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"My Brain Doesn't Speak That Language:" An Interpretative Phenomenological Analysis of Alexithymia in Autistic Women

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Abstract

Alexithymia is a trait characterized by difficulty identifying and describing one's emotions, as well as reduced attention to one's emotional state. Alexithymia is widely viewed as a transdiagnostic risk factor and an important target for treatment. This has led to a robust quantitative research literature. However, missing from contemporary research are first-person accounts of alexithymia. In the present study, we interviewed six high-alexithymia autistic women, seeking to illuminate unexplored aspects of the trait. Our results illustrate a diverse spectrum of alexithymic experiences beyond those captured in closed-ended questionnaires. Participants struggled to name their emotions, distinguish emotions from physiological sensations, and determine whether they experienced emotion at all. Often, participants only understood their feelings in retrospect. Finally, social judgment exacerbated the challenges of living with alexithymia. This study highlights the diversity of alexithymia and thereby helps lay the foundation for understanding how alexithymia relates to other affective processes.

Keywords: alexithymia, autism, qualitative, lived experience, emotional experience

Introduction

Camille is perplexed by emotion. She struggles to name and describe her feelings: sadness, frustration, guilt, anger, and happiness are familiar, but the rest seem a mystery. Most of the time, she keeps herself busy and distracted to avoid dealing with her emotions.

Camille is also autistic, which, in her words, "makes it harder for me to process emotions." She has trouble deciphering other people's emotions, too, and navigating relationships is difficult as a result. In social settings, she smiles and feigns interest in conversations. This, she says, makes other people happy, but it exhausts her and seems to distance her from her feelings. Still, even when an emotion slips from conscious awareness, she explains, it affects how she feels and acts "because it's there and I haven't dealt with it."

Camille–a participant in the present study–exhibits high levels of alexithymia, a trait characterized by difficulty identifying feelings, difficulty describing feelings, and a tendency not to focus on one's emotions (Preece et al., 2017). Alexithymia has been studied extensively, yet there is a dearth of research exploring the trait from the perspective of those who live with it. The present study, a qualitative exploration of alexithymia in autistic women, aims to fill this lacuna. In this introduction, we discuss the history of the alexithymia construct and its association with autism. We then delineate the limitations of current alexithymia measures and discuss lived experience research.

Alexithymia Research

The term "alexithymia" was first coined in the 1970s to describe patients who presented with a litany of physical complaints but struggled to articulate their emotions (Nemiah & Sifneos, 1970). As well as

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struggling to describe their feelings, these patients exhibited interpersonal difficulties and had trouble communicating (Apfel & Sifneos, 1979). They suffered from psychosomatic illness at higher rates than controls, and they were less likely to benefit from psychotherapy (Nemiah & Sifneos, 1970; Sifneos et al., 1977).

Over the following decades, researchers developed reliable, validated self-report questionnaires to standardize alexithymia measurement (Bagby et al., 1994; Gaggero et al., 2020; Preece et al., 2017). This study conceptualizes alexithymia using the attention-appraisal model (Preece et al., 2017). Within this framework, alexithymia is understood as a dimensional personal trait characterized by three components (Preece et al., 2017). Difficulty identifying feelings (DIF) is typified by statements such as, "When I'm feeling bad, I can't tell whether I'm sad, angry, or scared." Difficulty describing feelings (DDF) refers to struggles with putting emotion into words ("When I'm feeling bad, I can't talk about those feelings in much depth or detail"). Finally, externally oriented thinking (EOT) describes a tendency not to focus on one's own emotions ("I tend to ignore how I feel") (Preece et al., 2017).

The attention-appraisal model also proposes that alexithymia can come in two forms. In the first form, ability-deficit alexithymia, an underdeveloped emotion schema prevents a person from fully understanding their emotions. Camille exhibits ability-deficit alexithymia when her general confusion about emotions stops her from naming and describing her feelings. In the second form, avoidance alexithymia, avoidance becomes an emotion regulation strategy, shielding a person from intense or unpleasant emotions (Preece et al., 2017). Camille exhibits avoidance alexithymia when she deliberately distracts herself from her feelings.

Even as conceptualizations of alexithymia have evolved, many observations from the early literature have been borne out by subsequent research. Those with high alexithymia experience social-communication difficulties and lower self-reported relationship quality (Grynberg et al., 2018). High alexithymia is associated with emotion dysregulation and less frequent use of adaptive emotion regulation strategies (Preece et al., 2022). High-alexithymic individuals derive less benefit from psychotherapy (Grabe et al., 2008). Moreover, alexithymia is elevated in numerous physical and psychological conditions, including autism spectrum disorder (Hogeveen & Grafman, 2021; Kinnaird et al., 2019).

Autism and Alexithymia

An estimated 30-60% of the autistic population has clinically elevated alexithymia (Kinnaird et al., 2019). This subgroup includes Camille, the study participant introduced in the opening vignette. Camille has trouble describing emotions and distinguishing them from physical sensations. She expresses emotion differently and has been told that her voice is too blunt or intense. Other people's emotions also confuse her. She struggles to integrate body language, vocal inflection, facial expressions, and speech. Consequently, she feels that she "never really get[s] a good read on people."

