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"My struggles are largely sensory processing:" The sensory world of autistic people

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ABSTRACT

This article delved into the sensory experiences of autistic adults, drawing on ethnographic fieldwork conducted in British Columbia, Canada. Thematic analysis of qualitative data revealed how unusual perceptual sensitivities impact the emotional well-being of autistic people, complicating their social interactions and relationships and contributing to social isolation. However, autistic individuals adopt diverse sensory and social coping strategies, and constantly adapt their previous sensory and social experiences to particular social and physical environments. This enables them to deal with their sensory challenges while interacting and socializing with others and engaging in social relationships. These ongoing adaptative processes also produce distinctive sociability patterns and perceptions among autistic people, reflecting both the stress associated with social interaction and the intense desire for it. Accordingly, this study highlighted the need for greater awareness of sensory phenomena and of social and physical environments to understand the daily and life experiences of autistics individuals.

KEYWORDS

Autism; sensory; sociability; adults; social relationships

Introduction

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism as a spectrum of developmental disorders. According to the DSM-5, the autism condition is characterized by deficits in social communication and narrow and repetitive patterns of behaviors and interests. The inclusion of atypical sensory sensitivity as a criterion in the autism definition, introduced more recently, underscores the growing recognition of the pivotal role sensory issues play in understanding autism (American Psychiatric Association, 2013).

Unusual sensory sensitivities and responses are not uncommon in autism (Grapel et al., 2015; Schauder & Bennetto, 2016; Smith & Sharp, 2013; Tavassoli et al., 2014, 2018) and they have been reported in research since Kanner's study in (Kanner, 1943) as well as in autistic persons' autobiographical accounts (Causton-Theoharis et al., 2009; Grandin, 1992; O'Neill & Jones, 1997; Prince-Hughes, 2004; Yergeau, 2013). These atypical perceptual experiences are usually demonstrated by hyper and/or hyposensitivity to different sensory stimuli (Ben-Sasson et al., 2008; Smith & Sharp, 2013) and have been observed in different sensory domains such as the auditory domain (sounds), tactile domain (touch), gustatory

domain (taste), olfactory domain (smells), and visual domain (lights) (Butera et al., 2020; O'Neill & Jones, 1997; Smith & Sharp, 2013).

This article drew on my 14 months of ethnographic fieldwork (June 2019 to August 2020) conducted for my PhD research project in British Columbia (BC), Canada, which examined friendships among 21 autistic adults. The data illuminated sensory experiences of the participants and their perceptions of how sensory issues affect their daily and social life. In fact, descriptions of how participants felt in certain social environments and circumstances and their emotional and physical sensations and reactions to them was a central theme that continued to emerge in the interviews and conversations with the research participants about their friendships and social relationships was. During my ethnographic study, I paid close attention to the sensory, embodied aspects of autistic people's lives which, as we will see, constitute a necessary basis to understand communication, social interaction, and sociability in autism.

By examining sensory experiences, this study contributed to viewing autism as a complex corporeal and social experience rather than as a purely neurodevelopmental disorder. Illuminating how bodily—and particularly sensory—aspects, affect autistic individuals' daily, emotional, and social lives, this work answered Solomon's (2010, p. 252) call for ethnographic and social inquiry on autism that explores personal narratives on "sensory, and perceptual experiences of autism."

The majority of participants in this study favored the term "autistic person/individual/people" over "person with autism" or "on the spectrum." Some participants had no specific preferences or objections regarding terminology. Therefore, in this paper, I used the terms "autistic person/individual/people" to respect the preferences of those who identify as autistic individuals.

Unusual sensory experiences in autism

Sensory symptoms are described in the DSM-5 as "hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment" (American Psychiatric Association, 2013, p. 50). Emotional and bodily reactions to sensory inputs range from negative feelings of discomfort, distress, anxiety, and sometimes even physical pain to positive feelings of enjoyment, fascination, and pleasure (Ben-Sasson et al., 2008; Chamak et al., 2008; Jones et al., 2003; O'Neill & Jones, 1997; Robertson & Simmons, 2015; Smith & Sharp, 2013). Sensory processing difficulties can continue to be significant in adulthood and across the lifespan (Crane et al., 2009; Horder et al., 2014; Tavassoli et al., 2014).

Previous studies that investigated sensory aspects and experiences among autistic individuals consistently demonstrated the profound impact of sensory challenges on their daily lives, social interactions, and overall well-being. Unusual sensory sensitivities in autism were associated with poor social communication (Glod et al., 2015; Lane et al., 2010), language pragmatic difficulties (Geils & Knoetze, 2008), depression and anxiety (Smith & Sharp, 2013), loneliness and social isolation (Smith & Sharp, 2013; Syu & Lin, 2018), behavioral problems and emotional challenges (Baker et al., 2008), and even sleep difficulties (Mazurek & Petroski, 2015). Perceptual difficulties were also found to impact the cognitive abilities and skills of autistic people and negatively affect their academic achievements and performance (Ben-Sasson et al., 2007; Butera et al., 2020; Cline et al., 2016; Howe & Stagg, 2016; Weiner & Grenier, 2020). Some also suggested that sensory processing

difficulties are associated with aggressive behavior in autistic adults (Van Den Boogert et al., 2021) and children (Bitsika et al., 2017; Mazurek et al., 2013).

