much. (P4)

The lack of acceptance caused distress and contributed to masking behaviors to assimilate to non-autistic characteristics. A 24-year-old female expressed,

I probably gave myself an anxiety disorder from the anxiety I had of trying to make sure I fit in and trying to make sure that I could mask properly and make sure that nobody would notice that I’m different and spending so much time analyzing other people’s behavior so that I could have that behavior so that people wouldn’t notice that I’m different. And it was just like a constant state of, like paranoia that someone was going to know that I’m different. (P15)

The participants felt marginalized for their differences. There was a lack of understanding and empathy toward their challenges, and they perceived their support needs were overlooked. They felt obliged to adjust to the social communication behavior of the dominant non-autistic neurotype valued by society despite the adverse impact on their mental health. A 26-year-old female stated,

I feel like it’s almost like expected and required of me to mask for other people’s comfort, and that my comfort like wasn’t important. So, like whatever the cost to me, it was irrelevant. Everyone else was fine and good. (P3)

However, some participants rationalized moments as acceptable to conform to the majority society, as explained by a 28-year-old female,

I think for me personally, the way I like to think of it is everything in life is kind of a tradeoff. . . It’s a lot like economics and the fact like most things are tradeoffs. . . But the way that would relate to this conversation is the fact that at least for me, socially, I want to hit an optimal level. So, I’m able to do things that are important to me in life. . . You’re going to need to appear probably, usually not always, but you know, you need some level of social skills in order to obtain a good job and have an interview and not be fired and keep a job. And those things are, are for me like essential, like having friends is important to me. So, I might do some compromise in the beginning to appear, you know, to make more of an effort consciously to make sure that I’m doing actions that would make people more likely to want to hang out with me. . . But of course, there’s a tradeoff. Like you wouldn’t want to do that all the time, like in your free time. Or 100% of the day. Cause number one, that would be exhausting. Kinda like almost like kind of, it’s kind of similar to economics, you know, you find your optimization value, I suppose, like, doing it for short periods of time would be fine. . . (P13)

The participants rejected the negative views that the majority society projected onto their differences. They reported greater self-acceptance, empowerment, and advocacy toward their differences when they compared their viewpoints to their experiences during adolescence. A 24-year-old gender-fluid individual stated, “I feel like we can be valued members of society, we can be successful, without having to mask who we are” (P11). They believed it was time for the greater society to accept autistic social communication differences, as expressed by P10, a 24-year-old female,

I honestly feel like people are doing everything that they can to teach us how to fit into society. And I don’t think they can really do anymore. I think all that can happen now is to teach others how to deal with us. I think every effort has been

made to have us assimilate. And I kind of think it isn't working anymore. So, what they have to do is, learn how we work too.

4. Discussion

In the current study, we explored the social communication experiences and perspectives of autistic young adults, with conversation-level, verbally-speaking communication engagement, to examine their self-perceived relational experiences. Considering the overwhelming influence of the predominant non-autistic neurotype on society, this study sought to understand the self-perceived challenges experienced by autistic young adults related to their social communication. The participants shared first-person narratives to explain their current perceptions of how their social communication differences complicate their daily experiences.

The themes of this study support previous research findings that social communication differences among autistic adults are often perceived as deficits by the majority, of non-autistic society [3,43,44]. The data also reveal participants' perspectives on how negative perceptions influence their interactions and relationships with others and their sense of being valued by society. The discussion on the themes is intertwined because of the overlap of information and its relationship to the participants.

When considering challenges specific to social communication and interaction, the participants' reports were consistent with previous findings of difficulty with conversation discourse, use and understanding of non-verbal language, reading the intent of others, and establishing and maintaining relationships [36,45–48]. The participants further explained the factors that contributed to their challenges. One interesting finding was the consistent feelings of uncertainty across multiple themes. Participants reported uncertainty with language use, how they would be received by conversation partners, how to read and interpret the emotions of others, how to discern the sincerity of others, and how to determine the effectiveness of the social interaction. Recent research reveals a direct relationship between intolerance of uncertainty (IoU) and autism spectrum conditions [49–51]. IoU, associated with anxiety, assumes that ambiguity in situations often results in difficulty predicting the outcome of events. The consequence of such uncertainty is highly stressful, leading to negative thoughts of threat and provoking a fear of the unknown [52,53]. Although IoU is present in both autistic and non-autistic neurotypes, research has found higher levels of IoU in autistic children when compared to non-autistic peers [51,54]. Rodgers et al. [53] conducted a single case experimental study on four autistic adults to gather preliminary data on the feasibility of utilizing treatment strategies to target IoU. The targets of three of the participants were directly related to challenges with uncertainty surrounding social interactions. The results revealed improved confidence in dealing with uncertainty and related coping mechanisms. Although the results require further research to validate its efficiency, its success was maintained at follow-up, four weeks after baseline.