Do Camille's difficulties with emotion stem from autism, alexithymia, or both? This question has been the subject of increasing research over the past few decades. There is substantial trait overlap between autism and alexithymia: both are associated with impairments in emotion recognition, reduced empathy, trouble disentangling emotional and non-emotional internal sensations, and an apparent decoupling between physiological responses to emotion and subjective experience (Bird & Cook, 2013; Kinnaird et al., 2019). Nonetheless, some autistic people do *not* exhibit high alexithymia. These observations have prompted the alexithymia hypothesis of autism (Bird & Cook, 2013). According to the alexithymia hypothesis, it is co-occurring alexithymia, not autism itself, that accounts for the emotion processing atypicalities frequently seen in autism. In other words, alexithymia is highly comorbid with autism, rather than an inherent feature of autism.

The alexithymia hypothesis has received mixed support in the research literature. Some work, including literature reviews by Poquérusse et al. (2018) and Kinnaird et al. (2019), offers support for the alexithymia hypothesis. To name a few more specific examples, Gerber et al. (2019) found that alexithymia, rather than autism, predicts fewer social interactions in an ecological momentary

assessment of autistic adults. Trevisan et al. (2016) found that alexithymia, rather than autism, is associated with the production of emotional facial expressions.

Other findings, however, contradict the alexithymia hypothesis. For instance, Shah et al. (2019) found that trait autism was a better predictor of atypical empathy than alexithymia. In a study of facial emotion recognition, Keating et al. (2021) reported that autistic and alexithymic traits differentially correlated with performance on a facial emotion recognition task.

Gender further complicates this picture. There is mounting evidence that autism presents differently in women. Autistic females tend to demonstrate better social interaction and communication skills than their male counterparts (Wood-Downie et al., 2021). They frequently conceal and camouflage their social struggles, which may in part account for the finding that autistic women are diagnosed later. They also face higher rates of internalizing disorders such as depression, anxiety, and eating disorders (Hull et al., 2020).

Given the gender-specific nature of autism symptoms, conclusions drawn from male-dominated studies may not apply to autistic women. Of the 15 studies analyzed by Kinnaird (2019), 14 had predominantly male samples, and four were entirely male. To our knowledge, only one study has examined the overlap between autism and alexithymia in an all-female sample. Ketelaars et al. (2016) examined visual and vocal emotion recognition among autistic women and nonautistic controls. Compared to typically developing controls, autistic women were equally accurate in recognizing visual emotions but took longer to do so. Within the autistic group, alexithymia was linked to less accurate emotion recognition only for low-intensity visual emotions (Ketelaars et al., 2016). The strong version of the alexithymia hypothesis would predict that alexithymia should account for all emotion-processing impairments. These findings point to a subtle relationship that has yet to be fully explored.

To summarize, many autistic people have clinically elevated levels of alexithymia. However, the precise nature of this relationship remains unclear, as does the role of gender. It *is* clear, however, that autistic individuals with high alexithymia face significant challenges, including elevated anxiety and depression, greater social-communication difficulties, and heightened suicidality (Costa et al., 2020; Milosavljevic et al., 2016; Morie et al., 2019). There is thus an urgent need to understand and serve this population. To do so, we must first fill crucial gaps in the alexithymia literature.

Limitations of Alexithymia Measurement

As established in the previous section, there is a growing body of literature exploring the relationship between autism and alexithymia. This literature relies almost exclusively on self-report questionnaires that, like all measurement tools, have limitations. Thus supplementing quantitative self-report methods with qualitative one will allow for a fuller understanding of alexithymia.

One limitation of self-report questionnaires is that they are closed-ended. Respondents are limited to a predetermined set of statements, with no opportunity to express their experiences in their own words. The closed-endedness is even more problematic given that self-report questionnaires emerged from a body of research that reflects a particular perspective on alexithymia.

Early researchers made no secret of their frustration with alexithymic patients. Nemiah & Sifneos (1970) describe relationships with these patients as “pale, colorless, lifeless, dull and without any of the human warmth and resonance that usually develop between two people over a period of time” (156). Apfel & Sifneos even list countertransference as a feature of alexithymia: “The interviewer or the therapist is usually bored by the patient whom they find frightfully ‘dull.’” Perhaps unsurprisingly, these “frightfully dull” patients seem not to have been included in the development of alexithymia measures. Since those early studies, alexithymia measurement has shed overt countertransference, but self-report questionnaires were still developed without input from people with alexithymia, meaning that crucial aspects of the experience may have been missed.

These self-report measures have a second limitation, one that is shared by all summative questionnaires. Consider item two of the Perth Alexithymia Questionnaire: “When I’m feeling bad, I can’t tell whether I’m sad, angry, or scared” (Preece et al., 2017). In an ideal world, a respondent would

quantify their ability to identify their emotions on each occasion, then average those values to rate the item. This process would be repeated for every statement, producing a robust, unbiased measure of trait alexithymia. Of course, this never happens. Instead, respondents rely on heuristics. More recent examples are weighted more heavily. So are instances of intense emotion. State-dependent response patterns also play a role: if someone is in a bad mood when they answer a questionnaire, they will remember negative feelings more readily. Thus, summative questionnaire scores reflect subjective perceptions and are vulnerable to cognitive biases; they may not correspond well to in-the-moment measures.

If Camille were to participate in a traditional study of alexithymia, she would be limited to a set of statements developed without input from individuals with high alexithymia. She would rely on biased heuristics to rate those items, and she would not have the chance to articulate the particulars of her experience. To fill these gaps, we must turn to other methodologies–namely, those that prioritize lived experience.

