

Affective Contact in Autism: A Phenomenological Study of the Emotional Experiences of Autistic Adults

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Importance: Since the first descriptions of autism, difficulties with affective contact (e.g., interpersonal exchanges of feelings between individuals) have been considered a common feature of autism spectrum disorder, and these difficulties frequently manifest in occupational therapy interventions.

Objective: To (1) explore how autistic young adults describe their emotions and (2) suggest ways to improve the affective contact between autistic clients and their therapists.

Design: Virtual focus group interviews.

Setting: Online (Qualtrics) survey and Zoom focus groups.

Participants: Autistic adults (N = 24) who met the following inclusion criteria: self-reported diagnosis of autism spectrum disorder or Asperger syndrome, age 18–35 yr, able to understand English, and able to participate in a focus group or individual interview using verbal or written communication.

Results: Two themes were noted and are presented in this article: (1) Autistic people experience complex emotions and (2) autistic people's emotions are often (mis)measured and (mis)understood.

Conclusions and Relevance: The findings indicate that autistic people experience diverse, complex, and intense emotions and that these are connected to occupation. This suggests that occupational therapists must be attuned to the emotional dimension of occupation when working with autistic clients and that autistic clients may benefit from the use of embodied language to reference their emotions. Occupational therapists can help autistic clients recognize their bodily changes when experiencing emotions and to better identify and regulate their emotions. The results also show that there were many cases nonautistic people misinterpreted the emotions of autistic people on the basis of their facial expressions or words.

Plain-Language Summary: This article provides information about the emotional experiences of autistic people. The study found that autistic people experience complex emotions and that those emotions are often misinterpreted or misunderstood. The author provides information on how occupational therapists can use a neurodiversity-affirming and person-centered approach to support the emotional experiences of people in the autism community.

Positionality Statement: In this article, identity-first language is used when referring to autistic adults. This deliberate choice aligns with the principles of the neurodiversity-affirming movement. Autistic self-advocates have indicated a preference for this style of language over person-first language. The author would also like to acknowledge their positionality. As both a neurodivergent researcher and a self-advocate for the disabled community, this style of language aligns with their own experiences of and beliefs about their disability.

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The sharing of emotional experiences is a natural and inevitable part of occupational participation; therefore, it is difficult to imagine participating in an occupation or an activity without emotions playing a key role in that experience. Consider, for example, social participation in the classroom. A group of peers working together must navigate through vacillating emotions as they problem-solve while completing a learning activity. It is also difficult to imagine an occupational therapy session in which emotions do not serve at least some role. A clinician who begins their session with a question of "How are you?" or "Are you tired?" allows emotional experiences to be explicitly stated in that session. Often, though, emotions play a more subtle, implicit role in the therapy session as therapists and clients respond to each other's affective overtures or actions. In each of these examples different interlocutors aim to come to a common understanding, but this understanding may be particularly challenging when the affective interlocutors are autistic and nonautistic.

Since autism was first described by Leo Kanner in the 1940s, difficulties with affective contact have been considered a core feature of autism. In an article aptly titled "Autistic Disturbances by Affective Contact," Kanner (1943) proposed that being on the autism spectrum is the inability to form the "usual affective content" (p. 217). Kanner failed to provide a clear definition of affective contact but, according to his close colleague Georg Frankl (Muratori & Bizzari, 2019), is the term refers to the connection between two people as they share an intercorporeal emotional experience. For Frankl, autistic people have disordered communication, whereby "communication" "does not merely involve language, but implies corporeal, affective and pre-verbal elements . . . [and consequently] autism can be defined as a lack of 'affective language' that leads to a disturbance in 'affective contact'" (quoted in Muratori & Bizzari, 2019, p. 160). Affective contact, much like social contact, thus includes a connection between two people when they share, either through verbal or nonverbal means, an intersubjective experience. Affective contact also includes coregulation, that is, the internal and external (e.g., environmental) processes of emotional regulation (Gulsrud et al., 2010).

Affective contact as interpersonal misalignment was recently underscored in double empathy theory. This theory, initially formulated by Milton in 2012, proposes that disparate ways of being in the world, such as the differences between autistic and nonautistic people (Milton et al., 2022, p. 1901), cause difficulties in communication between interlocutors and that people, regardless of neurotype, share the responsibility of empathizing and adapting their communication method to fit the emerging interaction. The problem is that the recurring injustices perpetuated by the medical model place the burden squarely on the shoulders of the autistic person, and this may be one reason for the decades of neurotype bias that ensued. For example, Alkhaldi and colleagues (2021) found that autistic people are viewed as less likable compared with their nonautistic counterparts. In one study, nonautistic participants viewing 60-s video clips of people mock interviewing for a reality/game show formed more negative initial impressions of autistic people and were less inclined to pursue further interactions with them (Sasson et al., 2017). Interestingly, though, these

negative perceptions disappeared when the transcripts of these videos were presented to these nonautistic participants, leading some researchers to hypothesize that it is style, not content, that drives these negative perceptions (Sasson et al., 2017). Eye contact, as an example of one stylistic communication tool, can be a sign of social interest among nonautistic people but is often experienced as unpleasant by autistic people (Andréen et al., 2021). Double empathy theory not only elucidates the social challenges between interlocutors but also highlights the dynamics of power imbalances and neurotype biases that can persist in therapy relationships. These implicit neurotype biases may result in the continuation of the hegemony, wherein the prevailing authority of nonautistic perspectives can lead some clinicians to pathologize autistic communication styles and solely target the autistic person's communication style and not the dynamic interaction between interlocutors.