Contrastively, Bervoets et al. [55] dispute the IoU relationship and believe it is not an appropriate fit for autistic individuals due to the subjective and contextual variables present in autistic experiences. They assert that the IoU association with emotional regulation does not consider the significance of the predictive processing framework. In simplistic description, predictive processing entails the brain's processing of sensory input and its prediction of the various ways to interact with the stimuli [56]. Bervoets and colleagues suggest that the application of IoU to the autistic experience is pathologizing, with autistic individuals being portrayed as "oversensitive to the same inputs" (p. 3) of non-autistic individuals. While Bervoets et al.'s [55] position is highly respected, these researchers view IoU differently. The current research does not focus on the biological cause of difficulty; it focuses on information that may lead to strategies to mitigate challenges while respecting autistic differences. When considering the complexity of social communication and interaction with others, uncertainty is ubiquitous. Examining the impact of IoU may contribute to developing problem-solving strategies that can be used when targeting social communication in autistic individuals.

Another critical point echoed by all participants was the marginalization felt as a direct result of their differences in communication style and social behavior, despite their ability to communicate with various individuals at a conversation-level. Participants reported disrespect that varied from being overlooked or rejected to being verbally and physically assaulted. The history of dehumanization and stigmatization associated with autism may explain the egregious disrespect [28,57]. The marginalization experienced appears to be the result of a perfect storm of the historical application of the medical model to individuals who present differently and are seen as inferior to the predominant neurotype and the lack of knowledge and sensitivity of the bi-directional misunderstanding between the two neurotypes.

Historically, the medical model of disability has been used as a framework to categorize autistic needs. One researcher argues that society should implement the social model of disability universally for autistic individuals [17]. The social model of disability separates an impairment from disability and presents a neutral position toward an impairment. It identifies impairment as a “state of the body that is non-standard” [58] (p. 135) and is seen as a form of diversity. Alternatively, disability is viewed as the result of society’s failure to “acknowledge, include, and accommodate” [59] (p. 3) an individual’s physical, social, and emotional needs, preventing individuals from operating effectively within their environments, thus shifting the stigma away from the individual. The social model of disability aims to remove negative associations from the label of autism, view autistic differences as a form of diversity, and decrease the social barriers and inequities that autistic individuals experience. Direct support is not recommended since differences are not considered deficits requiring correction. Contrastively, support is provided by deconstructing the sociopolitical systems that guide the environmental and societal expectations that assert autistic differences to be deficient. One concern of the social model of disability is its failure to consider the complex relationship that impairment and disability have on an individual’s lived experiences [60]. Haegele and Hodge [60] assert that focusing on changing societal policies, environment, and expectations does not address the specific needs of individuals, particularly when one considers the plethora of differences amongst individuals with disabilities. Paired with the sluggardly movement of sociopolitical change in society that individuals lack control over [31], reliance on the social model of disability to ameliorate disparaging autistic experiences is a cause for great concern.

The social-relational model of disability considers environmental and societal displacement as well as lived experiences faced by individuals with disabilities. Cologon and Thomas, 2014, as cited in Mackenzie et al. [61] (p. 5), report that individuals may experience disability through “*barriers to doing, barriers to being, or impairment effects*”. *Barriers to doing* so include restrictions that society imposes on individuals, preventing them from efficient participation in activities. *Barriers to being* include the negative words and associations society has placed that disempower self-esteem and self-efficacy. *Impairment effects* include the direct experiences of individuals experience as a result of their differences being viewed as deficiencies and disregarded by society.

