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“We’re Operating Closer to the Red”: Social Communication Reflections of Autistic Young Adults

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Abstract

Social communication challenges in autistic individuals result in a variety of cognitive and affective reflections. This study explores the introspective thoughts about the social communication experiences of 15 autistic young adults to gain an understanding of how they feel during social engagement. An interpretive phenomenological approach was used to analyze the data. Three major themes emerged from the data that captured the challenges of the autistic adults: (a) “operating so much closer to the red”, (b) emotional overload, and (c) the highs and lows of social communication. Social communication differences in autistic individuals are attributed to a different neurotype and should not be considered a deficit. However, participant reflections indicate that they perceive a lowered social self-efficacy and elevated stress during social engagement when navigating daily activities. This may result in some individuals to seek professional support services to address social communication needs. The findings suggest that speech-language pathologists should encompass a holistic approach which incorporate person-centered care to work collaboratively with autistic adults, counseling services to address negative emotions and thoughts associated with communication, and consider strategies of stress reduction, such as mindfulness-based practices, to support whole person care.

Keywords: autism, autistic adults, social communication, personal perspectives, counseling, person-centered care, stress

“We’re Operating Closer to the Red”: Social Communication Reflections of Autistic Young Adults

Autism is a lifelong condition that impacts the development of social communication and interpersonal relationships (5th ed.; DSM-5; American Psychiatric Association, 2013). Prior research by Milton (2012) revealed social communication breakdown that occurs between autistic and non-autistic neurotypes is due to a ‘Double Empathy Problem’ (DEP). The DEP asserts that social communication misinterpretation between neurotypes is equally present in both groups because of a difference in neurological processing, interests, values, and mindset when navigating social situations (Banks et al., 2022; Edey et al., 2016; Milton, 2012). Crompton et al. (2020) researched information transfer and rapport building between three small groups, a) autistic-only individuals, b) non-autistic-only individuals, and c) mixed autistic/non-autistic individuals. Results revealed that the quality of information transfer and rapport between autistic-only and non-autistic-only groups were not significantly different; however, there was a distinctive breakdown in communication between the mixed autistic/non-autistic group. Despite the understanding of DEP in professional literature, such knowledge has not improved the social experiences of autistic individuals as they are often penalized with decreased social interactions and opportunities (Banks et al., 2022; Morrison et al., 2020). The social communication differences of autistic adults, which present as impairment in the predominate non-autistic society, will often adversely impact their ability to independently meet expected social and occupational milestones.

Research on the outcomes of autistic adults reveal disproportionate challenges in employment, post-secondary education, independent living, social relationships, and experiences with support services (Daugherty et al., 2021; Sosnowy et al., 2018). Roux et al. (2015) reported that the majority of cognitively-able individuals on the autism spectrum exhibit social communication challenges that impede successful navigation of social relationships, work, and/or higher education. While some cognitively-able young adults on the spectrum are able to progress and secure employment, establish relationships, and live independently throughout their adulthood, many individuals present with significant limitation in their social experiences (Anderson et al., 2014). This implies challenges with performing adult roles and responsibilities are related to difficulties, real or perceived, navigating social communication in majority, non-autistic spaces.

Banks et al. (2022) explored how autistic adults viewed their social communication when navigating daily experiences. Reflective statements made by the participants suggested many

perceived a lowered self-efficacy when navigating social experiences in daily life. Perceived self-efficacy is one's belief about their capacity to perform tasks which influences their attempts to do so (Bandura, 1994). Bandura asserts accomplishment and personal well-being are attained by a positive self-efficacy. Conversely, people with low self-efficacy doubt their capabilities to conquer challenges, view their perceived failures as personal deficiencies, and have risk aversion due to fears of failure.

Social Self-Efficacy

Social self-efficacy (SSE) is a social-cognitive construct described as “an individual's confidence in her/his ability to engage in the social interactional tasks necessary to initiate and maintain interpersonal relationships” (Smith & Betz, 2000, p. 286). Social self-efficacy influences an individual's decision to take social risks and/or feel a sense of success after a social interaction. Additionally, concepts such as self-acceptance, overall competence, and general self-worth have been significantly correlated to SSE (Connolly, 1989). Strengths in SSE were found to correlate with successful college performance (Ferrari & Parker, 1992), confidence in career determination (Tuck et al., 1995), and self-assurance in romantic relationships (Riggio et al., 2011). Contrastively, decreased levels of SSE were associated with loneliness, depression, and poor self-esteem (Ahmad et al., 2014; Wei et al., 2005). Considering the impact that SSE has on an individual's performance in daily life activities, it is assumed that similar relationships exist when examining communication interactions. Erozkhan (2013) found effective communication and interpersonal problem-solving skills contributed to a positive SSE. However, there are no known studies that examine the relationship between social communication profiles and perceived SSE in autistic adults.

Research on the self-efficacy of autistic adults is limited. Shattuck et al. (2014) reported a higher self-efficacy in college student's ability to acquire needed information and getting others to listen to them; however, lower self-efficacy was reported on their ability to “handle most things that come their way” (p. 4). Researchers have reported an increase in self-efficacy after autistic adults received specific vocational training (Kuper et al., 2020; Reeves et al., 2008; Ward & Esposito, 2019). Additionally, when examining employment and occupational skills, the general and occupational self-efficacy of autistic adults were found to be lower than non-autistic adults (Lorenz & Heinitz, 2014). Therefore, if low self-efficacy is associated with a decrease in confidence in personal capabilities, then one may infer that a similar relationship exists between perceived SSE and social communication performance.