The Need for Lived Experience

Across fields and literatures, there has been increasing recognition that lived experience provides a valuable form of expertise that can complement, enrich, and inform quantitative research (e.g., Beames et al., 2021; Davis et al., 2022; Gatera & Singh, 2023). This is particularly relevant to autism research, as surveys and focus groups have uncovered substantial discrepancies between autism research priorities and stakeholders' needs. Whereas research tends to focus on biological underpinnings of autism, stakeholders–including autistic people, caregivers, and professionals–emphasize the need to study services, intervention, and autism throughout the lifespan (Pellicano et al., 2014). In light of this misalignment, there have been calls for a "new era of autism research" that grounds research in the everyday experiences and needs of autistic people (Pellicano et al., 2018). This can be accomplished through lived experience methods.

In early stages of theory development, lived experience research can illuminate new areas of inquiry and identify experiences that existing theories fail to capture. For instance, camouflage, a term describing autistic people's efforts to blend in socially, was initially conceptualized through qualitative data analysis (Hull et al., 2020). These studies informed questionnaire development and subsequent quantitative studies, which have since elucidated correlations between camouflage and psychological well-being (Alaghband-rad et al., 2023). In another example of the benefits of lived experience research, Trevisan et al. (2017) used posts from an online forum to explore self-identified autistic individuals' views on eye contact. Atypical eye gaze is a hallmark of autism, and much attention has been devoted to its implications for social communication. Yet Trevisan and colleagues' study appears to be among the first to explore subjective experience (Garvey et al., 2025). The study's findings emphasize discomfort that many autistic individuals feel when forced to make eye contact, raising important questions about the ethical implications of forced eye contact and informing subsequent research (Baiden et al., 2025; Chen & Patten, 2021).

Finally, lived experience work can directly inform interventions. Eating disorders and autism are highly comorbid, with autistic individuals demonstrating increased symptom severity and less effective treatment, yet there are few guidelines on working with this population. Researchers in the UK conducted interviews with patients, carers, and clinicians to identify unmet needs that stakeholders agreed on (Tchanturia et al., 2020). These findings were used to create the PEACE pathway, an approach to eating disorder treatment adapted for autistic individuals, and researchers continue to study and refine this approach through further qualitative studies (Li et al., 2024). Each of these examples highlights the potential of lived experience research to tap into perspectives that may not be easily accessed through quantitative methods.

The present study aims to extend the benefits of lived experience research to studies of alexithymia in autism. We recruited and interviewed six high-alexithymia autistic women, then analyzed the

interviews in depth to identify themes that characterized participants' lived experiences. Our results confirm and enrich findings on alexithymia; they also highlight new, unexplored dimensions of the trait.

Method

Research Design

We used interpretative phenomenological analysis (IPA) to illuminate the lived experience of high alexithymia. Originally developed for health psychology, IPA allows researchers to gain an in-depth, richly detailed understanding of an experience (Eatough & Smith, 2017). An IPA study begins with in-depth, semi-structured interviews. Researchers then analyze interview transcripts to identify overarching themes across the sample (Smith & Osborn, 2015).

Several other features of IPA make it particularly well-suited to address our study's aims. First, IPA acknowledges bias, forestructures that might cloud researchers' understanding of experience. IPA acknowledges that we all perceive the world subjectively. Rather than striving for perfect objectivity, IPA encourages researchers to develop awareness of these biases (Eatough & Smith, 2017). From the very beginning of a study, researchers become aware of these biases, also called forestructures. As data collection and analysis unfold, researchers continue to reflect on their beliefs and perceptions. The results of an IPA study consist of two layers of interpretation: participants interpret their own experiences, and researchers interpret participants' accounts (Smith et al., 2021). By acknowledging the subjectivity inherent in this process, IPA enables a more nuanced, comprehensive understanding of the phenomenon.

Second, IPA's open-ended format allows participants to describe their experience in as much detail as they wish, and on their own terms. As Smith and Osborn (2015) explain, "participants can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story" (p. 59). Thus, researchers use a flexible interview guide that gives participants room to steer the discussion toward the most important topics. This open-endedness can circumvent the paradox of alexithymia measurement, which asks respondents to describe the experience of not being able to describe an experience.

Third, IPA attends to the particulars of each experience and each person. IPA's small sample size enables researchers to understand each individual participant and the particularities of their experiences (Eatough & Smith, 2017). In the first stage of analysis, researchers examine transcripts individually, without comparing across participants. Later in the analysis, as researchers identify common themes across the sample, individual experiences are still preserved, with analyses explaining both convergence and divergence (Smith, 2017).

Sampling, Eligibility, and Screening

To ensure the homogeneous sample that IPA requires, we established four primary criteria to determine eligibility. Participants needed to (1) identify as women, (2) score 107 or higher on the PAQ ($Z \geq 1$), (3) score above a six out of 10 on the 10-item Autism Quotient, and (4) self-report a formal diagnosis of autism. We asked participants to self-report a formal autism diagnosis, rather than verifying diagnoses ourselves, because past work indicates that using self-reported diagnoses leads to more balanced gender ratios in samples (D'Mello et al., 2022).

Lastly, our study's format selected for autistic individuals who were able and willing to participate in a virtual interview. Our paradigm's reliance on verbal communication made it less suitable for nonverbal individuals and those with intellectual disabilities, thereby creating homogeneity.

Participants

Participant recruitment ads were posted on Reddit pages and the websites of the Organization for Autism Research and the Association for Autism and Neurodiversity. Prospective participants completed a preliminary survey consisting of the Perth Alexithymia Questionnaire, the Autism Quotient-10, and demographic information (Lundin et al., 2019; Preece et al., 2017). The eligibility survey also included four experimental items used for exploratory purposes.