However, research on the impact sensory aspects have on autistic individuals' social life and social behavior has increased only in recent years (Belek, 2019; Clinice et al., 2016; Hilton et al., 2007; Smith & Sharp, 2013; Thye et al., 2018), and with more focus on children and less on adults (Crane et al., 2009; Gonthier et al., 2016). Belek (2019) discussed bodily and sensory aspects of the experience of autism. He explained how autistic people tend to narrate and describe their autism and condition in relation to bodily sensations and particularly how they use terms such as “meltdowns,” “shutdowns,” and “overload” to convey experiences of distress. Clinice et al. (2016) demonstrated the ways sensory considerations shape autistic people's decisions about their leisure and social activities. Bagby et al. (2012) highlighted one of the negative social outcomes of perceptual sensitivities: difficulty engaging in familial and communal activities. Kuhaneck and Britner (2013) explained how sensory processing issues impose on autistic children's ability to engage in and practice social play. Smith and Sharp (2013) examined sensory experiences in autistic adults. They found that for autistic individuals, sensory input could be a source of either distress or fascination and pleasure. Further, the authors showed that some of these strategies that autistic individuals use to deal with their over- and/or under-sensitivity to sensory inputs, such as social avoidance, often lead to reduced social interaction and even isolation. Robertson and Simmons (2015) conducted a focus group with six autistic adults and examined their perceptual experiences. In this study, participants described exposure to intense sensory stimuli as a distressing, tiring, and painful experience. To reduce distress, control over the sensory stimulus was the most common coping strategy reported by participants in Robertson's and Simmons' study (e.g., avoiding being touched or wearing earplugs). At the same time, participants reported feelings of pleasure and fascination when interacting with certain sensory stimuli, a feeling that autistic individuals often seek, Smith and Sharp also found.

Despite these recent research attempts, little is known about the impact of sensory experience on autistic individuals' social life and sociability patterns. Hence, this study, which illuminated the ways sensory processing and sensitivities affect sociability and social relationships among autistic adults, filled a gap in autism research.

Materials and methods

Goal of the study

Data for this study were collected within a broader ethnographic research project exploring the life and social experiences of autistic adults. This qualitative study specifically aimed to investigate the sensory experiences of autistic individuals and their perceptions of how their unique perceptual sensitivities impact their daily lives, social behavior and interactions, sociability, and overall emotional and physical well-being.

Participants

This study included 13 autistic participants: females, males, and participants who defined themselves as non-binary. The ages of the participants ranged between 20–60. All the

participants in the current study are autistic adults who live in the Lower Mainland area of BC, Canada (see [Table 1](#)). All participants were officially diagnosed with autism, except one participant (Erik) who identified as autistic person without clinical diagnosis.

All the participants in the present study have adequate communication skills and an ability for self-expression. In addition to engaging in interpersonal relationships such as romantic relationships or marriage, more than half of the participants are employed and hold jobs, either full or part time (eight participants are unemployed), hold a post-secondary diploma or a university degree, or were university or college students at the time of study participation (as mentioned in [Table 1](#)). Thus, the selection of the participants in this study reflects a purposeful sampling (Bogdan & Biklen, 1998) and therefore the participants and findings do not represent all autistic people and the full range of personalities, abilities, perceptions, and experiences among this group. Nevertheless, this study's population provided me with the opportunity to investigate matters concerning sensory experiences within the context of autism. The results and conclusions drawn from this research could potentially provide new perspective and insights for future research aimed to explore sensory issues among other autistic groups.

Recruitment and ethics

Participants were enrolled via advertisements placed in autism-related social institutions and clinics in British Columbia. Additionally, flyers were posted on various autism-related websites, including ACT-Autism Community Training and REACHBC. A snowball sampling method also facilitated the recruitment of participants who learned about the study through word-of-mouth from previous participants.

Ethical approval was obtained from the authors affiliated university prior to recruitment and data collection. All participants provided signed informed consent forms, which were written in clear and accessible language. Participants received these forms well in advance and had up to two weeks to review them thoroughly before deciding to participate.

Data collection

The data gathering consisted of participant observation; semi-structured interviews; and two focus group sessions using Zoom. After all face-to-face research activities were suspended due to the COVID-19 pandemic, officially declared on March 2020 by the World Health Organization, I conducted all individual interviews through telephone and video calls. Indeed, the new life conditions that the pandemic demanded allowed me to “create a flexible methodology” and to build a hybrid ethnographic experience that combined online and offline spaces (Johnson, 2022, p. 774).

The interviews and focus groups, each lasting between 1 to 1.5 hours, followed a phenomenological approach (Creswell, 2013) to gather rich data and achieve a deep understanding of autistic individuals' perceptions and descriptions of their experiences. Indeed, the interview and focus group sessions, primarily focused on the daily and social experiences of autistic individuals, with a specific emphasis on friendship and social relationships. However, as mentioned earlier, a recurring subject in these conversations was participants' descriptions of their feelings in various social and physical environments and how these sensations affected their behavior and interaction with others. Given the

Table 1. Participants’ demographic characteristics.