Kapp et al. [31] report that some autistic individuals may choose to adapt to the “neurotypical” world for practicality matters, a sentiment shared by some participants. In such cases, autistic adults have the autonomy to choose to receive direct services from speech-language pathologists (SLPs) and other healthcare providers to learn strategies to support them when navigating non-autistic environments. Shifting to a social-relational model of disability will empower providers to evaluate external challenges within sociopolitical environments that require advocacy or problem-solving strategies while addressing direct needs. Additionally, when providing direct support for individual needs, it is crucial for providers to view autistic communication as a difference rather than pathologizing its characteristics. Providers may also consider suggesting social communication treatment as an elective service to enhance social communication and interaction that is not rooted in a deficit-based model. The needs, as expressed by autistic clients, should drive the direction of services. When desired, support strategies should focus on a collaborative approach

that improves social communication based on individual goals (e.g., strategies for reading situational cues and non-verbal language [62], which may assist with interpreting others' intent, or strategies for communication exchanges on non-preferred topics if the individual requests assistance), while also facilitating self-advocacy. Conversely, treatment programs should discontinue strategies that aim to diminish autistic characteristics or promote the superiority of neurotypical behaviors (e.g., teaching variable intonation patterns or expressing non-verbal language with the ultimate goal of conforming to non-autistic expectations). SLPs and other healthcare and educational professionals can provide indirect support by educating the public, at individual and institutional (e.g., educational facilities, workplace environments, healthcare institutions, etc.) levels, on the double empathy problem to facilitate greater sensitivity and understanding.

Another key finding was participant statements that supported previous research that autistic individuals prefer to interact with other neurodivergent individuals [63] due to greater relatability. Crompton, Ropar, et al. [18] found that communication difficulties present in autistic–non-autistic dyads were not observed in autistic–autistic dyads or non-autistic–non-autistic dyads when sharing information. The incongruent communication styles between the two neurotypes resulted in challenges with connection on both sides, revealing that miscommunication was not unilaterally biased against autistic errors. The introduction of the double empathy problem [25] is accepted in autism advocacy but may not be knowledgeable in the majority of society. As both neurotypes learn about bi-directional misunderstanding, they should share the responsibility for repairing communication breakdowns rather than placing the blame primarily on autistic individuals by assuming errors are due to autistic traits.

The level of effort participants placed into connecting with others was astonishing and was also a significant finding of this study. It corroborates the assertion that autistic individuals put substantially more effort into understanding and relating to others than their non-autistic communication partners [25,64]. Some may argue that both neurotypes will experience challenges when connecting with others, may complete some form of research when interacting with new people or unfamiliar settings, and may substitute their social behaviors to avoid social stigma [64,65]. However, the extent to which autistic individuals are impacted is significantly greater and more harmful than non-autistic individuals [64]. For autistic individuals, masking is associated with impairments in mental health [15,66], a loss of one's identity, is based on a foreign social communication style and has been related to suicidality and unhealthy coping strategies [64]. With the detrimental cost of masking to autistic individuals, it is pivotal that healthcare providers and non-autistic communication partners carefully assess how they support social communication and interaction in autistic people. There is often an emphasis on the expectation that autistic people should diminish their autistic behaviors and communicate like non-autistic people to be successful. Therefore, non-autistic individuals and healthcare providers should consider implementing the neurodiversity paradigm into their practice, which empowers and advocates for the autistic identity. Public education and advocacy for acceptance are pivotal in the neurodiversity movement. An inaccurate misconception of neurodiversity is the claim that it denies the presence of disability and is against direct intervention support. Conversely, it recommends the advocacy of autistic voices to increase access to opportunities via appropriate accommodations and services [31].

Limitations and Future Research

One limitation of this research is the limited diversity of the sample. The experiences of autistic individuals reach beyond a diagnosis to include the intersectionality of differences such as race, culture, sexuality, and socioeconomic status. While this study's reported social communication experiences can serve as a guide, it is essential to prioritize individual characteristics. The lack of involvement of an autistic researcher is also a limitation. An autistic consultant provided feedback on the manuscript's interview questions, themes, and language. However, this paper presents the perspective of a neurodivergent, non-

autistic SLP relearning concepts of autism and neurodiversity. Although some may view the researcher's position as unfavorable, it likely represents the perspectives of several SLPs, other healthcare providers, and non-autistic individuals striving to shift their views to meet the needs of the autistic population respectfully.