There is no known published research on the SSE of autistic adults in daily communication experiences. Contrary to research that found an association of a lowered perceived social competence with symptoms of depression in autistic children on the autism spectrum (Vickerstaff et al., 2007), an investigation of the relationship between SSE and depression in adults was inconclusive (Butler, 2012). The metacognitive skills of autistic adults were examined by analyzing the introspective accuracy and bias of their cognitive and social cognitive self-assessment (DeBrabander et al., 2021). Although the study did not examine SSE, the findings revealed autistic adults perceived their performance on social cognitive tasks to be less than their perception of the average (non-autistic) person's performance. Interestingly, this decreased self-appraisal was not present on general cognitive tasks. DeBrabander et al. (2021) concluded autistic adults may have internalized beliefs that they have below average performance on social cognitive tasks. Furthermore, when examining the relationship between social self-efficacy and the mental well-being of autistic adults, Camus et al. (2022) found autistic adults who interacted with groups of people they identified with had higher social self-efficacy than those who interacted with people they did not identify with.

Stress in Autistic Adults

Distress in autistic adults has been widely explored (Cage et al., 2018; Gillott & Standen, 2007; Haruvi-Lamdan et al., 2020; Moseley et al., 2021; Park et al., 2019). Distress (also referred to as *stress*) is a “perceived threat (real or imagined) to one’s mental, physical, or spiritual well-being, resulting from a series of physiological responses and adaptations” (Seaward, 2015, p. 3). Repeated exposure to stressors may alter one’s view about themselves or their capabilities to perform under such circumstances. Additionally, one’s measure of success in stressful situations will contribute to their appraisals of self-efficacy.

In a society that praises non-autistic values, such as efficient social interactions and adjusting to constant change to achieve markers of success, the core characteristics of autism spectrum, are counterintuitive. Haruvi-Lamdan et al. (2020) reported the presence of cumulative and complex effect of stress and trauma related to negative social occurrences in autistic adults. Hirvikoski and Blomqvist (2015) reported intellectually-able adults perceived an elevated level of stress and a low level of coping ability. Bishop-Fitzpatrick et al. (2015) reported autistic adults had significantly higher levels of perceived stress when compared to non-autistic adults with matching characteristics. The study further revealed greater perceptions of stress associated with poorer scores on measures of social functioning and social disability. However, the directional effect of stress and social functioning was

not predicted. Furthermore, when examining the sources of stress and anxiety in adults with an intellectual disability, autistic adults were found to have higher levels of stress and anxiety than non-autistic adults (Gillott & Standen, 2007).

Confirming the presence of stress in autistic adults is ineffectual without understanding what contributes to their perception. Researchers have found that knowledge shared by autistic adults provide in-depth insight based on their first-hand experiences and are less likely to share perspectives that focus on stigma and deficits than non-autistic individuals (Gillespie-Lynch et al., 2017; Kapp et al., 2013; Pellicano et al., 2014). The personal experiences of autistic adults may elucidate what contributes to the perception of elevated stress levels during social interaction. Hull et al. (2017) reported elevated stress levels related to social camouflaging. Autistic young adults identified interaction with others, fearful anticipation, disappointment, concerns for others, and experiences within their immediate environment to contribute to feelings of anxiety, which induced elevated perceptions of stress (Trembath et al., 2012).

Perceived Interpersonal Communication

Literature on the interpersonal communication perspectives of autistic adults revealed a variety of views. Cummins et al. (2020) reported both positive and negative views towards communicating with others. While autistic adults acknowledged the benefit of social interaction, it was also reported to be effortful. Furthermore, researchers found that autistic adults reported feelings of isolation (Cummins et al., 2020; Muller et al., 2008; Orsmond et al., 2013) and frustration, sadness, anxiety, and incompetence (Hurlbutt & Chalmers, 2002) concerning their interpersonal skills. They also described feeling confusion during moments of social interactions (Sperry & Mesibov, 2005) and wanted greater emotional intimacy with others (Muller et al., 2008). The information gained from the interpersonal perspectives of autistic adults illuminate their internal state when communicating with others. However, considering the complexities of social engagement, further examination of the reported feelings is beneficial to grasp their potential impact.

Purpose of the Study

The aim of this study is to gain greater understanding into the perspectives of young adults on the autism spectrum. It will examine cognitive and affective reflections of experiences related to their social communication profiles in daily life experiences. The information gained from this study will attempt to provide guidance, from the personal narratives of autistic young adults, on how speech language pathologists (SLPs), other health care professionals, and non-autistic individuals may

support autistic adults in social situations.

Method

This study is a phenomenological qualitative design that is part of a larger study on the personal perspectives of social communication experiences in autistic young adults (Banks et al., 2022). It uses interpretive phenomenological analysis to understand how autistic adults give meaning to their social experiences. This study focuses on the personal descriptions and perceptions of feelings and thoughts related to their social communication experiences.

Participants

A total of 15 autistic adults, ranging from 18 to 28 years ($M = 23.4$, $SD = 3.38$), participated in this study. Participants self-identified their ethnicities as African American or Black ($N=2$), Biracial or Multiracial ($N=2$), Caucasian or White ($N=9$), and Hispanic or Latino ($N=2$). Most of the participants were either undergraduate or graduate students or had completed college degrees. Five participants had satisfactory part-time employment based on their status as a student and one participant had a full-time, long-term career. While most participants learned of their diagnosis in youth and adolescence ($N=9$), six people learned at the age of 21 or older.

Fourteen participants received some level of support service throughout their life. Counseling services were most often reported for concerns with anxiety or depression. Four participants received speech and/or language support services not related to social communication in their youth. Furthermore, three of the participants received social communication support from non-SLPs in their adolescence and adulthood. Additional characteristics are presented in Table 1.

Procedures

Purposive sampling was used to recruit autistic adults who were high school graduates with conversational level verbal skills within the target age range (Etikan et al., 2016). Recruitment was conducted via online advertisements on social networking sites and e-mailed invitations to autistic adult support community organizations and Offices of Disability Services (or equivalent) of a variety of community college and university campuses.

This research project utilized ethical guidelines to safeguard against potential harm to participants. Ethical approval was granted from the university's Institutional Review Board (IRB#5190319). After reviewing the written informed consent and given the opportunity to ask questions, participants gave verbal consent to participate.