Pseudonym	Self-Identified Gender	Age Range	Location	Place of Birth	Education Level	Employment Status	Marital Status	Age at Autism Diagnosis
Alice	Female	30–39	Metro Vancouver	France	Bachelor’s degree	Unemployed	Married	After age of 30
Andrew	Male	25–29	Metro Vancouver	Canada	Undergrad student	Employed	Has a partner	Under age of 5
Emily	Female	25–29	Metro Vancouver	Canada	Bachelor’s degree	Unemployed	Single	After age of 20
Erik	Transgender	30–39	Metro Vancouver	Canada	Undergrad student	Employed	Married	No official autism diagnosis
Frank	Transgender	Above 50	Metro Vancouver	Missing data	Missing data	Unemployed	Single	After age of 30
Helen	Female	40–49	Metro Vancouver	Canada	Bachelor’s degree	Employed	Single	After age of 20
Jennifer Jolie	Female Female	25–29 Above 50	Fraser Valley Fraser Valley	Canada Canada	Online courses Bachelor’s degree	Employed Employed	Single Married (has 4 children)	During high school After age of 40
Linda	Female	30–39	Fraser Valley	Canada	Bachelor’s degree	Employed	Married (has 2 children)	After age of 30
Neil Olivia	Male Queer	20–24 25–29	Fraser Valley Metro Vancouver	Canada Singapore	High school graduate Undergrad student	Employed Unemployed	Single Has a partner	Under age of 5 After age of 20
Tony	Male	Above 50	Metro Vancouver	Canada	Bachelor’s degree	Employed	Single	After age of 30
Victoria	Female	25–29	Metro Vancouver	Data missing	Post-secondary diploma	Unemployed	Has a partner	After age of 20

importance of this subject, questions specifically addressing sensory experiences were included.

Further, from the very beginning of my fieldwork, I became aware that the interviews included rich data and insights that I obtained beyond the talk/words that my participants exchanged with me; thus, each face-to-face interview constituted a rich site for observation. While conversing and interacting with the participants, I observed and became aware of how the external physical environment of the meeting, my physical body, and my behavior affected the interview process and the whole research encounter. On many occasions, I noticed that the lack of a suitable environment negatively affected the ability of autistic individuals to participate effectively in conversations with me. For instance, I observed how other “background” noises and loud sounds, such as the sound of the coffee grinder inside cafés, affected some participants’ ability to focus on the conversation and to communicate with me. These intrusions explain why, when I met participants at cafés or other locations, it was important for them to choose a small and quiet space with as few distractions as possible. Therefore, during data collection, I paid special attention to the physical environment of the study.

Data analysis

The analysis that I developed in this study is based primarily on the qualitative data that I gathered in interviews and focus groups. I transcribed all audio recordings of the interviews and the focus groups and imported them into NVivo 12 software, which I used to organize and code the data. For my analysis and interpretation of the data, I used the qualitative thematic analysis approach, defined as “a method for identifying, analyzing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). During a process of repeated reading of the transcripts, I familiarized myself with the data before the initial codes were identified and generated. All initial codes were then combined and organized into themes. Further, my analysis of the data went beyond the semantic or descriptive level, and also involved exploration and interpretation of underlying concepts and meanings in participants’ accounts, achieving a what Braun and Clarke (2006, p. 84) described as “latent” level of thematic analysis.

Results

The findings were organized into three main themes: *Senses and the body*: presenting participants’ sensory experiences and physical sensations and these experiences and sensations’ impact on their daily functioning and emotional state. *Senses and the environment*: discussing participants’ strategies and ways of coping with their sensory challenges. *Senses and sociability*: describing how sensory aspects affect autistic individuals’ social lives, particularly their friendship relationships.

‘Why I’m sitting in this place:’ senses and the body

Sensitivity to sound and light

Erik is a 30-year-old married transgender person who uses the pronouns “they/theirs.” After we decided to meet, Erik wrote in their e-mail: “Please note that I have

misophonia and so I ask that you not eat or chew gum during the meeting.” I met Erik in a small quiet local café. While I was carefully slurping my hot tea trying to make no “oral noise,” Erik explained how misophonia, and sensitivity to certain sounds more generally, not only bother them but even prevent them from doing the activities they love the most:

... if I can change things, then at a movie theater there should be no food and no gum, and you cannot chew at movies.

Erik added:

Like, think of turning volume down in shows and I will be able to go. I love waterfalls but they are too loud, I cannot do it.

Other participants reported similar experiences with noise and its interference with communication. I met Frank (also uses the pronouns “they/theirs”) in a café located very close to the building where they live. Frank’s struggle with keeping track of the conversation was readily apparent, especially when trying to ignore the very crowded and noisy street right across from the café. After chatting for few minutes at the café, Frank said that the place is very noisy for them, so we decided to relocate to a small yard in the entrance of their building to continue our conversation. On our way, Frank continued to share with me how noise negatively affects them, especially their ability to communicate with people:

I mean, my conversation should stop, I have to wait until the noise passes or in some cases I have learnt to tune it out, so that I can talk when there is noise and the other person can hear, so...