Double empathy theory, which is rooted in the Social Model of Disability, shifts the focus of affective contact disruptions away from the individual and prompts clinicians to explore ways to enhance interpersonal connections. The Social Model of Disability suggests that disabilities arise from social conditions and social belief systems. In contrast to a medical model, which situates disabilities within the individual, this social model suggests that systems, and not people, cause disabilities (Oliver, 2013). Instead of urging modifications to how autistic people communicate (e.g., promoting eye contact), clinicians operating within this theory aim to identify strategies for improving mutual understanding and collaboration between people who have diverse modes of experiencing the world. Moreover, clinicians should aim to extend to mixed-neurotype interactions the feelings of belonging that autistic people report when interacting with others with their same neurotype (Crompton et al., 2020).

One possible reason for this rift in affective contact between autistic and nonautistic people may be that a person's experience and expression of emotion are situational to their contexts (Moskowitz & Young, 2006), bodies, and occupations (see Dallman & Triplett, 2020). Although each of these factors and their impacts on affective contact may be of interest to an occupational therapist, the focus of the present article is on the direct role of differing bodies (i.e., differing neurological systems) in affective contact. Because a person's experience of their emotions is situated within their bodies, it is likely that the preferred and more natural style of affective contact between people who have different styles of neurological processing (i.e., autistic/neurodivergent people and neurotypical people) will differ. Differences in autistic people's neurological processing may explain why they move (Trujillo et al., 2021), sense (Little et al., 2017), use language (Coburn & Williams, 2020), and perform on tests of social cognition (Morrison et al., 2020) differently from their neurotypical peers.

These differences in neurological processing may also change how people process and communicate about their emotions. For example, in a recent study an autistic adult shared how stimming, which encompasses a variety of repetitive behaviors, such as hand flapping, skin picking, or rocking (Charlton et al., 2021; Kapp et al., 2019), helped them release their internal emotional experiences: "I think [stimming behaviors] help me realign the energy in my body better so stuck energy can flow out of me instead of stay in me and cause me pain" (Charlton et al., 2021, p. 5). Some autistic people report that stimming helps them self-regulate when unpleasant emotions occur, whereas others might stim when they are feeling overwhelmed with work or by a present situation. Stimming may also aid in the emotion regulation and shifting of focus of autistic people who have intrusive thoughts that are preventing them from focusing on a task at hand (Kapp et al., 2019). This is one of many examples of how autistic people regulate their emotions differently from nonautistic people, and these differences in selfregulation style may influence the affective contact between autistic and nonautistic people.

The majority of emotion-based occupational therapy interventions for autistic people target either selfregulation or coregulation, and I am aware of no interventions that directly promote improving affective contact. The Alert Program has been found to be effective in improving self-regulation for both children (Mac Cobb et al., 2014) and adults with developmental disabilities (Allison et al., 2019), and The Interoception Curriculum: A Step-by-Step Guide to Developing Mindful Self-Regulation (Mahler, 2019) was shown to be effective in improving the parent-reported emotion regulation of their autistic children (Mahler et al., 2022). Although self-regulation is a key and important factor in affective contact, I propose that a key first step toward improving the affective contact between autistic and nonautistic people is an understanding of how autistic people prefer to express their emotions, which can provide the theoretical grounding necessary to further support development of the Interoception Curriculum and other similar programs. In gaining a better awareness of how autistic people express emotions, occupational therapists can ensure that the epistemic authority of autistic experiences-that is, the authority of who defines and describes autistic experiences (Hens et al., 2019)-is returned to the autism community.

My approach in this study was informed by a neurodiversity-affirming framework, which proposes that differences in neurologic processing (e.g., those observed among autistic people) are natural parts of human variation that should be celebrated, not stifled (Dawson et al., 2022). Within this framework the focus of occupational therapy interventions should be not to problematize autistic behaviors but instead to improve the contact between autistic and nonautistic people (Dallman et al., 2022). Accordingly, I took a step back to understand how autistic people prefer to communicate and express their emotions with the hope that occupational therapists can use this information to develop new and innovative interventions that improve affective contact between autistic and nonautistic people. In so doing, this study returned to the issue first presented by Frankl and, more recently, by Muratori and Bizzari (2019) by asking, what is the best way to improve the affective contact between autistic clients and their therapists? The two aims of this study were to (1) explore how autistic young adults describe their emotions and (2) suggest ways to improve the affective contact between autistic clients and their therapists.

Method

The overall objectives of this embodied hermeneutic phenomenological study were to understand how autistic young adults describe their emotions and to identify ways to improve affective contact between autistic clients and their therapists. The embodied hermeneutic phenomenological approach is well suited to uncovering complex facets of the human experience, such as emotions (Crowther & Thomson, 2020). In accordance with an embodied hermeneutic phenomenological approach (Harrison & Kinsella, 2022), my aim was not to generate a final set of meanings about emotional processing among autistic people but instead to embrace an emergent approach and allow for new interpretations and findings from the data. I acknowledge my own biases that were present in the research process. I became interested in this research topic while working as an occupational therapist with autistic high schoolers; I saw a chasm between the way educators and therapists communicated with autistic students. I am a strengths-based and neurodiversity-affirming practitioner who also has the lived experience of being neurodivergent and has multiple family members on the autism spectrum. In the context of this study, I approached the research questions and the data analysis believing that neurodivergent people see and process the world differently.