Table 1

Demographic Description of Participants (N=15)

Gender		Race	
Female	10	African-American/Black	2
Male	4	Biracial/Multiracial	2
Gender Fluid	1	Caucasian/White	9
Age		Hispanic/Latino	2
18 – 21	6	Geographic Location	
22 – 25	4	West (CA, WA, AZ)	6
26 – 29	5	Midwest (IN, MI, WI)	3
Highest Level of Education Completed		South (GA, KY, YA, TX)	5
High School	8	East (NY)	1
Bachelor's Degree	6	Identity Language Preference	
Master's Degree	1	Autistic Adult	4
Higher Education Status		Adult with Autism	3
Full-Time Graduate Student	2	No Preference	8
Part-Time Graduate Student	1	Employment Status	
Full-Time Undergraduate Student	5	Full-Time Employed	1
Part-Time Undergraduate Student	1	Part-Time Employed	6
Not Enrolled	6	Unpaid Internship	1
		Unemployed - Actively Looking	2
		Unemployed – Not Looking	5

Note: All participants provided their preferred racial identity. (Banks et al., 2022)

An informal, conversational style, semi-structured interview was used to engage in a meaningful interaction about the research topic. Each interview provided the perspective of the participant's experience and received an iterative analysis before being examined collectively for data analysis (Banks et al., 2022).

Zoom video conferencing was used to conduct individual interviews. The interview, developed by a licensed SLP and the first author, asked questions related to their personal social communication and interaction. The interviewer disclosed her status, as a non-autistic SLP who sought to understand young adult, autistic, social communication experiences, to each participant. Interview questions were reviewed by a non-participant autistic individual to provide feedback on the presented questions to safeguard sensitivity and suitability (Cummins et al., 2020); adjustments were made as appropriate after receiving feedback (Banks et al., 2022).

During the semi-structured interview, some questions were re-worded, re-organized, or omitted based on the participant's responses during the conversational-style exchange. Credibility was achieved during the interview as questions of clarification and statements were rephrased to confirm the interpretation of their response (Doyle, 2007). Additional questions were asked to follow-up on a unique, or ambiguous perspective.

Data Analysis

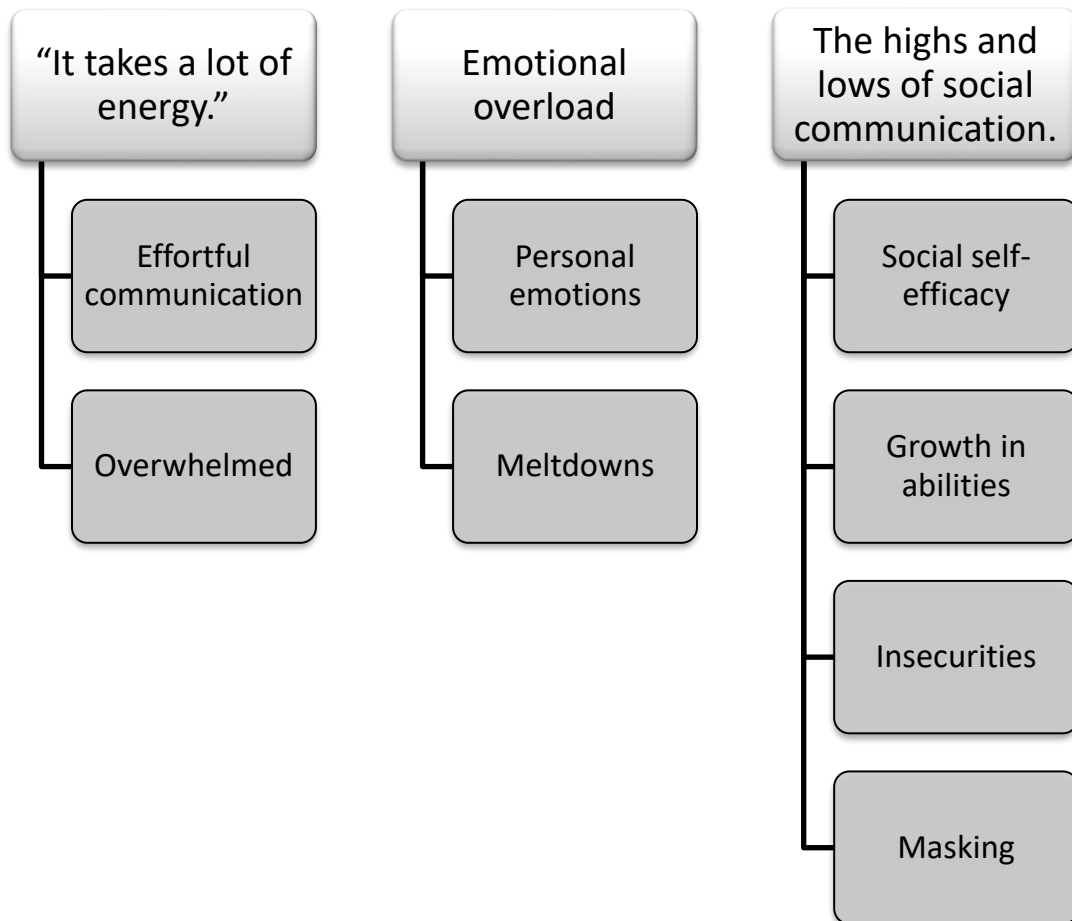
Interviews were recorded and assigned codes and themes by the first author (Banks et al., 2022). The aggregated data was organized and analyzed to determine commonalities and draw conclusions of the participants' perspectives related to the research question (Porter et al., 2020). Reflexivity was established using analytic memos written after each coding session and interpretations of the data. Finally, Synthesized Member Checking (SMC) was utilized to verify and give credibility to the analyzed data (Birt et al., 2016). Participants were emailed a chart with the analysis of their collective interviews. The data was organized by codes, categories, a description of each category, and sample excerpts from the participants that corresponded with each code. The participants were asked to review the chart to determine if they identified with the summarized analysis. They were also asked to provide comments if they had a disconfirming view or wanted to add supplement information. Six of the 15 participants returned the SMC feedback. Upon receipt of the participant's feedback, the comments were evaluated, and adjustments were made as appropriate.