My observation and encounter with Frank at the Café’ and their description of how noise affects them, helped me understand that what would be simple conversations for the average person were very challenging for Frank due to their sensitivities.

Other social spaces such as classroom activities, that depend on conversation, can prove particularly challenging for autistic people. Andrew reflected on his current experience as an undergraduate student and mentioned classrooms as an example of the type of stressful and challenging environment that he encounters on daily basis:

In classes, in particular when there is group work in the class, you know, you’ve got everybody talking in one room at the same time, I am trying to hear what people are saying but hear others in other groups who are talking at the same time, so that is a bit more challenging.

As a response to my question of what makes certain sounds annoying or “noisy” and how it feels for him, Andrew differentiated between organized and unorganized sounds and pointed out the importance of “sound (and light) quality” as main factors that determine, in his view, his physical and emotional reactions to different auditory and visual stimuli:

... It is kind of ironic, I go to a dance pub full of loud music until late at night, but a bunch of people in a room can be bothersome to me ... I think it is also not just the level of the sound but the quality of it. If there is a bunch of people talking all at once, if I am hearing those people at the same time this is basically noise and there is nothing correlating all the sounds together. But if it is music, if it is good music, then that is fine.

At the same time, Andrew also emphasized how his over-sensitivity can be positive and even very helpful in his occupation as a professional sound and light technician. For

example, Andrew described how he “uses” his physical sensation of discomfort as evidence for an impairment in sound that should be fixed:

Like, me being sensitive to sound or light can be really stressful at times, but it can also be really helpful and allows me to do my job well. So, if I hear something that is not sounding right and it makes me physically uncomfortable, it is my job to ensure the sound is good . . .

In other words, this example not only showed how Andrew’s unusual sensitivity can be “useful” but also illustrated how Andrew was also able to adapt to his sensitivity to sound rather than constantly being disabled by it.

Sensitivity to smell and touch

In addition to sounds and light, sensitivity to smell and touch in social spaces can also produce uncomfortable overstimulation. Alice also reported perceptual sensitivities as Andrew did, and expressed how she usually gets overstimulated and overwhelmed by noise and lights, she is also sensitive to certain smells. She also mentioned that when she feels anxious, she “cannot stand noise or smells” and that these sensory stimuli can even make her “aggressive.” Alice, who I met in a local café for an interview, also discussed with me how much sensory considerations are central in her experience, especially in her social life and practices:

Social spaces are not the best. You cannot find places without music going on or without screaming. I enjoy cocktails and beers but noisy places . . . If you ask me about my experience, I speak about the sensory parts.

Alice, like Andrew, also described the positive sides of her sensory processing and how she is even able to find enjoyment and pleasure in visual sensations: “Being able to enjoy the lights. Like how the lights changing during the day and during the seasons.” More than that, Alice decided to share with me her marriage story to illustrate the “happy” and pleasurable sides of unusual sensory sensitivity. When I asked her why and how she chose her husband, she said, “I think there is something in his smell, like he smells something special, something about the smell . . . ”

Unusual sensitivities in the tactile domain were also reported by other participants in this research. A few months after I met Neil for an interview, I conducted an online focus group discussion with five autistic participants to discuss their experience of autism. Neil was one of the group members, and, in response to the question of how participants describe their experiences of sensory processing, he explained his unusual reactions and sensitivity to certain lights by classifying lights according to their types and intensity. In his case, Neil believes, hypersensitivity to lights usually results in physical fatigue and reduced general motivation:

I have a lot of sensory issues around lights, like all these new LED lights and blue lights take energy out of me. So . . . I find the world more challenging every day.

Neil, also reported unusual sensitivities in the tactile domain, particularly discomfort with being touched or hugged. Neil’s description of his childhood experience demonstrated this sensory difficulty: “As a child I didn’t like being held,” Neil said when he described for me

his diagnosis experience and how his mother “started noticing that he was little bit different,” to use his words.

Being touched and other sensory experiences generated negative emotional and physical reactions among some participants and affected their daily behavior and decisions. For example, Emily was the first to respond to my question to the online focus group participants, asking them to describe sensory symptoms and how they affect their life experiences. Emily shared:

For me, I have a touch sensitivity, I wouldn't like it if a friend tried to hug me, and I think that sometimes it becomes awkward when you tell somebody “I don't like to be hugged.”

Jennifer, another group participant, added:

For me, my sensory issues are sensitivity to voices, like if they are too loud, I'll get completely overwhelmed. And I have some sensory issues of touch.

In addition to being touched, over-sensitivity to touching certain surfaces or objects was also raised by some participants. Going back to Neil, for example, in our interview meeting he explained his feeling toward “sticky surfaces” and his emotional reactions to them:

... I don't like sticky surfaces or feeling and things like that. I find for some reason early in the morning everything feels sticky and overwhelming.