Participants who met eligibility criteria were invited to participate in Zoom interviews. In total, eight interviews were conducted. One participant was excluded from the final sample due to a language barrier that posed significant challenges for reliable interpretation. A second participant was also excluded from analysis because, despite scoring above the cutoff on the PAQ (Z = 1.1), she did not endorse difficulty describing and identifying emotions during the interview. The final sample included six participants, which is typical for IPA (Eatough & Smith, 2017).

Table 1. Participant Characteristics

Pseudonym	Age	Year of autism diagnosis	Preferred terminology	Perth Alexithymia Questionnaire full-scale score	10-item Autism Quotient score
Tess	31	2022	autistic, on the spectrum, autism spectrum condition	156	9
Harper	26	2023	person with autism	151	10
Camille	19	"I think 2017 or 2018"	autistic	144	10
Mariah	25	2022	autistic	130	7
Skye	22	2021	autistic, on the spectrum, Asperger's	120	8
Abigail	40	2020	autistic	150	7

Note. The PAQ is scored out of 168 total points. The AQ is scored out of 10 total points.

Consent and Compensation

Before each interview, the experimenter obtained oral and written consent, explained the format, and allowed participants to ask questions. Participants were compensated with a $15 Amazon gift card upon completion of the interview.

We took care to ensure that our interview format was adapted to the needs and preferences of autistic individuals. Previous studies indicate that transportation to and from research sites and sensory sensitivities are the most frequently cited barriers to research participation (Haas et al., 2016). Our virtual interview format circumvented both of these obstacles. Because research has also indicated that autistic individuals appreciate knowing what to expect from research participation, we sent an information form to participants before the study.

Data Collection

Interviews were semi-structured, as is typical for IPA, and conducted using a schedule refined through pilot interviews. In keeping with IPA's commitment to "let the thing speak for itself" and bracketing preexisting understandings of a phenomenon, we refrained from using the word alexithymia. Instead, our interview schedule began with a question about participants' experience of emotions. The interviewer then used the participant's language to formulate additional questions (e.g., "Does the difficulty processing emotions affect your relationships?").

Interviews lasted 45-70 minutes and ended when the conversation naturally stopped. Interviews were recorded with participants' consent. Transcription software was used to generate transcripts, which were

manually reviewed for accuracy. LKW conducted and recorded all interviews and manually verified the automatically generated transcript. She allocated pseudonyms and removed identifying details before sharing transcripts with the rest of the research team.

Analysis

Following the procedure described in Pietkiewicz & Smith (2014), analysis began with multiple in-depth readings of each transcript. Exploratory comments were made in the left-hand margin, and preliminary themes were noted in the right-hand margin. A table of personal experiential themes was created for each transcript. Next, all six transcripts were analyzed collectively. Themes appearing in at least three transcripts were combined with illustrative quotes to produce a table of themes across the sample. LKW conducted the analyses and, with KP, developed individual and group themes. KP reviewed analyses to confirm that the data supported personal experiential themes.

Throughout the study, LKW kept a reflexivity journal to document thoughts about interviews and data analysis (Smith & Osborn, 2015). Journal entries described LKW's initial impressions of interviews and explored how LKW's existing beliefs and understanding of alexithymia shaped analysis. Thus, the reflexivity journal provided a structured opportunity for self-reflection and reflexivity.

Results

Analysis revealed five themes shared across participants' interviews. The first two themes–*difficulty understanding emotions* and *difficulty processing emotions*–reflect participants' internal experiences of emotion. The next two themes–*difficulty communicating emotions* and *norms and normality*–encapsulate relationships and social interactions, while the final theme, *coping*, explores participants' efforts to manage and make sense of emotion. Across all themes, we use participants' preferred terminology to describe their experiences. Because only Abigail described herself as having alexithymia, the term alexithymia appears infrequently.

Theme 1: Difficulty Understanding Emotions

Participants expressed persistent, pervasive confusion about emotions. Mariah noted, "A reoccurring [sic] theme of my life is that I don't understand my emotions." She could only decipher her feelings in retrospect, never in the moment. Skye described having a "limited emotional spectrum," and Camille reported that "all the emotions that I think I could experience…would be sadness, frustration, guilt, and anger and happiness." Tess struggled to identify feelings at all. She emphasized that this was "not a vocabulary issue; it's really just trying to attach a specific feeling to those words."

In the following excerpt, Harper provides a window into this confusion:

I don't know if I'm upset about something, whether I'm angry or whether it would be better to describe it as frustrated or if I'm upset about something that happened. I don't know if it's because I'm angry at somebody, or if I'm just sad that it happened or stuff like that. (Harper)

There is a strong sense of turmoil in this account. Harper's thought process is circuitous and elliptical, beginning with "upset," cycling through "angry" and "frustrated" before arriving back at "upset" again. Even the premise of her initial question reflects her confusion: is "upset" a precursor to anger, a form of frustration, or something else altogether? The cause of Harper's emotions is equally difficult to pinpoint, but she seems certain that emotion is present. She feels something, even if she cannot say what.