Findings

Three primary themes emerged from the data that demonstrated the participants' reflection on how their social communication skills impacted their relationships and daily life experiences. See Figure 1 for a thematic map of the analysis. Excerpts from the participants' interviews are shared with pseudonyms utilized to safeguard their identity.

Figure 1

Thematic Map



“Operating So Much Closer to the Red”

Participants reported expending a great amount of effort during social interaction regardless of their perceived competence by others. Spontaneous communication or exchanges that required little thought or preparation rarely occurred which contributed to their fatigue. To prepare for interactions, the participants reported that they a) researched upcoming experiences and planned specific details of anticipated interactions to feel prepared, b) felt the need to “perform” as other people and mask their

behaviors to feel socially accepted, and c) perseverated on self-deprecating thoughts after their social exchanges for a lengthy amount of time analyzing or critiquing their behaviors. Masking, also referred to as ‘camouflaging’, are strategies and behaviors used by autistic individuals to hide their characteristics, thus assimilating to the social norms of the non-autistic neurotype (Bradley et al., 2021; Cage & Troxell-Whitman, 2019; Hull et al., 2017). Justice, an 18-year-old female discussed how missing social cues, which cause communication breakdown, is very stressful. Such situations cause her to “just analyz[e] every single thing that happened in that situation like over and over and over in my brain.” Furthermore, their strategy to ‘learn’ new people, which involved observing and learning other’s personalities and adjusting to each person individually instead of generalizing social communication behaviors to a variety of people (Banks et al., 2022) was reported to be effortful. The mental energy used during social exchanges resulted in physical exhaustion after lengthy social interactions for many. Brielle, a 28-year-old female stated,

So, I don't struggle so much with the social thing now. It just is very exhausting for me because I feel like I have to, I feel like I have to play a role. I have to play the normal person, like I have to play the human role anytime that I'm interacting with a person and so it just is very exhausting. So, I still struggle with it that way, not so much the awkwardness or any kind of social anxiety, but just, it's exhausting.

Brielle continued by providing the following analogy to describe the effort felt and the importance of understanding her social communication profile as a difference and not a deficit.

Because of how much stimulus we process compared to other people, it's, it's not that our, like on the car gauge where like the red part of the RPM is, it's not that our, it's not that our red part is way closer to the side than other people, it's that we're, it's that we're operating so much closer to the red. So, it's just like identifying it as a difference in how we operate, not an inherent weakness, I think it's really important because then we can care for ourselves better.

Participants also reported feeling overwhelmed by the amount of energy used during social interactions. Processing various information simultaneously, feeling uncomfortable or insecure in social situations, engaging with others for lengthy periods of time, and/or sensory overload from external (e.g., the environment) or internal (e.g., multiple negative thoughts) factors were reported to contribute to their anxiety. Some reported moments of “going nonverbal”, as described by Ari, a 20-year-old female, prevented their ability to speak and “autistic shut down”, as shared by Brielle, prevented interaction with others despite having the physical capacity to do so. Zoe, a 24-year-old

gender fluid individual explained their experience with going nonverbal as,

But when I mean going nonverbal, it's that I physically can't or it's painful or overloading for me. It's almost, I used to have braces and I had bands like, to basically, they didn't hold my jaw shut, but they were stiff enough that I had to actually try to like open my mouth. It feels more like somebody has literally wired my mouth closed. And I can form thoughts, but it's very difficult for me to force them out. I'm like physically incapable of speaking even though I know it's not a physical issue. It's psychological, neurological, but like, there are times like and usually when that happens, I've got all of these words and these ideas and thoughts and things that I want to communicate. And I can't.

The effort felt during moments of social interactions was echoed when discussing the use and understanding of emotions in self and others.

Emotional Overload

Participants reported the ability empathize with and feel shifts in other's emotional state. However, they struggled with identifying or labeling the emotional state of others particularly when their nonverbal language did not match their message, knowing how to respond to other's emotions, and recognizing interpersonal and environmental factors that triggered a change in the reaction of other people's emotional states. Conversely, many participants reported strengths with understanding and identifying their personal emotions, although they may have had difficulty verbalizing them. Feelings of anxiety were reported by several participants when in social situations they were not prepared for or comfortable in. Additionally, frustration was reported during uncertainty in social dilemmas.

Participants reported their attempt to regulate their emotions to remain calm when they felt apprehensive in social situations. However, during elevated levels of sadness, anger, frustration, or anxiety, they had difficulty managing their emotions and they reported having meltdowns. A meltdown, which was reported to differ from autistic shut down, was described as an uncontrollable sense of negative thoughts and emotions. Although meltdowns manifested in all the participants', it varied in how they were experienced. Variations included intense crying, screaming, slamming or throwing things, losing the ability to speak, or feeling depleted until they calmed. Simone, a 28-year-old female shared,

Uncontrollable crying, screaming, throwing things. Just complete lack of control of myself. I can be talking but, like, I'm not actually thinking through what I'm saying. I've

actually had blackouts during meltdowns. Where I don't remember them anymore even though I was like, completely active during it. I think meltdowns are the biggest thing that scares me because I can become very volatile and dangerous to others and myself. But like I have a good handle on them, but that doesn't mean that I have like, that they're not going to happen. And that's a, that's a scary line to walk because right now I'm doing well.

Finally, the participants discussed the expression of their personal emotions. Many reported expressing minimal to no emotion despite feeling a variety of emotions internally. Brielle reported,

Like I often feel like kind of an alien... Like, am I a person or not, because like, everything that y'all are experiencing, I'm not relating to any of this. So like, there is a lack of a lot of the emotion that I feel like other people feel or like feelings or things that other people relate to, that I just don't relate to. But there are a lot of times where I am in fact feeling something or having a reaction on the inside. Like I do think something's funny, or that something sad, but I don't express it. So, so there are aspects of like, I do feel it, I just don't express it. But it is also the fact that I do feel like I feel a lot less than other people do.