Additionally, the data collection method may have limited diversity in the sample. The face-to-face video conference format used during the interview may be anxiety-provoking and a deterrent for potential participants. Our sample was also limited to participants who had a secure internet and a private space where they felt safe and comfortable enough to discuss these topics of such sensitive matters. Other methods of interview interactions, such as written responses on a shared document, email exchanges, or asynchronous recorded responses, may have mitigated such concerns and provided greater participant diversity [67]. Finally, qualitative research offers in-depth information about a limited sample size, which may provide valuable insights. However, caution should be applied when considering how they generalize to the broader population of autistic young adults.

Future research should consider the double empathy problem and critically evaluate the use of the medical model of disability while exploring the social communication characteristics common among autistic individuals across different developmental stages (from childhood through adulthood) and abilities (from non-speaking communicators to fluent conversationalists). Social communication can vary based on diverse backgrounds and experiences. This study presented limitations in the diversity of its participants. Therefore, future research should explore differences in the experiences of diverse groups due to cultural, gender, sexuality, or linguistic variations. As healthcare providers and non-autistic individuals explore ways to provide meaningful support to autistic adults, future research should investigate their perspectives toward communication support, meaningful service delivery models, and appropriate goal setting for various situations and settings (i.e., work, relationships, etc.).

5. Conclusions

The findings of this study contribute to the growing body of first-person narratives documenting the experiences of autistic adults. It explores the self-perceived relational experiences of conversation-level, verbally-speaking communicators by examining their social communication experiences and perspectives when engaging with others. Social communication and interactive engagement are pervasive challenges for autistic individuals. This study helps non-autistic individuals and healthcare providers to understand the autistic person's perspective based on their reported lived experiences. One critical finding that helped elucidate their experiences was an overwhelming feeling of uncertainty across multiple situations. All participants expressed varying levels of uncertainty regarding how they would communicate with others, how others would perceive them, how to gauge the sincerity of others' interactions, and how to understand others' emotions. Their uncertainty resulted in discomfort within themselves and interactions, which appear to contribute to their challenges or decision to present masking behaviors. Participants reported persistent efforts to establish, maintain, and engage in social connections with non-autistic individuals in daily activities, except when they felt a strong level of comfort. Researchers have identified differences in autistic communication styles, values, and outlooks that are effective when communicating with other autistic partners or non-autistic individuals they feel comfortable around [11,68]. However, non-autistic society does not universally accept their communication differences. As a result, all participants discussed feeling marginalized for their different communication styles and social behaviors despite their ability to engage in in-depth conversations with various individuals.

This is significant, as it highlights the discord caused by these incongruent communication styles. Although communication is a bi-directional exchange between individuals, the onus for assimilating to the style and expectations of the majority, non-autistic society is placed on the autistic individual, thus adversely impacting their feelings of identity and value in society. When considering the roles and responsibilities of adulthood, effective

social communication skills are pivotal for an individual to navigate their daily living activities successfully.

This study reveals compelling information that explains factors that contribute to the complexities of autistic social communication. It adds to the current research that emphasizes listening to and respecting autistic voices, advocating for change in sociopolitical barriers, and presenting support strategies that empower autism inclusion within our society. As healthcare providers and non-autistic individuals strive to provide meaningful support to autistic individuals, this study challenges them to critically examine their perspectives on autistic communication and how it affects an autistic person. We hope that our work increases awareness, sensitivity, acceptance, inclusion, and support of the social communication needs of autistic young adults by non-autistic individuals (Although there is no clear consensus on the preference of language choice for identity in the autism community [69], identity-first language has been adopted by many self-advocates and scholars [70] as it represents autism being an “identity-defining feature that cannot be separated from the individual” [71] (para. 4). Furthermore, identity-first language has been used to support disability rights, neurodiversity, diversity frameworks, and respect to the autonomy of autistic people [69,72]. Therefore, the authors used identity-first language to discuss individuals on the autism spectrum in this article).

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