In other cases, however, emotions themselves were fleeting, elusive, ephemeral. Abigail called these "medium emotions" and contrasted them with "deep" ones:

Deep emotions, like anger or stress or sadness, those emotions I can easily identify and feel, I'm almost starting to think more deeply or more intensely than other people do. Where we have started to say that other emotions or positive emotions are like a medium. And so I don't really even recognize those…because they're less loud in my brain than just sensory stimuli…So they end up getting not

even acknowledged, I would say. Or they seem super fleeting and hard for me to kind of figure out what it is (Abigail)

Here, Abigail situates the confusion in the emotions themselves. Deep emotions are defined by their intensity, which makes them recognizable. Elsewhere in the interview, Abigail explained that deep emotions were marked by physical sensations that overwhelmed and debilitated her. Medium emotions, in contrast, were "less loud," drowned out or confused with sensory stimuli. Physical sensations could mimic medium emotions, creating additional confusion: was the fluttering in her stomach anxiety or hunger? Abigail finds herself in a paradoxical position, with emotions she cannot feel or even acknowledge. Her lack of agency is notable as well. Emotions overwhelm or elude her. They seize her attention or escape her notice. Whether the emotions are deep or medium, Abigail has little control over recognizing and handling them.

Unlike Abigail, Mariah rarely experienced deep emotions. She connected the faintness of physical sensations to her longstanding pattern of emotion avoidance:

I don't feel like I was able to truly express my emotions as a young person, so it has been so much of just hiding the emotions and ignoring the emotion, that it's hard for me even now that I want to understand the emotions, it's hard to be like, 'What is happening inside of me?' The physical symptoms like heart racing and stuff is [sic] really one of the clues that I try to lean into, but even that I don't feel very significantly. It's almost as if I've all but shut out emotions entirely. And they're just barely there. It's like a Lacroix version of emotion where it's just like, there's a taste in there.

A subtle shift in phrasing marks a gradual change in Mariah's experience of emotion. Before, there "has been so much of just hiding the emotions and ignoring the emotions," implying that Mariah is the one hiding and ignoring her feelings. Even so, the passive construction ("so much of hiding") suggests a lack of agency. Later in the interview, Mariah reinforces this notion by describing her emotions as "hidden away." Her question–"What is happening inside of me?"–underscores the confusion. Emotions are powerful forces that shape her behavior and internal state, yet she cannot understand them.

Mariah's detachment from emotion was shared by other participants, who used a range of verbs to convey the same feeling. They spoke of forgetting, shutting out, ignoring, hiding, or not being able to access emotions. Detachment could be unintentional, as reflected in Mariah's account. It could also be deliberate and strategic. Camille intentionally distanced herself from her emotions:

I like to always be busy and distracted and doing something because it's like, it feels normal for me, I don't have to digest the other things going on in my life that could be hard to deal with, like the emotions.

This quote indicates that, to some degree, she is aware that "always be[ing] busy" functions as a coping strategy. Nonetheless, the process is not entirely deliberate:

Sometimes I kind of forget that [my emotions are] happening until it's like someone's like, "Hey, you seem really sad right now." And I'm like, "oh, yeah, I guess I do seem really sad right now, I forgot that that's something that I can feel." So I'd say they kind of feel like a, like a second afterthought for me, but it's like, I know that they're there. I know that they're going, but then I kind of just get so caught up in other things that I forget that it's, it's there it exists, and it's making me feel and act certain ways, because it's there and I haven't dealt with it.

Theme 2: Difficulty Processing Emotions

The phrase "processing emotions" came up repeatedly in every interview. The inability to process emotions was experienced as a core feature of participants' struggles. In alexithymia, Abigail explained, emotions "don't work through your brain correctly, I guess. Or they go in and are processed in a different way." Tess also said that her difficulties stemmed from an inability to process emotion, which, in turn, was linked to naming emotions: "I couldn't process my emotions because I couldn't give them specific words."

Meanwhile, Harper and Skye wondered whether their neuropsychological testing results might yield insight into emotion processing. Both participants had learned from neuropsychological testing that they had slow processing speed relative to their full-scale IQs. Skye speculated that processing speed might extend to emotions: "Maybe I haven't felt emotions because they haven't kicked in yet."

The verb "process" evokes images of computing. A computer receives input that it must parse and interpret. To process emotion, then, is to break down and understand what is already present. If a computer receives more input than it can handle, it might glitch, freeze, or crash. Analogously, participants, became overwhelmed, panicked, and uncertain when flooded with emotion. Mariah likened this state of overwhelm to what someone might experience in a car crash. Harper felt "like there's a tornado going on inside my head…You don't really know where to start."

This state of overwhelm became most pronounced—and problematic—in tense interpersonal interactions. This category included any conversation charged with negative emotion. Camille provided the most detailed account of her thought process during such situations:

It's like, Okay, do I focus on the way that they're talking to me? Or do I focus on the things that they're saying, or do I try to focus on their hand movements? Or do I try to focus on their facial expression? And so in terms of what else am I feeling it's maybe confusion [laughing]. I don't even know where to start with how I'm supposed to interpret the situation (Camille)

Camille views interactions as if through a microscope. She perceives each component individually, and so she is forced to make tradeoffs. In focusing one element, she inevitably misses another. Later in the interview, she added that she "never really got a good read on people" because of her focus on details. Notably, Camille is the only participant in the sample who emphasized her struggles to understand other people's emotions, as well as her own. She made it clear that the two challenges were closely intertwined: her confusion about the other person's feelings produced anxiety and fear, which she struggled to decipher. Her mounting distress made conversations even more overwhelming.