Participants

Participants in this project (N = 24; see Table 1) were recruited via convenience sampling from my ongoing research studies and from sites where, at the time of data collection, I was engaged in ongoing collaboration (i.e., Towson University). Inclusion criteria were as follows: residing in the United States, self-reported diagnosis of autism spectrum disorder or similar condition (e.g., Asperger syndrome), ages 18–35 yr, and able to participate in a virtual interview or focus group. Participants were excluded from the study if they had a cooccurring intellectual disability. To reduce the power dynamic between researcher and research participant, I allowed participants to communicate with the research team using a variety of methods. For example, during the focus groups, participants were encouraged to

Table 1.	Participant	Demographic	Characteristics
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Characteristic	n (%)
Sex	
Male	9 (37.50)
Female	9 (37.50)
Nonbinary	4 (16.67)
Other	1 (4.17)
Age, yr, <i>M</i> (<i>SD</i>)	28.25 (7.71)
Race	
White	16 (66.67)
Black	2 (8.33)
Asian	1 (4.17)
Biracial or multiracial	5 (20.83)
Hispanic	2 (8.33)
Education level	
Some high school	1 (4.17)
High school graduate or GED	7 (29.17)
Some college	5 (20.83)
College graduate	8 (33.33)
Graduate degree	3 (12.50)
Household income, \$	
<20,000	8 (33.33)
20,001–40,000	4 (16.67)
40,001–60,000	4 (16.67)
60,001–90,000	2 (8.33)
>90,000	5 (20.83)
No response	1 (4.17)
Married	2 (8.33)

communicate in a way that is comfortable to them (e.g., verbally, written, a combination). After focus groups, participants were encouraged to continue to provide their reflections about the research topics through email or text.

Procedure

The participants took part in one of six Zoom focus group interviews to discuss their emotional experiences. The focus groups were facilitated by me (the primary facilitator) and a trained graduate research assistant (secondary facilitator and note-taker). Topics for the interview, in line with the embodied phenomenological approach (see Harrison & Kinsella, 2022), included the embodied experiences of emotions, the experiences of emotions during occupational participation, and questions about how participants communicate about their emotions with others. Before each interview, I sent participants a brief email that included information about how to join the virtual focus group and how to submit responses to interview questions and a brief description of my professional background as an occupational therapist. I believed it was important to communicate this information to participants ahead of time to reduce anxiety or stress that may come with a novel experience such as taking part in a research focus group. Zoom software used artificial intelligence to generate an initial transcript, which was corrected and anonymized by a graduate research assistant. The Zoom video was used as a backup for correction of the transcription. Data were coded and subsequently analyzed using an interpretative phenomenological analysis (IPA) framework (Smith et al., 2009). In line with the principles of IPA, the focus of the interview questions was on how participants describe and make sense of their emotions and emotional experiences. All research procedures were approved by the Towson University institutional review board for data collection. After I transferred to another institution, the institutional review board of Rutgers, the State University of New Jersey, approved the analysis methods reported in this article.

Data Analysis

I reviewed audio recordings throughout the data collection process and ended data collection when new recordings yielded no new information from previous recordings and thus data saturation was achieved (Braun & Clarke, 2021). In the initial round of open coding, four team members analyzed two of the same transcripts; met to discuss, compare, and contrast codes; and developed the initial code book. The initial code book consisted of a total of 122 codes. Because coding was done iteratively, the initial code book was a living document and was updated as each coder analyzed subsequent individual transcripts. Each transcript was analyzed using NVivo (Version 12) by a minimum of two of the four coding team members. When coding, the coders reviewed each manuscript multiple times, identified units of meaningful text, and evaluated these segments against previous text segments for their originality and significance in describing the phenomenon of interest. Once agreement was reached, I merged the overlapping codes, resulting in a total of 99 codes. Using the data analysis strategies discussed by Krueger and Casey (2015), I organized these 99 codes into five themes. For brevity, only the two themes most relevant to this study's aims are discussed in this article (see Table 2). Last, I continued the iterative analysis by rereading each transcript to verify that all themes were applicable to the data. Throughout the data analysis, the research team met to discuss the research findings, codes, thoughts, and reactions, following guidance on achieving rigor in qualitative research (Morse, 2015). The team members consciously reflected on and suspended their preconceptions and bracketed their personal biases during data collection and analysis. In addition, each research team member kept a reflective journal to act as a stimulus for reflexivity throughout the analysis process.