Conversely, Amiyah, a 24-year-old female, reported having large expressions of emotions. She shared, "like when I'm happy I stim and squeal and do all kinds of stuff. So, I've, like, dampened the feeling of emotions because mine look different from other people's." The participants shared that their differences in emotional expression caused many to feel misunderstood and sensitive to how others perceived them. This resulted in them masking to produce socially expected emotional expressions to prevent judgment.

The effort and emotions discussed provided insight on how participants perceived their social communication skills to impact their experiences. Their insight was further expounded in the final theme.

The Highs and Lows of Social Communication

Participants reported strengths in conversing with others during intimate exchanges, having an extensive vocabulary, being a direct communicator, noticing other's emotions and being able to solve problems in structured situations. Ethan, a 26-year-old male stated,

I would say biggest strength definitely comes in more personal interactions. Not large groups, large groups, I do struggle. But smaller, more, more personal groups, I do tend to succeed more. Just because I'm able to, there's not too many conflicting, conflicting people talking, I'm able to process what each person is saying and what each person is contributing.

However, they reported less confidence with initiating interactions, having expanded conversations, conversing with a variety of people or large groups, and interpreting other's emotions, social cues, and non-verbal language. Amir, a 24-year-old male shared,

But the thing is, is that how can I develop relationships with using deeper talk with somebody? Like, you know, how can I, that's, that's what I want to work on more is like, when I see that one person that I desperately want to talk to how do I get better with conversation with that, you know?

They felt discomfort with initiating conversations, self-doubt during social interaction, and a level of rejection by others. Some believed their challenges resulted in superficial relationships with others. Zoe said,

Like it's not an actual friendship. It's just, this is what we have in common. This is what we can talk about because I'm not capable of really going past that. Like if they don't initiate that and they don't bring up something that I'm able to talk about than it never moves any deeper than that.

Additional stressors included difficulty keeping up with the pace of a conversational, feeling confused during conversational exchanges, and misunderstanding non-verbal language and/or social cues. Uncertainty about the effectiveness of their self-taught social skills (Banks et al., 2022) and several participants feared being judged as inadequate leading to apprehension about their social communication. Some participants refrained from asking clarifying questions because of possible disclosure of their challenges with following the conversation. Kelsey, a 26-year-old female shared her perspective about asking clarifying questions,

I think those questions still do make me feel kind of like, incapable or like incompetent. And so because it feels like I'm kind of admitting like, 'Oh, I don't understand' and everyone else seems to understand. Which also, who knows what they [understand].

Social communication mishaps were inevitable and impacted participants differently. While one participant reported optimism for the best outcome in when a social mishap occurred, other participants reported feeling various levels of discomfort, anxiety, incompetence, frustration. Amir specifically stated he felt "demoralize[ed]" when he experienced social challenges that he believed were easy for "neurotypicals". Such mishaps also made participants feel rejected and/or devalued by others.

The participants found value in feeling a sense of belonging, interactions with people they

related to, and having relationships with people who accepted them without explanation. Some participants denied challenges with their social communication affected their relationship with others. However, others believed their challenges negatively impacted their relationships and reported a desire to improve their social relationships.

Kelsey described feeling a “double-edged sword” due to the constant awareness of their social challenges. They were searching for greater self-acceptance and made attempts to balance their ruminative thoughts with their desire to be authentic in social environments. Although not discussed by the male participants, the female participants discussed masking for social acceptance by the allistic, or non-autistic, community. The female participants were skeptical about being authentic around allistic individuals and believed their overall self-comfort was not viewed as important to the allistic population. Taylor, a 20-year-old female, believed masking was necessary to present “some level of social skills” in situations of personal value such as employment or friendships; however, it should be done in moderation. Kelsey shared that masking “was kind of a privilege,” because many autistic individuals are not able to do so. However, similar to Zoe, she firmly disagreed with masking’s association of being a “better autistic because [it] looked more neurotypical.” Masking was reported to contribute to their exhaustion and a decline in their mental health. Kelsey added,

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. And they were, you know, they felt good about me.

Despite their challenges, all participants reported growth in their social communication skills when they reflected on past experiences from adolescence. The maturity experienced in young adulthood resulted in greater exposure to a variety of social situations. Their exposure led to greater practice in social communication skills which was believed to contribute to improvement in initiating and sustaining conversations, knowing what topics to discuss, and reading non-verbal language. Many participants reported feeling less social anxiety when needing to engage with others and more self-acceptance and self-compassion when social mishaps occurred.

The results of the SMC feedback revealed that all respondents identified with the analysis of the three themes with no dissenting comments. Some respondents provided affirming comments to expand on the presented perspectives. An example of such expansion is displayed by Kelsey’s comment which stated,

Not wanting to risk being viewed as incapable is huge. So much internalized ableism, and so

much trying to slide under the radar as autistic puts so much pressure on me to not need help, despite fully acknowledging that I am human and needing help isn't a bad thing. Disability justice perspectives on interdependence have helped me unpack this a bit.

Discussion

This study sought to gain a deeper understanding of the cognitive and affective impact of the social communication profiles of autistic adults in daily life experiences and relationships with others. It also aspired to guide SLPs on effective support strategies and facilitate improved sensitivity and acceptance to autistic adults.

Overall, the participants provided vivid details and appeared open and sincere in sharing their perspectives. Their descriptions varied when reflecting on their social communication experiences. While most of the participants expounded on their introspection, two of the participants were less descriptive when explaining affective perceptions. When asked follow-up questions to further explore their perspectives, one participant's responses were tangential or vague. The other participant was reticent. Although some questions triggered changes in their nonverbal language that conveyed feeling upset or less confident, they adjusted their nonverbal language to a positive disposition, shifted the topic, or made statements to minimize their experience such as "But I feel that the same would go for anybody" when asked follow-up questions. In those moments, the researcher respected their boundary and moved to the next question.