When participants successfully processed emotions, they did so with significant time and effort. Abigail used an app to track physical sensations systematically. She focused on one body part at a time, noting muscle tension and physical feelings, before piecing it all together. Tess filled out worksheets to identify her primary emotions of each day. She sometimes succeeded, but by the time an emotion made sense, the situation had long since passed. Mariah, too, could only understand feelings in retrospect, which interfered with relationships. She explained, "If I'm having a disagreement with my partner or something, I have to take a step back because I need time to think about what even I'm feeling. So I feel like I'm five steps behind a normal person." These social implications are further explored in the next theme.

Theme 3: Difficulty Communicating Emotions

Whereas the first two themes focus on participants' individual experiences of emotion, the third examines the implications of these experiences in social interactions. Difficulty understanding and processing emotions created a barrier to communication, interfering with conversation, relationships, and overall understanding of emotion language.

"It's very hard for me to communicate my emotions because I don't even know them," Mariah said. Abigail and Harper both emphasized the difficulty of answering a question like "How are you?" For Abigail, that question "[would] never be answered correctly," while Harper described a sense of alienation and loneliness that the communication barrier created:

People ask you, like, how are you doing, what's making you upset, or how are you feeling today, and you don't really know how to answer them…usually I have an automatic response, so [if] someone asked me how you're doing, I automatically say, 'I'm good.'

Harper's struggle to articulate her emotions was also apparent in the interview itself. For the first half of the interview, which focused on emotions, she spoke hesitantly, pausing for long stretches between sentences. As soon as the conversation switched to more concrete topics, such as her experience of

receiving an autism diagnosis, Harper's speech changed markedly. She answered questions in paragraphs rather than sentences, elaborating on her responses unprompted.

Beyond specific interactions, confusion about feelings also made it harder for participants to understand what others meant when they talked about emotions. Skye seemed thoroughly perplexed by the concept of happiness:

I guess I'm sure I've felt happy. But it's just like when people explain happy, it's confusing to me because I don't know if it's just like, this prolonged state of just…what is that? I guess, what does that feel like, happiness, to people?…When I'm hanging out with my friends and I'm having a good time and laughing and stuff…is that called happiness?

This excerpt illustrates two layers of confusion: Skye struggles to understand the abstract meaning of "happiness" and to connect that definition to her own experiences. She later added, "My brain doesn't speak that language [of emotion]."

Theme 4: Norms and Normality

Skye's allusion to the "language" of emotion indicates that she grapples with more than an inability to communicate. She also feels like a foreigner, separate and distant from others. The sense of otherness, of being outside the norm, came up in most interviews, expressed through statements about "most people," "other people," "normal people," or "neurotypicals."

Skye was particularly fascinated and flummoxed by "most people." She pursued her autism diagnosis because of her sense that "internally I was just different," and throughout the interview, she emphasized discrepancies between "most people" and herself. She sounded like the narrator of a nature documentary, describing the peculiar habits of a little-known species. "I like knowing how people work," she explained. Through methodical observation, she had deduced some of the social expectations and rules surrounding emotion. She had sadness "figured out," she said, because she knew when it was considered appropriate. Often, however, those judgments about the appropriateness of emotion conflicted with Skye's own experiences: she understood when it was normative to feel sadness, but she still struggled to feel it.

Mariah was also attentive to social expectations, many of which were at odds with her natural instincts:

I think it's really just drilled, it's been drilled into my head ever since I can remember, to act in a certain way. And kind of do what's expected of you, rather than anything that you might want to do yourself or that you anything that like, comes naturally.

These expectations included making small talk, "being polite," "performing your gender and performing niceties and all these things that people don't really do for themselves, but more for other people." These behaviors, which she performed habitually, eventually permeated her identity and her sense of self: "that's the person that you are, because that's what a good person looks like."

Mariah's mention of being a "good person" hints at the moral flavor of these social expectations, which were more than just factual claims about how most people behaved; they also reflected normative beliefs about how people *should* behave. Accordingly, violating these norms could result in judgment and scrutiny. Abigail experienced this stigma regularly:

I would say, only 50% of my interactions with strangers are positive. You know, I, I, I haven't totally figured it out. But I come off as intimidating or unhappy or mean, or I don't know, I've heard all kinds of negative things directed at me. And I used to just kind of go like, what, why? Why was that? Like, I'm not meaning that at all. So it's a total mystery.

Strangers' words accumulated, eventually producing a sense of wrongness that was difficult to shake. Participants escaped scrutiny and criticism through masking**.** They feigned interest in conversations, adjusting facial expressions and vocal tones to project a sense of friendliness and warmth. They masked by concealing emotions, too, especially positive ones. Masking had its benefits, but it came at a cost.

As Tess explained, “when you mask, you mask everything,” including emotions. Feigning and suppressing feelings removed participants from their emotions, making those feelings even more distant.

Camille explained:

I feel like I mask a lot, too, to kind of just make it easier for other people of, like, I tried to just be happy, or try to understand the conversations that are happening and fit into those. And then the end the day I'm like, beat because I'm like, Oh, my gosh, I was masking this whole time. And now I'm not. And I feel it because I'm not anymore…, it's always, when I'm not doing it anymore that I realize, oh, man, that was I shouldn't have done that. That was too much.

Her account closely echoes Mariah’s description of gender expectations as “things that people do…for other people.” There are also parallels with the detachment from emotion described in theme one. Camille loses track of her emotions. Only after the fatigue sets in does she realize that she has worn herself out. After sharing this, Camille added that her experience was closely related to her childhood: “in my childhood, it was kind of mask [to] survive because of the people I grew up around.” Those people would punish her “physically or emotionally” for behaving “in any way that didn’t seem normal to them.” Even after leaving this environment, Camille found that habitual masking followed her, further obscuring her emotions.