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Table 2. Coding Scheme

Initial Code	Merged Thematic Framework	Sample Quote
 Emotions as intense Extremely sensitive Escaping reality I identify as very emotional 	Authentic expression of emotions	"In these spaces, I feel free to be myself and to not have to worry about being judged, ridiculed, or rejected by others. It feels safe to let my guard down, to be vulnerable and get to know someone on a deeper level."
 Dislike of scales Metaphors to describe emotions Preferred way to be asked about emotions 	Autistic people's emotions are often (mis)measured	"Yeah, I've had a lot of surgeries and all, and it's 'Rate your pain from one to 10.' How about saying, like, 'Can you tell me what you're feeling like,' like how, you know, 'cause, like, I used to have to ask, like, 'What do you mean by one to 10?' "
 Empathy Other interpretations of my emotions Socially unacceptable expressions of emotions 	Autistic people's emotions are often (mis)understood	"I kinda go against [Simon] Baron Cohen's idea that autistic people don't have empathy. Where I definitely do care a lot about what people think of me because, like most autistic people, I've been bullied before, I've had people misperceive me before. I want to have effective communication; I just can't always figure out the right way to do it."

Results

Two themes emerged from the data: (1) autistic people experience complex emotions and (2) autistic people's emotions are often (mis)measured and (mis)understood.

Theme 1: Autistic People Experience Complex Emotions

Autistic participants' descriptions of their emotions included rich, dynamic, and embodied language. Oftentimes, this language used a combination of traditional emotional words, such as "happy," paired with grounded and embodied language such as references to sensations in the stomach. These expansive descriptions of emotions extended into the positive, negative, and neutral domains of emotional experiences:

I actually feel like sometimes I can feel emotion more intensely than people without autism, because you know, usually we're depicted as emotionless beings, but I feel like sometimes I'm more emotional than other people, if that makes sense, like, not that I'm more emotional, but I experienced it more intensely.

This participant noted that they often feel emotions more intensely than their neurotypical peers and that these intense emotions run contradictory to neurotypical descriptions of emotions.

Positive Affect Emotions

Participants described a range of positive affect emotions, which included feelings such as calmness, enjoyment, and euphoria. For example, one participant was describing the positive experience of connecting with a pleasant colleague: "When I get really happy, I feel calm, and I feel almost like, you know, like, it's kind of like the butterflies in your stomach but not really like lovestruck, more just like 'happy-struck."" Similarly, another participant shared, "I actually feel what I consider the emotion happy very rarely. . . . I think my main positive emotion is like, content, kind of, it's just a scaled-down, calmer version." Participants' descriptions of these positive emotions often emerged when they discussed their activities. One participant discussed building with LEGOs: "When I build [with] LEGOs, for example, it's just it's [an] activity where I feel very relaxed and sort of like very focused whenever I [build] the project and then, when I'm done I just feel this sense of elation." For this participant, one occupation, assembling LEGOs, was impregnated with emotions the participant described positively: feeling relaxed shifted to focused, focused shifted to elation, and elation shifted to a sense of purpose.

Negative Affect Emotions

Participants also described a range of negative affect emotions, which included feelings such as anger, depression, and frustration. For example, one participant described anger feeling "like a whole-body tensing; it's everywhere. It often causes a headache. [Other people know that I am angry because] . . . there's a lot of swearing." Similar to the ways that participants described positive emotions, these descriptions of negative emotions also included embodied language. One participant's descriptions of their sadness read as follows:

Usually I get I get very, very, like, I feel kind of a weight on my shoulders [and] on my chest and like, like, heavier than normal, um, and then my brain will get kind of foggy, and I'll just keep like thinking over and over again about the thing that's making me upset.... From the outside, it just looks like I'm very calm or very focused on something or perhaps just like not focused on anything at all, just like kind of sitting there. Another participant described feelings of frustration when engaged in a social occupation: "When I have a misunderstanding with someone . . . that just, it makes me very frustrated and that emerges as the bees." The participant was saying that this feeling of frustration felt like an internal buzzing of bees, a sensation they later described as "uncomfortable." For others, frustration during occupational participation included externalized experiences:

The frustration is me generally every once awhile, OK, I will slam a pencil down, . . . or I'll, you know, if [I'm working] on Photoshop [I'll] flip the lid [of the laptop] down and walk out of the room . . . swearing.

For this participant, it was their actions, or externalized behaviors, while engaged in occupation that provided them insight into their current frustration levels. When they slammed down their pencil or quickly closed their computer, they became aware that they were feeling frustrated.

Like the LEGO example presented earlier, participants described how one occupation (e.g., reflection) can be filled with a variety of negative emotions and that these emotions can move fluidly together. One participant provided the following description:

I think the most damaging anger is when you feel indignant from an injustice that has been inflicted on someone else who is marginalized and vulnerable. . . . This usually leads to a feeling of helplessness, of being inept and unable to make a meaningful difference, which can in turn lead to self-pity and wallowing in misery for the abject state of the world. And all of this began with anger!

For this participant, "damaging anger," which they described as being a debilitating anger, shifted to a feeling of helplessness, to self-pity, wallowing, and, last, to misery. This is one of several examples wherein participants described how emotions shifted while they engaged in an occupation.

In addition to describing a combination of both positive and negative emotional experiences, participants also described emotional states that reflected "a reasonably stable state—perhaps not exactly happy, but not in the midst of experiencing a painful emotion, either. I think of it as being in a more neutral state, kind of in a state of homeostatic balance." These homeostatic emotions were often described in connection to their co-occurring activities or occupations. As one participant shared, "By doing something that I enjoy doing it helps me kind of, like, feel relaxed and content and. . . . it's something that sort of, like, helps me kind of get a sense of purpose." Similarly, another participant shared the following:

Like, I feel like there are moments that sort of make me happy, in which I feel like you know, like, if I have a nice coffee in the morning, or anything like that it sort of gives me this sense of just happiness. Just a sense of elevation, a sense of just, you know, my spirits rising. But I just feel like at the default it's just a sense of just . . . being in the present, I guess. It's hard to really say, like, whether or not I'm happy about it; it's just a state of being, I guess, so it's hard to even really say, like, if there is really a positive or negative emotional thing to say about it; it's just a very neutral kind of sense of emotion.