Other participants also had very specific sensitivities to touching surfaces with particular textures. In our video interview, Victoria provided a description of how the fear of getting touched turns Victoria's very basic daily activity of taking public transportation into a very challenging and stressful experience:

So, I have a lot of issues with touch. So, if someone touches me, or like something too soft, or like food texture ... I cannot take transit if people sit close to me and I'm like “please don't touch me.”

As participants' testimonies and the various quotes above clearly showed, sensory sensitivities and overstimulation can lead to anxiety and other negative emotions. At the same time, anxiety and depression also impact individual's sensory processing patterns either by increasing sensitivity or by “numbing” it, both of which make processing different sensory inputs harder and more challenging. This was evident in the interview with Alice who, when anxious, “cannot stand noise or smells” and becomes more “aggressive,” and in the following quote from Neil's narrative on how depression weakens and debilitates his perceptual abilities. Neil stated:

I used to have very sensitive hearing. If I am feeling depressed, then all my senses are damped you know.

Participants' descriptions like Neil's and their stories demonstrated the centrality of hyper- and/or hypo- sensitivity to sensory stimulation in autistic people's daily experiences. Responding and adapting to these sensory challenges is the daily living reality that makes autistic individuals “always exhausted,” as some described it. The following quote from Linda's personal account clearly reflected that reality, as well as the

centrality of it in the autism condition, a condition which Linda defined as “a sensory experience of the world:”

I think for me, like, I experience the world as autistic, and to me it's like an energy sensory experience and that is very different from a neurotypical experience.

In short, besides a few positive sensory experiences reported by some participants, sensory sensitivities in different domains mostly lead to negative emotions and bodily reactions that range from discomfort to being overwhelmed and anxious, to feeling physical tiredness and sometimes even pain. These emotional and physical conditions also make sensory processing more challenging for autistic people. The following section will discuss participants' strategies and ways of coping with their sensory challenges and environments.

Senses and the environment: ways of coping

Participants identified a number of strategies and bodily techniques they employ to deal with their over/under sensitivities to sensory stimuli. To block or reduce the intensity of auditory stimuli, many mentioned using ear plugs and head/earphones. “I wear ear plugs if I go anywhere that can be damaging (to sense of hearing) to reserve my ears for my work . . . ,” Andrew claimed. For Victoria, ear plugs are essential for her daily function: “So, I'm trying to minimize (noise) and have ear plugs and stuff to still be able to go (outside).” However, decreasing loud and “unorganized” sounds through ear plugs is not the only technique Victoria uses to cope with her hypersensitivity. Alternatively, covering her ears with headphones and listening to loud but “organized” sounds, such as music, which blocks and replaces external “noises,” is also reported as another useful strategy that she adopts frequently. Jennifer also differentiated between organized and unorganized sounds when she described a similar way of coping with oversensitivity in the auditory domain: She claimed:

If I am in public then I have my earphones on, and I can make it louder cause I don't wanna hear anyone around me. . . . Yeah, I cannot stand unorganized mess.

In other words, to regulate and control auditory stimuli, Victoria and Jennifer not only attempt to decrease loud sounds using ear plugs, but they also seek loud but organized sounds (by listening to loud music) to eliminate external “noise,” to calm themselves, and even to enjoy auditory sensations.

Still exposure to and coping with intense sensory stimuli cannot always be managed successfully. Lack of control over sensory stimuli often leads to negative emotions, such as extreme stress and anxiety, and triggers immediate bodily reactions manifested primarily by physical withdrawing. In our interview meeting, Tony touched on this matter. He described how being around “lots of people shouting” makes him “get overstimulated,” and how his lack of ability to control his feelings and reactions makes responses such as leaving or “getting out” of the place the only solution available to him:

When I am in a setting with lots of people around me, people shouting like that, I can get overstimulated . . . After a while I just wanna get out of there.

Similarly, Victoria's reasonable belief that crowded places could increase her chance of “being touched” guides her to adopt the very common coping strategy of avoiding sensory

stimuli. Avoidance and even fear of outdoor spaces and activities that Victoria perceives as sources of inconvenient experiences and anxiety shape her daily schedule, since she must arrange her day in ways that help her to order to avoid crowded environments, as she explained to me:

I'm quite content mostly being at home, I got all my stuff here, I got my cat, I got my boyfriend, just no one annoying me . . . but if I, like, want to go out I try to avoid crowded transit and try to schedule appointments at the middle of the day, so I don't have to take two hours to get home.

Avoidance is also a strategy used by Olivia (a queer person who uses the pronouns “they/ theirs”) who described their sensory avoidance strategy as deciding not to “leave the house” as much as possible. This was their answer when I asked them about their leisure time and social activities:

I am very tired person. It is hard for me to leave the house. It is hard for me to go into a public place where there are lots of sounds and smells and colours, they are like overwhelming, so I just like to stay in a place that is quiet and safe and familiar.

Jolie is a mother of four children, two of whom are also autistic persons. After living with autism for many years, she believes that feeling anxiety and dealing with sensory stimuli on a daily basis are the most challenging aspects of autism, as she shared in the group discussion. Reflecting back on her 42 years of life experience with autism, Helen reinforced Jolie's opinions by stating in the group discussion that “when she gets older, it's just getting worse, and just worse.”