Additionally, although many of the participants discussed high levels of effort, worry, and stress regarding their social communication, there was an outlier who acknowledged their challenges but appeared less stressed. This participant reported to be less affected by others' thoughts, a greater sense of emotional control, and described positive perspectives. They attributed their perspective to their history with support services, which was unique when compared to the other participants. Direct counseling services, which included topics of social communication, self-advocacy, and problem-solving skills, were received throughout high school. Additionally, this participant completed two semester courses on interpersonal skills at a community college.

Overall, the participants' reflections of their interactions with non-autistic individuals revealed three key findings, aligned with current research, which may influence their capabilities during moments of social communication. First, there was a consistent report that social interactions required a substantial amount of mental effort (Cage & Troxell-Whitman, 2019; Hull et al., 2017; Muller et al., 2008). Participants felt overwhelmed, apprehensive, and rejected during social communication.

Supporting Camus et al. (2022), their interactions with non-autistic adults, who are people they did not identify with, resulted in lowered social self-efficacy as demonstrated by feelings of self-doubt, masking their natural style of social communication, and having aversive feelings towards social engagement. Although they identified moments of success, their challenges had a greater impact on their experiences. Consistent with DeBrabander et al. (2021) participants presented a self-diminished view of their personal social communication skills. Regardless of the effectiveness of their social interaction, they often identified, perseverated, and/or analyzed any perceived imperfections. Their perpetual criticism and self-doubt, which may be attributed to their history with negative social responses from others, may suggest their perspective of a low social self-efficacy.

Second, despite differing experiences, all participants reported various levels of feeling overwhelmed. This caused a variety of reactions that might have culminated in feeling mental and/or physical exhaustion, “going nonverbal”, “autistic shut down”, or meltdown behavior. Their descriptions support Hirvikoski and Blomqvist’s (2015) findings that autistic adults have high levels of self-perceived stress and insufficient coping skills. Our findings provide first-hand descriptions that validate the relationship between distress and decreased social functioning (Bishop-Fitzpatrick et al., 2015; Bishop-Fitzpatrick et al., 2017). Similar to Bishop-Fitzpatrick et al. (2017), there was no clear indication of the direction of such relationship. Furthermore, Bishop-Fitzpatrick et al. (2015) inferred autistic adults would experience differences in psychosocial and biological stress in social situations when compared to allistic adults; however, there is no known research to confirm this hypothesis. Our findings disclose the participants’ internal responses when moments of social communication were effortful and felt overwhelming which suggests the presence of a psychophysiological reaction during moments of perceived distress.

Third, our findings revealed the complex perspectives surrounding the participants’ understanding and expression of emotions in others and self. While participants’ descriptions inferred elevated self-efficacy when understanding and identifying their emotions, lower self-efficacy was implied when considering their interpretation and response to others’ emotions. Their divergent expression of emotions appeared stressful because they perceived discomfort in others and/or felt their intentions were misinterpreted. This appeared to influence their decision to mask their expressions to present like non-autistic neurotypes and ease other’s discomfort. Distress was greatly associated with all masking behaviors, which supports previous research findings (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019; Hull et al., 2017). This finding further indicates self-perceived stress

associated with divergent social behavior and feelings of marginalization by non-autistic individuals.

The results of this study highlight concealed complexities related to social communication challenges in autistic young adults who present with conversational level verbal communication. It also reflects a lack of perceived support from SLPs and non-autistic individuals. Their narratives were congruous with perceptions of lowered social self-efficacy and an elevated perception of stress. This finding may imply a relationship between perceived social self-efficacy, self-perceived stress, and the performance of social communication skills.

Clinical Implications

Powerful perspectives were shared that articulated the need for non-autistic neurotypes to be more supportive in community spaces. The findings of this study are enlightening; however, without action, the information is ineffectual. An awareness of the internal stress in autistic individuals should contribute to non-autistic individuals being understanding if asked to clarify or restate information or patient if asked to interact via alternative methods such as texting, writing, or communication devices during moments of social engagement. Additionally, negative assumptions should be averted if autistic adults present unexpected social communication behaviors or responses.

Neurodivergent social communication in autistic individuals is not a deficit. It is a difference in neurotype which presents as a disconnect in the values and outlook between autistic and non-autistic people (Banks et al., 2022; Edey et al., 2016; Milton, 2012). Therefore, differences in social communication should not be the sole requirement for the recommendation of direct social communication support services. However, we cannot ignore general society's slow movement towards inclusive understanding and accommodating the differences present in the social profiles of autistic people. The impact of social communication challenges when navigating daily life experiences may result in autistic adults seeking support services to learn non-autistic neurotype social interactive skills (Kapp et al., 2013). Interestingly, Camus et al. (2022) suggests "social self-efficacy may be a good target for interventions seeking to support autistic people's well-being" (p.19). In such moments, clinical implications suggest a holistic approach when providing direct support strategies to autistic adults seeking to improve their social communication. Speech-language pathologists should work collaboratively with clients to develop treatment programs with person-centered care (PCC) to develop specific goals and intervention strategies related to the improvement of specific skills and counseling services that center on client emotions as well as education on treatment, problem-solving, and self-advocacy strategies to facilitate an increase in social self-efficacy.

Clinically, autistic adults must feel valued, supported, and empowered by SLPs for the client-clinician relationship to be effective. A PCC approach to support the social communication skills of autistic adults is vital. Person-centered care involves valuing an individual's knowledge, experience, self-determined needs, and autonomy to work collaboratively while determining the focus of care (DiLollo & Favreau, 2010; Tippet, 2012). Feeling a low sense of control over one's health decisions has been associated with less optimism of treatment efficacy and less initiation of care (Adams & Drake, 2006; Seeman & Seeman, 1983). Additionally, Santhanam and Hewitt (2021) reported autistic adults found social communication intervention to be ineffective or marginally effective as their treatment goals were often unclear and they felt clinicians treated them less mature than their age and/or intellectual abilities. Therefore, providing a PCC approach may empower autistic adults to take authority in their social communication needs, increase buy-in into their support strategies, and improve social self-efficacy.