Other participants described these neutral feelings as a "sense of purpose" when immersed in an occupation.

Theme 2: Autistic People's Emotions Are Often (Mis)Measured and (Mis)Understood

Autistic People's Emotional Experiences Are Often (Mis)Measured

Participants overwhelmingly reported that traditional measures of emotion do not adequately capture their emotional experiences and that typical quantitative scales of pain or other subjective experiences fail to adequately characterize their experiences. For example, one participant noted, "I understand the necessity for applying categorical labels for emotions such as 'happy' and 'sad,' but I also know that the experience is much more complex than just the feelings associated with these words." This participant went on: "I'd say that there are different shades of happiness, as well as different shades of sadness." Participants felt that these shades (or types and intensities) of happiness, sadness, and other emotions were lost when researchers and clinicians asked about their emotions using traditional quantitative scales.

Participants reported several challenges with quantitative scales. First, when these scales use words like "happy" or "sad," they felt the measures failed to adequately capture the depth of their emotional experiences. As one participant noted, "For me, I think kind of, like, almost like a caricature or like a cartoon kind of happy, like the smiley face emoji, and, like, someone who is very talkative and very extroverted and very smiley." Participants overwhelmingly reported that these typical emotion words, such as "happy" or "sadness," did not adequately characterize their emotional experiences, and thus they were less likely to endorse them when completing clinical measures. One participant shared, "I much prefer when people say, 'Oh, I'm feeling excited,' or 'I'm feeling proud,' or 'I'm feeling anxious' or 'frustrated' over just saying 'I'm mad,' 'I'm sad,' 'I'm happy.' It doesn't convey a lot of information." In lieu of verbal answers, most participants reported a preference for discussing their emotions in written form. As one participant noted,

My positive emotions are not obvious, though. . . . Usually it's easier for me to make a connection with a person where I'm able to tell them how I feel and how interacting with them makes me feel by writing them, as it is much easier for me to communicate through writing than it is for me to do this in person, in real time, because most often (unless I'm in a particularly euphoric and expansive state of mind), the words just don't come to me in the moment.

Writing provided this participant an outlet through which to organize their thoughts and to refine their language about their emotional states.

Autistic People's Emotional Experiences Are Often (Mis)Understood

All of the participants reported that affective contact can be difficult between autistic and nonautistic people and is particularly challenging when nonautistic people misinterpret the emotional expressions of an autistic person. As noted by one participant,

I've had people say like "Wow, you look really happy right now" when I'm just kind of chilling out. I'm not sure what about me looks extremely happy, and then I've had people think I was much [more] angry at them than I actually am.

Similarly, another participant shared how nonautistic friends would misinterpret their emotional expressions: "I guess the thing about me is that I usually have moments when people would actually, like, would, like, say, like 'Darius [pseudonym], why do you look so sad?' . . . when, in that particular instance, I'm not feeling negative." For these participants, social occupations were experienced negatively when a nonautistic person misinterpreted their emotions. One participant shared that stimming around nonautistic people would elicit negative reactions from them, whereby the nonautistic person got upset if they saw the autistic adult stimming. This participant further clarified, "But, like, when it's my loved ones, they actually get really excited because they know that I'm so happy whenever I'm stimming." For this participant, when someone knew them well enough to accurately interpret their emotions, it was reassuring. When people misinterpreted this autistic participant's emotions, they felt uneasy. In general, most participants reported that nonautistic people fail to read and understand the emotions of autistic people and that "Usually [autistic people are] depicted as emotionless beings," when in reality they described rich emotional experiences, often misunderstood by nonautistic people.

Because participants often felt an ardent desire for others to understand their emotions, they described spending a considerable amount of effort to ensure that neurotypical people understood their experiences. As one participant shared, "Because I know for neurotypical [people], that this is a pretty natural thing they understand that they're supposed to smile when they're happy. But that's something that took me quite a few years of therapy and training to understand." In these cases, participants reported adapting their preferred style of interaction to accommodate the preferences of the neurotypical interlocutor during social exchanges. However, participants reported that adapting their communication preferences to fit the needs of the nonautistic person was tiring:

Yeah, [it] is very, very draining because, so, someone told me very bad news, and they expected me to be

like "Oh, wow," or [they expected me to] feel for them, and [I am] just like sorry, "sorry," like, they are expecting that you know big emotion for me to like—I don't [know how to] . . . act like, you know, give them those emotional [words they are expecting]. I don't know. I just feel I feel guilty sometimes about [not expressing emotions in this way], I feel guilty, like, not being able to give them an expression they want to see. I feel guilty.

This participant experienced a sense of guilt when they did not communicate their emotions in a manner that aligned with the nonautistic person's preferred style.