Following Jolie and Helen, Linda also drew on a perspective of time to share her experience with her sensory difficulties. These difficulties have never disappeared, Linda noted, but her ways of living with them have changed with age so that she is now able to “balance her sensory needs.” Linda also described how she has been able to get rid of her habit of drinking alcohol, a coping tool that she used to adopt in the past to deal with her inability to control sensory overstimulation:

I just wanna say that when I look back, I was younger . . . I would drink a lot of alcohol to go to the club or things like a bar. Now I see it was actually a way of numbing some of my sensory stimulation, cause now if I go to a bar I would get overwhelmed very quickly . . . And as I become a mother, I have to figure out how to balance my sensory needs . . .

Jolie also replied to Linda and added:

“When I was at university and later, I used alcohol to help numb the sensory issues a little bit but also the social anxiety,” Jolie continued.

Linda replied: “Yeah, for me it just made things easier . . . ” [Linda and Jolie laughed].

The use of alcohol to “numb the sensory” and to deal with social anxiety was somewhat common and was reported by Victoria as well. Victoria also mentioned the use of alcohol in our one-on-one interview by stating that she finds “drinking” very helpful when she “hangs out with friends:” “If I go out and I'm drinking I'm less sensitive.”

Erik also believed that living with their sensory symptoms and accepting them is better than fighting them. Like Linda, Erik compared their past with their present perception of sensory experiences to illustrate their journey of learning to live with and accepting their sensory needs:

Like, I cannot see movies in theaters. I cannot. I want to. I used to force myself when I was younger, because I did not understand why it is horrible for me and I thought it is my problem, and now I stopped forcing myself because it is a horrible experience. But it is also sad because I don't see movies.

Linda ended the long group discussion on sensory processing in autism by making the argument that it is the “modern world” that is to blame for creating challenging and more sensory-stimulating environments that make autistic individuals’ experience more challenging. “It has become harder for autistics to function in the modern world because there is so much sensory stimulation,” Linda explained her thinking about this to the group members. Alice even asserted that it is also her responsibility to “educate people” and to make them be more patient toward autistic persons’ needs in general, and more tolerant to their sensory needs in particular.

However, along with acknowledging non-autistics’ and the public responsibility to create more sensory-friendly environments, or even blaming society for making autistic people’s experience tougher, as Linda did, all of the participants tried to find practical ways to adapt to and even create their own environments. Participants also tried to stay socially active while dealing with their personal sensory needs on daily basis, and tried to find individual ways to reduce their suffering and distress. Erik, who still dreams of “no food and no gums in theaters,” accepted and understood that “a lot of people cannot sit [in a theater] for long without food;” and Victoria, who understood that “expecting the whole world to be quiet” is “not realistic,” are good examples of this pragmatic approach.

Senses and sociability: friendship and social relationships

Participants described the impact of sensory challenges on their interpersonal relationships and social lives. Victoria shared in our online video conversation her struggle with certain sounds and smells that determines, to a large extent, where she is able to meet friends:

Like, I say to friends let’s meet in my house or their house and then . . . but like, going to restaurants and people are chewing, and it smells too bad.

In addition, Victoria’s distress at being touched, as I understood later in our conversation, explains her “desire” to stay at home most of the time: “I mostly just hang out at home, play video games, talk with friends online and stuff,” she said.

The view of “home” as a safe and comfortable environment and space to socialize with friends was raised repeatedly by other participants. Erik, for example, prefers to stay at home as much as possible and even when they “hanged out outside,” they always questioned their decision of leaving their home. “And I ask myself why I am here, why I am like sitting in this crowded noisy place? Colouring in my color book when I could do it at home,” Erik wondered in our interview meeting.

Helen shared her thoughts with the focus group members on how she thinks her way of processing sounds and smells in particular not only impacts her decision where to meet friends but also largely rules her choices on the kinds of people to interact with. Helen narrated:

If people talk really fast it’s hard to understand them, or people who [smell bad] is a big issue for me . . . smelling certain things like perfumes or smells that they [people] have, this is a big

major thing for me that I struggle with So, people who are like that, I cannot be around them.

Helen's words received immediate support from Jolie who presented her perception of how sound sensitivity not only makes information processing and communication challenging, but also limits autistic individuals' ability as well as opportunity to create new friendships:

In a noisy environment, I have trouble keeping up with the conversation and keeping track on the conversation and then being heard when my voice doesn't get heard very well, so it pretty much silences me in a loud environment like loud restaurant. So, if you are going to school and your class is going to a pub after, so that's not a place that you can really go and engage, then it certainly affects the ability of people that you are trying to make friendships with.

Andrew shared with the group his experience following Helen's and Jolie's comments on communication troubles caused by auditory processing difficulties:

Yeah, I definitely identify with loud conversations, a lot of people talking at once, like it's funny, I can go to raves and festivals and music concerts and be okay with that with ear plugs in, but people chatting at once hurts me more.