Ultimately, masking undermined participants’ sense of self:

I think masking really follows you in any situation and anything that you do. I don't know that there's ever been a scenario where I'm just like, ‘wow, I really acted my true self there.’ (Mariah)

Theme 5: Coping

How, then, did participants cope with these struggles? Most participants expressed interest in therapy, but they faced logistical and financial barriers to working with clinicians. Only Mariah had worked long-term with a therapist who helped her unravel her inner experience. Therapy was expensive, and specialized providers were difficult to find. Tess lived near one of the world's largest cities, and still, she was unable to find a specialist in autism and ADHD for women. Abigail and Tess also noted that existing research on alexithymia seemed to approach the issue from a neurotypical perspective. They wondered whether researchers who did not live with autism and alexithymia could fully grasp their experiences.

Further, Abigail was frustrated with the lack of support she received after her diagnosis. The word “alexithymia” appeared on her diagnostic report, yet nobody explained it to her. A year passed before she discovered the term’s meaning and realized how well it described her:

I, like if I could change something about the diagnosis process, it would definitely be that, like some type of follow up, especially for like adults, it's so it's like, okay, here you go. Go on with life now. And then you're like, Okay, now what? You know? And like, do-- are there resources like how do I get that? Like, what does this mean all that stuff? So you're kind of left to your own figuring it out, you know?

In the absence of formal treatment, participants developed their own strategies to handle day-to-day challenges. Infographics and emotion charts offered a useful structure to help participants name their emotions. Participants also sought out basic facts about emotion: which types of emotion existed, and how they manifested in the body. First-person experiences were also helpful. Several participants went online to read accounts of not understanding one’s emotions. Finally, participants sought social support. Camille reported turning to her partner, who was “very emotionally intelligent,” to make sense of her experiences. Similarly, Abigail’s husband played the role of a translator, helping her understand how her emotions aligned with and diverged from norms

In addition to learning about general features of emotion, participants also developed their own individual understandings of their own feelings. This often involved recategorizing and

reconceptualizing feelings to produce a new understanding that would help participants cope more effectively. Tess, for instance, had experienced frequent panic attacks since childhood. However, after being diagnosed with autism as an adult and reading other people's accounts of autism, she started to wonder if some of her panic attacks were really meltdowns:

When someone say well, I had this meltdown because of this, my meltdown look like this, this. I was like, "Oh, that looks like my panic attack or my anger issue and they do happen at the time where I could have a meltdown." I was like, "okay. Let's think about it. Keep that in mind." And next time it happens. Reflect on it and then it happens. And I'm like, "Yeah, that's definitely a meltdown."

Tess determined that about half of what she had deemed panic attacks were better described as meltdowns. This new classification led her to coping strategies. She realized that she was sensitive to noise and that wearing earplugs and taking breaks from loud environments reduced the frequency of her meltdowns considerably. She became more attuned to the physical signs of panic attacks, such as nausea and hyperventilation. Tess emphasized that she had not fixed her difficulties, but she felt more capable of managing them:

I still don't know how to name my emotion[s]…I don't know if it will come, if it will ever be fixed. But I also know I have struggled, and I know that I need to talk about my emotion to be able to kind of work on it on a long, long run.

Tess's words convey a mixture of optimism and realism. While she views her difficulty with emotions as a persistent, perhaps lifelong struggle, she is hopeful about the possibility of growth. Several other participants also discussed the theme of acceptance. Abigail saw it as an alternative to change: "I have tried to a point that it's too much like I will try until I collapse, to figure something out. So that's a new shift is that I'm trying to work on just acceptance over trying so hard." For Camille, acceptance was more positive:

Part of who I am is interpreting emotions and things in a certain way. And I would say, like, maybe changing that, I feel like that would change other parts of who I am, too. And I wouldn't want to lose those parts of myself to sacrifice it for the emotions, because I do have relationships with people that I really value and enjoy. And I think those people are even more emotionally intelligent and compensate for what I maybe lack and can bring that forth in the relationship and maintain it because they really care.

Discussion

This study set out to illuminate the lived experience of autistic women with high alexithymia. We accomplished this using interpretative phenomenological analysis. We conclude by discussing the implications of our findings and highlighting future research directions for further study of the individual and social aspects of alexithymia.

Individual Aspects of Alexithymia

Our findings closely align with existing conceptualizations of alexithymia. Difficulty identifying feelings, difficulty describing feelings, and externally oriented thinking figured prominently into interviews, with some of participants' statements echoing alexithymia questionnaire items almost word for word. Notably, difficulty fantasizing, long considered a core feature of alexithymia, did not come up in the interviews at all.

Our findings are also congruent with the idea that alexithymia stems from underdeveloped emotion schemas (Preece et al., 2017). Participants reported having a limited emotional spectrum, where only a handful of emotions felt familiar. These were typically emotions like "sad," "happy," "stressed," or "frustrated." More specific, narrowly defined emotions, such as envy, disappointment, embarrassment, or pride, were never mentioned. Further, participants' general confusion about emotions seemed to reflect difficulty understanding not only their own emotions, but also emotions in general. It seemed

like they were missing basic information about emotion, as reflected in Camille's comment, "Maybe I don't understand, or maybe I just wasn't taught."