Discussion

The overall objective of this study was to explore how autistic young adults describe their emotions and suggest ways to improve the affective contact between autistic clients and their therapists. The participants in this study described a range of positive, negative, and neutral emotions that were directly tied to their participation in occupation; unfortunately, many participants described cases of problematic affective contact wherein nonautistic people misunderstood the emotions or the emotional intent of the autistic person. In these cases of bidirectional communication breakdown, autistic participants described a range of negative feelings, such as guilt. Participants' descriptions of feeling guilt implies a sense of social responsibility on the part of the autistic person to make nonautistic people understand their emotions during social interactions. This may explain the alarming rates of autistic masking, or the conscious or unconscious process of suppressing one's "natural responses and adoption of alternatives across a range of domains[,] including social interaction, sensory experience, cognition, movement, and behavior" (Pearson & Rose, 2021, p. 52). This suppression of one's natural modes of being can function as impression management, but because it is rooted in social stigma it can be problematic given that it reproduces hegemonic beliefs about optimal social functioning (see Pearson & Rose, 2021, for a further discussion of masking). Masking has been linked to mental health comorbidities, including depression (Evans et al., 2023).

Although these social breakdowns are problematic, the fact that they may cause an autistic person to mask, and consequentially decrease their well-being, is even more problematic. Occupational therapists have an important role in helping improve the quality of social interactions between autistic and nonautistic people (Sterman et al., 2023). These communication interventions should focus on improving bidirectional communication for both autistic and nonautistic people and must not focus solely on teaching an autistic person about neurotypical communication needs. Certainly, a necessary and important component of these interventions will include fostering self-advocacy among autistic people, which should equip them with the skills to advocate for their communication preferences. These approaches are in line with those based on double empathy theory (see Milton et al., 2022, for a review).

In this study, participants used nontraditional words to describe these emotional experiences; for example, one participant described the feeling of frustration as like "bees" inside them. Clinicians who aim to help autistic clients regulate and process their emotions must recognize that some autistic people may prefer to communicate about their emotional experiences using a style different from the clinician's own style. This may mean that there is a need for new interventions, although I believe programs such as the Interoception Curriculum (Mahler, 2019; Mahler et al., 2022) may serve as a starting point to create individualized interventions that are specific and appropriate for the autistic population. To that end, occupational scientists have introduced the term affectus to describe the embodied emotional experiences that arise through occupational participation (Dallman & Triplett, 2020); however, the term has yet to be integrated into the occupational therapy literature. I believe occupational therapy interventions that aim to improve emotional processing among autistic people could benefit from conceptualizing emotions in this way. "Affectus" suggests that emotions are not static and instead shift throughout occupational participation and that emotions are embodied, and as a consequence these shifting emotional experiences will be expressed and felt differently by people of different neurotypes. Indeed, the participants described emotions in this way; several of them highlighted how the emotional experience of one occupation (e.g., drawing) can change throughout the occupation, shifting from frustration to pride. Occupational therapists should consider how occupations may serve to shift emotions, both positively and negatively, during occupational participation and how to leverage the unique emotional experiences of autistic people to design appropriate interventions. In addition, because emotions are embodied and individual, the term "affectus" suggests that occupational therapists must place the epistemic authority of a person's emotional experience with members of the autism community.

The present findings also indicate that the participants experienced diverse, complex, and intense emotions and that typical forms of measurement (e.g., asking "How happy are you?") may fail to capture this complexity. Participants, when asked to describe their emotions, preferred nontraditional emotional language and narratives. This finding may explain why researchers and clinicians often report that autistic people are unable to describe their emotions or that autistic adults have muted emotional responses (Trimmer et al., 2017). If autistic people describe their emotions using language that differs from the nonautistic language that clinicians prefer to use, then the issue may be one of bidirectional communication, or double empathy (see Milton et al., 2022, for a review), and not on the part of the autistic person. This, in turn, suggests that occupational therapists should be cautious when using measures and interventions that rely solely on neurotypical expressions of emotions (e.g., treatments that rely on self-report of emotional terms, such as "happy"). In classrooms and therapy sessions, it is common for teachers and clinicians to begin with a morning check-in, asking questions like "How are you?" to autistic children. Oftentimes, clinicians offer several options, like "happy" or "sad," but the present findings suggest that most autistic people may not identify with these traditional emotional words. A more diverse array of options is necessary to capture their unique emotional experiences. Moreover, because participants described their emotions differently, and often used embodied language, it may be useful for occupational therapists to consider how bodily experiences capture emotion regulation for autistic clients. For example, occupational therapists could include pictures of hands flapping (to represent varying feelings associated with flapping hands) or pictures that reference the stomach (to represent varying feelings associated with butterflies or other stomach-focused sensations) in emotion-regulation interventions. In so doing, they may better capture the embodied emotional diversity of emotions autistic people report.

The participants also shared many cases in which nonautistic people misinterpreted autistic emotions on the basis of their facial expressions or words. This finding should serve to caution occupational therapists in making decisions about a client's emotional state solely on the basis of neurotypical assumptions about how emotions should be, or are typically, expressed. It suggests that occupational therapists should adopt an empathic, self-reflective stance to understand how each autistic client might express their emotions.