Jolie, while continuing to focus on the example of friendship, replied to Andrew and added her observations on how difficulties in information and sound processing interferes with communicating with others, and even leads to a feeling of exclusion and of being an outsider:

And I think it affects your ability to make friends as well, because if you are part of a group and everybody else seems to be able to manage it, and can have conversation with the person besides them, and have their voice heard, but then you are having trouble hearing your voice and trouble keeping track of the conversation that you are supposed to. It also affects if people want to be there, because someone can sit there but cannot be part of the conversation, it doesn't do good things for the group.

Andrew used the example of sensorial intolerances and his personal interpretation of how they influence autistic persons' social experiences, to share with the group his disagreement with the claim of autistic people's disinterest in friendships and desire for loneliness:

. . . other social spaces may not be comfortable to [autistic] people. Like, I see that there are a lot of spaces that people go to that may be excessively loud and noisy or just too crowded with people, and people might just prefer hanging out with one or two people, . . . and people just say; "oh, they prefer being alone," . . . but I think it can often be misinterpreted that way when it's more just that it's challenging to make these connections and go out and be social.

The over-sensitivity to different sensory stimuli not only determines, to large extent, the kind of activities autistic individuals do/not do with friends or the social spaces they attend, but it also shapes their friendships choices and preferences. Participants' accounts also supported the assumption that shared experiences and understandings of daily difficulties, including sensory ones, are key factors in choosing friends. For example, Erik tried to explain why social interactions with neurotypicals are more challenging for them:

. . . they [neurotypicals] don't understand depression or anxiety and why we are exhausted all the fucking time. They don't understand that you cannot do things and they are always like . . .

“will go to such and such places” where it is really loud, . . . and where everybody will be eating and, misophonia.

Similarly, Olivia also expressed in our interview meeting their opinion on how intolerance and lack of sensitivity to autistic individuals’ sensorial needs, among others, makes befriending neurotypicals a less preferable choice:

They [neurotypicals] are just operating on a different level . . . other neurodivergent people will likely not wear very strong perfume . . . And this is just to accommodate this basic understanding that a lot of neurodivergent people have adverse reactions to certain stimulus, or there is certain sensory things where it is like neurotypical people don’t care, they just put on a bunch of perfume . . .

In our phone interview, Emily also mentioned employment, which she currently lacks, as an example of another life domain that can be highly affected by her struggle with unusual sensory responsiveness. She imagined a workplace with intense social interactions, such as a small company where everyone knows and works closely, as highly challenging. “It is harder [to find a job] just because I need a job that matches to my needs. Like a job where there’s not too much social interaction,” Emily stated.

As the various examples showed, sensory experiences shape autistic people’s sociability and friendship patterns, such as who to interact with, where, and how. Tony’s descriptions, for instance, added and provided convincing insights on how avoiding intense sensory stimulation is also related to the number of friends autistic people have, or the number of friends they prefer to meet and interact with at the same time. Tony referred to crowded and noisy environments and how they disturb his daily social interactions, even if he is surrounded only by a group of friends: “When I am in a setting with lots of people around me, people shouting like that, I can get overstimulated.” “And this affects your ability even to be with friends?,” I asked. He responded, “Oh yeah, especially with a large number of friends.” Similar to Tony, Andrew also shared his view on how, due to sensory processing difficulties, interaction and communication with a small number of people is more convenient, another example that sheds light of why some autistic individuals may prefer having and “hanging out” with a limited number of friends. Andrew even drew on the current example of the COVID-19 outbreak to illustrate the point he shared with the online group members that the pandemic has made the task of socializing and communicating with friends much easier:

I actually haven’t minded COVID-19 restrictions for six people in one table . . . and just hanging with a smaller group of people in general that makes it easier in a way . . .

To explain the impact of sensory issues on their interpersonal relationships and social lives, some participants also commented on how sensory considerations shrink autistic peoples’ opportunities for establishing romantic relationships. Neil didn’t hesitate to express his frustration and disappointment to the group discussion members. He shared his long, unsuccessful journey to find a romantic partner. In his description of his personal experience, Neil referred to sensory aspects as the main reason that prevents him from being able to be present in those settings where, he supposed, people usually meet and get to know each other:

I am trying to start dating . . . it’s very hard when you know somebody who is very extroverted and doesn’t have sensory issues. Like, you don’t like crowds, so, you know, I don’t enjoy going

to party like Britney Spears on a regular basis, or bars and stuff like that where people meet, so it has been challenging you know. I'm 24 years old and I haven't been on a date for years, it's upsetting.

In our one-on-one interview meeting, Neil was able to identify the reasons that can explain his ongoing "failure" to find a romantic partner. These were always related to his attempt to avoid intense environments and interactions. Neil told me, while a small smile appeared on his sad face, "I don't get out enough, so that is my problem. People are not going to meet me at my house, right?" Moreover, it appeared that Neil's close network of friends, who, as he reported, are all autistic persons and share similar life experiences, just contributed to perpetuating this condition. "But also, there is not a lot of places where you can go if you don't really have social introverted friends, you know. All my friends [autistics] have the exact same problem as I do," Neil desperately recounted.