The application of counseling services to address the emotions related to social communication skills and experiences is another clinical implication derived from the data. Utilizing counseling skills to help clients sort through their attitudes and feelings is an aspect of PCC (Kaderavek et al., 2004). We believe pairing specific strategies to address social communication challenges in a safe environment while empowering autistic adults to work through their negative perspectives, problem-solve through challenges, and practice self-advocacy will support their needs and prepare them for socializing in daily experiences. Such preparation may activate belief in their capabilities (i.e., improve social self-efficacy) and develop a greater sense of control, thus decreasing their perception of stress.

Counseling services fall within the SLP's scope of practice and differ from psychotherapy provided by mental health professionals Crowe (1997, as cited in Riley, 2002). Whereas psychotherapy addresses psychological and emotional concerns caused by a variety of mental illnesses and emotional challenges (American Psychiatric Association, n.d.), counseling provided by SLPs is designed to address negative emotions and thoughts specific to communication disorders (American Speech-Language Hearing Association [ASHA], 2016). Moreover, the aim of counseling is to empower independent problem-solving skills, encourage an individual's internal locus of control, and develop a shift in perspective to greater self-efficacy in their communication abilities (Riley, 2002).

Finally, our findings suggest a benefit in presenting stress reduction practices when providing support services targeting social communication. Mindfulness-based practices have been found to

reduce stress in a broad range of clinical and non-clinical populations (Chiesa & Serretti, 2009; Grossman et al., 2004; Khoury et al., 2015) and ameliorate ruminative thoughts of worry and anxiety (Parmentier et al., 2019). Speech-language pathology is emergent in their implementation of mindfulness-based practices in the treatment of fluency disorders, adult cognition, and language disorders, and more recently voice disorders with encouraging results being reported to effectively meet clients' needs (Boyle, 2011; Medina & Mead, 2021; Orenstein et al., 2012). Moreover, researchers have found mindfulness-based therapy for individuals on the autism spectrum (MBT-AS) to be effective in decreasing depression, anxiety, and ruminative behaviors as well as improving general psychological and physical well-being (Kiep et al., 2015; Spek et al., 2013). Finally, autistic adults who participated in an 8-week mindfulness-based stress reduction program reported success in preventing meltdowns and controlling emotions post treatment (Beck et al., 2020). The aforementioned support strategies are conceptual when addressing social communication concerns, however, previous research imply potential for treatment efficacy in their approaches.

Limitations

Our results should be read with caution as the nature of this study is subjective, highly personal, and differed based on the participant's awareness, comfort-level, and/or acknowledgement of their introspection. When considering self-perception, similar experiences may be appraised differently due to confounding factors such as varying skill level, one's upbringing, previous experiences, mindset, cultural background, gender identity, additional diagnoses, and/or mental health at the time of the interview. Also, the amount of information received on some of the topics may have been limited. Due to the personal nature of the interview, if participants appeared uncomfortable or distressed the researcher transitioned to a different topic. Finally, because of the shared data set (Banks et al., 2022) additional limitations, such as lack of diversity and lack of variety in communication profiles, may also apply.

Future Research

This study provided personal perspectives that revealed feelings of great effort and stress surrounding their social communication experiences. Despite the rich descriptions provided by the participants, the qualitative nature prevents generalization of such findings to a broader spectrum of autistic adults. Future research is recommended to determine its prevalence across communication levels.

The descriptive explanations suggest the perception of depressed social self-efficacy in autistic

adults. While we hypothesize a lower social self-efficacy will decrease social communication performance, this information is not confirmed based on the present data. Therefore, research on the levels of social self-efficacy in autistic adults and its relationship to social communication skill performance warrant future examination.

This study also explicated an overarching presence of stress in participants, manifested in psychological and/or psychophysiological symptoms, related to their socializing skills. Hence, further research is needed to confirm its relationship and determine efficient support strategies to decrease overall stress during moments of social engagement.

Finally, the study proposed indirect and unconventional support strategies to ameliorate feelings related to social communication challenges, as well as improve social self-efficacy and overall well-being for the autistic adult. Despite the optimism of the recommendations, future research is needed to examine effectiveness. Potential research should examine the effect of PCC, counseling services, and/or mindfulness practices when supporting social communication skills in the target population. Determining efficacy of social communication treatment can be laborious. The interrelated components that work together for effective interactions are deeply entangled. Therefore, researchers may need to examine the strategies and their impact on specific components related to an individual's desired targets separately (e.g., initiating conversation, reading nonverbal skills, self-advocacy skills, etc.) to determine its efficiency.

Conclusion

Our findings revealed a strong affective response suggesting the perception of a depressed social self-efficacy and elevated distress surrounding the social communication experiences of the participants. Although it does not propose generality, it provides substantial support that suggests internal factors must be addressed to effectively address the social communication challenges autistic adults face. The clinical implications suggested were conceptual with an attempt to explore strategies to support overall well-being. SLPs have a broad scope of practice, therefore, professionals who support autistic adults should be knowledgeable about the wide heterogeneity in the neurotype and the variety in their social communication needs while incorporating PCC in their practice to work collaboratively with clients. Additionally, SLPs should improve competency in their counseling skills, while being aware of their professional limitations, and consider training in mindfulness-based practices for stress reduction to address the cognitive and affective experiences of the autistic adult. They should be prepared to refer, consult, or collaborate with mental health professionals as

appropriate. Finally, it is the hope that this study contributes to the growing body of research that aims to assist autistic adults with finding resources to feel supported in their environment and satisfied with their personal experiences.