Limitations

This study was limited in several important ways. First, the participants included only autistic young adults who had access to enough communication such that they could respond to questions using at least three- to fiveword sentences. Although the research team attempted to improve the external validity of the study by allowing participants to respond to the questions in ways that are comfortable to them (e.g., verbally, text-based chat), the study methods inherently limited who could participate and as a result may have inadvertently excluded some autistic voices. More research is needed to better understand how to better include autistic people who lack formal communication strategies in emotion-based research. I believe that ethnography with autistic collaborators who play a key role in the analysis of the data may be particularly important for this kind of research.

This study also included only autistic adults, whereas most autistic clients receiving occupational therapy services are children. I believe that autistic adults can provide valuable insights into the emotional experiences of autistic people in general and that these insights will apply to the emotional experiences of autistic children. However, future research should verify these findings with autistic children.

In addition, this study is limited in that participants included only people with a self-reported diagnosis of autism. Although self-reported diagnoses are considered valid and are commonly used in research, future studies would benefit from inclusion of standardized measures of autism symptoms (e.g., the Autism Diagnostic Observation Schedule) to examine whether the findings differ across people with different autism symptoms.

Implications for Occupational Therapy Practice

The aim of this study was to understand the emotional experiences of autistic adults. The findings can guide occupational therapists who work with this population. Occupational therapists should consider the following in their work:

- Take a person-centered approach to understanding emotional experiences in the autism community, which should include a discussion of an individual's bodily sensations that happen during occupational participation as opposed to traditional emotional words.
- Avoid making assumptions about emotions felt by autistic people on the basis of facial expressions alone; instead, seek to understand the autistic client's emotional experiences from their perspective.
- Recognize that a useful target of occupational therapy interventions may be self-advocacy, wherein autistic clients learn how to help others understand their emotional experiences. This self-advocacy work can bridge the gap between nonautistic and autistic communication styles when discussing emotions.
- Remember that autistic people regulate their emotions differently than nonautistic people, and although their regulation style differs from nonautistic people's emotion regulation, they offer great benefit to the autistic person. Occupational therapists should foster the continued development of neurodivergent-inclusive emotional regulation strategies during therapy sessions.

Conclusion

This study aimed to understand how autistic people experience and communicate about their emotions and to explore potential directions for future occupational therapy interventions. Participants vividly described a spectrum of positive, negative, and neutral emotions that were intricately linked to their engagement in occupation. They reported instances of disrupted affective contact that led to bidirectional communication breakdowns. Occupational therapists are urged to embrace their role in improving the quality of social interactions between autistic and nonautistic people, emphasizing bidirectional communication improvements rather than focusing solely on conforming to neurotypical communication styles.

This study also revealed the diverse and intense emotional experiences of autistic people, challenging traditional measurement methods. The use of nontraditional language underscores the importance of recognizing varied communication styles in therapy. I advocate a more nuanced understanding of autistic people's emotions, cautioning against the sole reliance on neurotypical expressions in assessments and interventions. By emphasizing the importance of self-advocacy and neurodivergent-inclusive emotion regulation strategies, this study provides practical implications for occupational therapy practice, urging a person-centered approach and a more empathic understanding of autistic people's emotional experiences.

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References

- Alkhaldi, R. S., Sheppard, E., Burdett, E., & Mitchell, P. (2021). Do neurotypical people like or dislike autistic people? *Autism in Adulthood: Challenges and Management*, *3*, 275–279. https://doi.org/ 10.1089/aut.2020.0059
- Allison, J., Shotwell, M., Keeling, B., & Simon, R. (2019). Effects of the Alert Program[®] on communication, social interaction, and occupational performance in adults with developmental disabilities. *American Journal of Occupational Therapy*, *73*(4, Suppl. 1), 7311520410. https://doi.org/10.5014/ajot.2019.73S1-PO3027
- Andréen, L., Galazka, M., Hadjikhani, N., Jeuris, S., Masulli, P., & Johnels, J. Å. (2021). Developing tolerance to eye contact in autism: A feasibility study with adults using behavioral, interview, and psychophysiological data. *Psychology of Language and Communication, 25,* 240–263. https://doi.org/10.2478/plc-2021-0011
- Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13, 201–216. https://doi.org/10.1080/2159676X.2019.1704846
- Charlton, R. A., Entecott, T., Belova, E., & Nwaordu, G. (2021). "It feels like holding back something you need to say": Autistic and nonautistic adults' accounts of sensory experiences and stimming. *Research in Autism Spectrum Disorders*, 89, 101864. https://doi.org/ 10.1016/j.rasd.2021.101864
- Coburn, K. L., & Williams, D. L. (2020). Development of neural structure and function in autism spectrum disorder: Potential implications for learning language. *American Journal of Speech-Language Pathology*, 29, 1783–1797. https://doi.org/10.1044/2020_AJSLP-19-00209
- Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). "I never realised everybody felt as happy as I do when I am around autistic people": A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24, 1438–1448. https://doi.org/10.1177/1362361320908976
- Crowther, S., & Thomson, G. (2020). From description to interpretive leap: Using philosophical notions to unpack and surface meaning in

hermeneutic phenomenology research. International Journal of Qualitative Methods, 19. https://doi.org/10.1177/1609406920969264

Dallman, A. R., & Triplett, B. (2020). Emotion, affectus, and occupation: A scoping review. *Journal of Occupational Science*, 27, 251–263. https://doi.org/10.1080/14427591.2019.1668831