In addition, our findings illustrate various forms of emotional avoidance that participants reported and experienced. These results are consistent with the distinction between ability-deficit and avoidance alexithymia. As its name suggests, ability-deficit alexithymia describes an inability to describe and identify feelings, while avoidance alexithymia constitutes an emotion regulation strategy. Our participants reported being unable to name their emotions (ability-deficit alexithymia) and forgetting, ignoring, hiding, or shutting out feelings (avoidance alexithymia). Moreover, several participants' accounts hinted at a longitudinal relationship between ability-deficit and avoidance alexithymia, wherein chronic emotion avoidance led to an inability to understand feelings. These first-hand accounts set up a hypothesis that could be tested in longitudinal studies.

A recurring theme in our interviews was the idea that participants' emotions could only be deciphered in retrospect–hours, even days or weeks, after a situation. Past studies suggest that high-alexithymia individuals process emotion more slowly (Luminet et al., 2021). However, these results come from a paradigm on the scale of seconds, whereas our participants reported needing hours or even days to make sense of their feelings. Thus, future work may benefit from using methodologies with greater granularity–for instance, ecological momentary assessment–to understand these dynamics.

Finally, the cognitive processes seen in autism may account for participants' self-reported difficulty processing emotions. People on the spectrum exhibit detail-oriented cognition, favoring local over global coherence (Happé & Frith, 2006). This tendency was particularly prominent in Camille's account of not knowing what to focus on during a conversation. If detail-oriented thinking is associated with alexithymia, then high-alexithymia individuals may benefit from therapies targeting cognitive flexibility.

Towards A Social Perspective

Alexithymia has long been linked to social communication difficulties. Typically, this research situates social-communication challenges in high-alexithymia individuals, suggesting that these challenges arise from individual impairment.

Our findings paint a different picture. Certainly, participants suffered from alexithymia, but they also suffered from being high alexithymia in a low-alexithymia world. They described being judged, criticized, and misunderstood because of their atypical experiences of emotion. The ostracism they faced intensified their distress and undermined their ability to make sense of their feelings. This finding indicates a need to understand both sides of high-alexithymia individuals' interactions.

Past work on autistic people's social interactions offers a useful template for this type of research. Recent work has begun to reconceptualize the social-communication difficulties observed in autism as the product of bidirectional misattunement–that is, a relational impairment, not an individual one (Davis et al., 2021; Matyjek et al., 2025). This new conceptualization has prompted studies of interactions between autistic and nonautistic people, examining variables such as mutual gaze, intonation, pauses in conversation, and subjectively rated social interaction quality (Matyjek et al., 2025). A similar approach to studying alexithymia could yield a better understanding of how high-alexithymia individuals' interactions unfold and how both parties perceive them.

Such an approach could also offer insight into masking, which emerged as an essential component of alexithymia's social aspects. By feigning or concealing emotions, participants could conform to norms and blend into social situations, which may be advantageous in some contexts. Nonetheless, participants' description of masking ("when you mask, you mask everything") closely aligns with qualitative studies of masking in autism, which describe it as a barrier to authenticity (Chapman et al., 2022). It is worth exploring whether alexithymia is a mechanism in these relationships and whether these findings apply to non-autistic people with high alexithymia.

Finally, the current data also highlight the importance of understanding developmental influences on alexithymia. Past work has demonstrated a correlation between adverse childhood experiences and

adult alexithymia (Kick et al., 2024). Adverse experiences may prompt children to suppress their emotions, thereby increasing alexithymia. It is also possible that when caretakers do not attend to children's emotional states, children have few opportunities for emotional learning. Autistic individuals may be especially vulnerable to a mismatch between internal experiences and external feedback, as autism is associated with atypical facial displays of emotion (Poquérusse et al., 2018). Moreover, it is uncommon for emotion skills to be taught explicitly. Children who do not intuitively grasp emotional concepts are thus likely to lag behind, Similarly, invalidation from caretakers may interfere with emotion recognition.

Collectively, these social implications of alexithymia offer a range of starting points for additional research. Future studies can elucidate interactions between high- and low-alexithymia individuals, examine the relationship between alexithymia and masking, and explore the effect of early childhood experiences on the development of alexithymia. Our findings also underscore the importance of teaching emotion understanding, particularly for autistic individuals.

Limitations

The most important limitation of this study stems from its qualitative, exploratory nature. The small sample size and idiographic focus do not allow for generalizable claims, nor can this research design determine whether participants' experiences reflect autism, alexithymia, or some combination thereof. A second limitation lies in the sampling methods. Externally oriented thinking is a core feature of alexithymia, and many people with high EOT may be averse to lengthy interviews about their emotions. Although our participants exhibited high alexithymia, they were also willing and motivated to discuss their experiences, meaning that the findings may not generalize to extreme levels of EOT.

Finally, it bears mentioning that our participants represent just one of the many profiles of autism spectrum disorder, so the study's results likely do not reflect the experience of those with severe or profound autism.

Concluding Comment

To our knowledge, this is the first qualitative study to shed light on first-person experiences of alexithymia. Our findings offer a window into alexithymic experience and highlight the importance of understanding alexithymia in a social context. Further research is needed to assess the generalizability of these results.

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Conflict of Interest

The authors declare no conflict of interest.

Ethical approval

This research was approved by the Institutional Review Board of Stanford University (IRB-7273).

Data Availability

Interview transcripts generated during the current study are not publicly available due to concerns for participant privacy.

Author CRediT Statement

LKW conducted data collection and analysis and drafted the manuscript with assistance from KP. JJG provided critical revisions. All authors approved the final manuscript for submission.

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