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Expanding Workforce Diversity and Health Care Equity in Communication Disorders Research: An NIH Institute Director's Perspective

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Expanding Workforce Diversity and Health Care Equity in Communication Disorders Research: An NIH Institute Director's Perspective

The National Institute on Deafness and Other Communication Disorders (NIDCD) is part of the National Institutes of Health (NIH), the primary federal agency for conducting and funding medical research. Since NIDCD's establishment in 1988, it has conducted and supported research that has led to critical discoveries in our mission areas: hearing, balance, taste, smell, voice, speech, and language. The institute contributes to biomedical and behavioral research advances through *intramural* research conducted in our facilities in Bethesda, Maryland, and through *extramural* research, funded at universities, laboratories, and institutions throughout the country. These research efforts have improved the lives of millions of people with communication disorders.

NIDCD has long worked to increase the diversity of the research pipeline across our mission areas, and since becoming the institute's director in 2019, I have made [expanding diversity, equity, inclusion, and accessibility within NIDCD and its extramural workforce](#) one of my chief aims. When scientists and trainees from differing backgrounds work together, their unique perspectives and experiences stimulate creativity and innovation, contributing to the excellence of the biomedical research enterprise. Diverse teams are also more likely to ensure that members of underserved populations participate in clinical studies and that the research addresses questions that are meaningful to these communities.

Here are a few examples of recent and ongoing initiatives we have undertaken to diversify the workforce in our scientific research areas and to expand our support of research that addresses health care inequities.

Leveraging Mentorship and Research Experience

Anyone who has benefitted from having a supportive career advisor knows the value of mentorship. In 2021, NIDCD initiated new programs aimed at fostering workforce diversity through the creation of mentoring networks and expanded research opportunities. The programs, which use an [NIH grant mechanism](#) called the R25, are open to a range of experience levels, from undergraduate to early-to-mid-career faculty. Through mentorship from experienced researchers, the program offers mentees the opportunity to gain valuable knowledge and skills and a way to begin building their professional networks.

In addition to mentorship, having a hands-on research experience, even one that lasts just a few months, can spark a lifelong interest in pursuing research. With the goal of setting trainees on a path toward a career in research, the [NIDCD Diversity Scholars Program](#) aims to provide access to

research experiences for qualified applicants from underrepresented groups. The program supplies funding for high school, college, and graduate students; postdoctoral researchers; and eligible faculty members of diverse backgrounds. It is also open to investigators who are or become disabled and who need additional support to continue their research. Our diversity scholars are funded through NIH research supplements, which provide additional funds to an existing grant for a specific purpose.

The NIH R01 Grant: The Foundation for an Independent Research Career

The [NIH R01 grant program](#) is the agency's largest funding mechanism, supporting thousands of researchers across the country and around the world. With funds provided for salaries, equipment, supplies, and travel, an R01 grant can be the foundation of a scientist's research program. In April 2022, we issued an R01 funding opportunity announcement titled [NIDCD Research Opportunities for New Investigators to Promote Workforce Diversity](#). The program is open to early stage and new investigators from diverse backgrounds conducting research in any NIDCD scientific area. Unlike most R01 programs, this one does not require the inclusion of preliminary data in the application. By omitting this requirement, we hope to attract the most innovative proposals from the broadest possible pool of talented scientists.

Advancing Research that Addresses Health Care Disparities and Inequities

Disparities in access to health care and in treatment outcomes occur throughout our health care system, including the area of communication disorders. More research is needed to identify factors that could close the gap in care. To raise awareness of our interest in funding research to level these inequities, NIDCD issued a 2021 Notice of Special Interest titled [NIDCD Health Disparities and Inequities Research](#). These types of notices are designed to alert the broader research community to potential funding within priority areas for the institute.

We have also partnered with another NIH institute, the National Institute on Minority Health and Health Disparities, to fund research on structural bias in our mission areas through a funding opportunity titled [Understanding and Addressing the Impact of Structural Racism and Disparities on Minority Health and Health Disparities](#). We recently awarded a grant through this program to a team of scientists studying structural racism and discrimination toward young children with communication disorders. We hope that research findings stemming from these sorts of opportunities contribute to the refinement of health care practices and to policy recommendations that promote equity in care.

Expanding Workforce Diversity and Health Care Disparities Research: An Ongoing Priority at NIDCD

As we prioritize diversity in the communication disorders research workforce, including within our

own institute, and expand our support of health care disparities research, I am pleased to acknowledge our new chief diversity officer, [Cendrine D. Robinson, Ph.D., M.P.H.](#), who joined our leadership team in 2022. Dr. Robinson's role includes directing our ongoing and future diversity, equity, inclusion, and accessibility efforts and participating in NIH-wide initiatives. Our ultimate goal is to create and maintain a culture of inclusiveness in the communication disorders research community and to erase inequities in health care delivery and treatment outcomes.

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References

Comprehensive Information from NIDCD on Building a Diverse Scientific Workforce.

<https://www.nidcd.nih.gov/research/building-diverse-scientific-workforce>

NIDCD Diversity Mentoring Networks and Research Experiences R25 Programs: Frequently Asked Questions. <https://www.nidcd.nih.gov/training/R25-diversity-frequently-asked-questions>

Research Supplements to Promote Diversity in Health-Related Research (NIDCD Diversity Scholars). <https://grants.nih.gov/grants/guide/pa-files/PA-21-071.html>

Funding Opportunity Announcement: NIDCD Research Opportunities for New Investigators to Promote Workforce Diversity. <https://grants.nih.gov/grants/guide/rfa-files/RFA-DC-23-001.html>

Notice of Special Interest: NIDCD Health Disparities and Inequities Research.

<https://grants.nih.gov/grants/guide/notice-files/NOT-DC-21-003.html>

Funding Opportunity Announcement: Understanding and Addressing the Impact of Structural Racism and Disparities on Minority Health and Health Disparities.

<https://grants.nih.gov/grants/guide/rfa-files/rfa-md-21-004.html>

Addressing Structural Disparities for Children with Early Communication Disorders.

<https://reporter.nih.gov/search/3YmpPTdfb0WWHidWdpP76A/project-details/10474135>