Dallman, A. R., Williams, K. L., & Villa, L. (2022). Neurodiversityaffirming practices are a moral imperative for occupational therapy. *Open Journal of Occupational Therapy*, 10, 1–9. https://doi.org/ 10.15453/2168-6408.1937

Dawson, G., Franz, L., & Brandsen, S. (2022). At a crossroads— Reconsidering the goals of autism early behavioral intervention from a neurodiversity perspective. *JAMA Pediatrics*, 176, 839–840. https:// doi.org/10.1001/jamapediatrics.2022.2299

Evans, J. A., Krumrei-Mancuso, E. J., & Rouse, S. V. (2023). What you are hiding could be hurting you: Autistic masking in relation to mental health, interpersonal trauma, authenticity, and self-esteem. *Autism in Adulthood: Challenges and Management*. Advance online publication. https://doi.org/10.1089/aut.2022.0115

Gulsrud, A. C., Jahromi, L. B., & Kasari, C. (2010). The co-regulation of emotions between mothers and their children with autism. *Journal of Autism and Developmental Disorders*, 40, 227–237. https://doi.org/ 10.1007/s10803-009-0861-x

Harrison, H. F., & Kinsella, E. A. (2022). Embodied hermeneutic phenomenology: Bringing the lived body into health professions education research. In S. Crowther & G. Thomson (Eds.), *Hermeneutic phenomenology in health and social care research* (pp. 110–131). Routledge. https://doi.org/10.4324/9781003081661-7

Hens, K., Robeyns, I., & Schaubroeck, K. (2019). The ethics of autism. *Philosophy Compass*, 14, e12559. https://doi.org/10.1111/phc3.12559

Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217–250.

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). "People should be allowed to do what they like": Autistic adults' views and experiences of stimming. *Autism, 23*, 1782–1792. https://doi.org/10.1177/1362361319829628

Krueger, R. A., & Casey, M. A. (2015). Focus groups: A practical guide for appleid research (5th ed.). SAGE.

Little, L. M., Dean, E., Tomchek, S. D., & Dunn, W. (2017). Classifying sensory profiles of children in the general population. *Child: Care, Health and Development, 43*, 81–88. https://doi.org/10.1111/ cch.12391

Mac Cobb, S., Fitzgerald, B., Lanigan-O'Keeffe, C., Irwin, N., & Mellerick, N. (2014). Students with social, emotional, and behavioral difficulties: The Alert Program trial in post-primary schools. *Journal* of Occupational Therapy, Schools, and Early Intervention, 7, 106–119. https://doi.org/10.1080/19411243.2014.930606

Mahler, K. (2019). The interoception curriculum: A step-by-step guide to developing mindful self-regulation. Kelly Mahler.

Mahler, K., Hample, K., Jones, C., Sensenig, J., Thomasco, P., & Hilton, C. (2022). Impact of an interoception-based program on emotion regulation in autistic children. *Occupational Therapy International*, 2022, 9328967. https://doi.org/10.1155/2022/9328967 Milton, D. E. M. (2012). On the ontological status of autism: The "double empathy problem." *Disability and Society*, 27, 883–887. https://doi. org/10.1080/09687599.2012.710008

Milton, D., Gurbuz, E., & López, B. (2022). The "double empathy problem": Ten years on. Autism, 26, 1901–1903. https://doi.org/ 10.1177/13623613221129123

Morrison, K. E., DeBrabander, K. M., Jones, D. R., Ackerman, R. A., & Sasson, N. J. (2020). Social cognition, social skill, and social motivation minimally predict social interaction outcomes for autistic and non-autistic adults. *Frontiers in Psychology*, 11, 591100. https:// doi.org/10.3389/fpsyg.2020.591100

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25, 1212–1222. https://doi.org/10.1177/1049732315588501

- Moskowitz, D. S., & Young, S. N. (2006). Ecological momentary assessment: What it is and why it is a method of the future in clinical psychopharmacology. *Journal of Psychiatry and Neuroscience*, 31, 13–20.
- Muratori, F., & Bizzari, V. (2019). Autism as a disruption of affective contact: The forgotten role of George Frankl. *Clinical Neuropsychiatry*, 16, 159–164.

Oliver, M. (2013). The social model of disability: Thirty years on. Disability and Society, 28, 1024–1026. https://doi.org/10.1080/ 09687599.2013.818773

Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood: Challenges and Management*, 3, 52–60. https:// doi.org/10.1089/aut.2020.0043

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*, 7, 40700. https://doi.org/10.1038/srep40700

Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis. Sage.

Sterman, J., Gustafson, E., Eisenmenger, L., Hamm, L., & Edwards, J. (2023). Autistic adult perspectives on occupational therapy for autistic children and youth. OTJR: Occupational Therapy Journal of Research, 43, 237–244. https://doi.org/10.1177/15394492221103850

Trimmer, E., McDonald, S., & Rushby, J. A. (2017). Not knowing what I feel: Emotional empathy in autism spectrum disorders. *Autism*, 21, 450–457. https://doi.org/10.1177/1362361316648520

Trujillo, J. P., Özyürek, A., Kan, C. C., Sheftel-Simanova, I., & Bekkering, H. (2021). Differences in the production and perception of communicative kinematics in autism. *Autism Research*, 14, 2640–2653. https://doi.org/10.1002/aur.2611

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