Unlike Neil, Victoria has succeeded in establishing and maintaining a romantic relationship. However, concerns about her sensory challenges and how to deal with them still exist. These concerns explain her hesitant attitude toward the possibility of being a mother and raising children. "I'm slightly worried about the fact that, like, I have a bad time with noise. But I was very against that [having kids] until kind of recently," Victoria said to explain how romantic and marriage relationships can open new challenges for autistic people.

Discussion

Confirming the findings from previous research, the current study showed how autistic individual experience difficulties in sensory processing, which are demonstrated by hypersensitivity and hyposensitivity across multiple sensory modalities (Butera et al., 2020; O'Neill & Jones, 1997; Smith & Sharp, 2013; Thye et al., 2018). As the data in this study also demonstrated, sensory sensitivities mostly generate negative bodily and emotional reactions of discomfort, anxiety, physical tiredness and even pain, but also positive feelings of enjoyment, relaxation, and pleasure. The finding is consistent with other studies where similar physical and emotional descriptions and reactions were reported (Ben-Sasson et al., 2008; Chamak et al., 2008; Jones et al., 2003; O'Neill & Jones, 1997; Robertson & Simmons, 2015; Smith & Sharp, 2013). Further, in contrast to Kern et al. (2006) claim, for participants in the present study, perceptual difficulties did not decrease with age and remain significant in adulthood, or can even "*get worse*" with time, as Helen put it.

Furthermore, participants' accounts illustrated how unusual sensitivities to sensory stimuli produce and are reproduced by intense negative emotions, creating a loop of sensory-emotion influences. For example, Alice becomes "*anxious and aggressive*" when confronting intense sensory stimuli, and when she is anxious she is unable to "*stand noise or smell*." Similarly, when Neil is depressed his senses are "*damped*." This observation is similar to the concept of the "vicious cycle" discussed by Smith and Sharp (2013, p. 896) in which stress caused more perceptual sensitivities and vice versa.

Participants mentioned a number of techniques to regulate and control various stimuli, such as using ear plugs or earphones. By using headphones and listening to loud music, for instance, participants replace "unorganized loud noise" with "organized loud sound," which not only blocks external noise but also provides pleasurable sensations, enjoyment, and relaxation. In other words, to regulate and control auditory stimuli, autistic people often

seek loud but organized sounds (by listening to loud music) and use the same sense of hearing to eliminate external “noise,” to calm themselves, and even to enjoy auditory sensation. Similar coping techniques were reported in Robertson and Simmons (2015) as well as Smith and Sharp (2013).

The current study demonstrated that sensitivity to sound and touch makes even basic daily activities highly challenging (such as taking a public transportation, in Victoria’s case). These findings added more evidence to earlier research data that demonstrated how atypical sensory sensitivities negatively affect daily functioning of autistic people (Suarez, 2012; Tavassoli et al., 2014). Moreover, caution and worry about exposure to intense sensory stimuli, the findings in this study showed, usually lead to avoidance of outdoor social spaces and activities. Thus, sensory considerations often prevent autistic persons from engaging in activities they might envision as enjoyable because social spaces and activities that fit their sensory needs tend to be more restricted. Social avoidance of over-stimulating environments is a theme that was mentioned in other studies as well (Ashburner et al., 2013; Cline et al., 2016; Robertson & Simmons, 2015; Smith & Sharp, 2013).

Although social avoidance can be effective, it also entails reducing autistic individuals’ opportunities to meet new people and form new relationships as well as limiting the time, spaces, and activities that they can share and enjoy with friends. In cases of high over-stimulation and lack of control over stimuli, participants adopted the strategy of physical withdrawal, an unpleasant experience that, most probably, escalates fear of social environments and encourages more isolation and less desire for social engagement. Social avoidance or withdrawal as leading to loneliness was also reported by participants in prior research (Smith & Sharp, 2013; Syu & Lin, 2018).

The findings of the current study also helped explain common socialization and friendship patterns in autism and shed light on the interplay between sensory and social behavior. For instance, sensory considerations shape autistic people’s decisions to join in activities and share spaces with friends. Avoidance of intense sensory environments and sensations, which participants commonly described as “exhausting,” makes indoor spaces and activities with a limited number of friends a preferred choice for autistic individuals. Examples of engagement in actions that limit exposure to intense sensory stimuli include meeting with friends at home, watching movies, or playing video games. These preferences represent autistic individuals’ attempts to adjust friendship activities to personal sensory and communicative needs and environmental limitations. These sensory and communicative considerations might provide an explanation for the smaller number of friends often reported by autistic people—see reviews by (Bauminger-Zviely & Kimhi, 2017; Petrina et al., 2014), as well as the preference for indoor spaces and on-on-one activities (Bauminger-Zviely & Kimhi, 2017; Kuo et al., 2013; Sedgewick et al., 2016).

Drawing on the findings of this study, it can be assumed that friendship and socialization patterns common among autistic people, such as a preference for indoor activities for a limited time with a small number of friends, do not reflect a real desire for social introversion and loneliness. Rather, these preferences reflect autistic individuals’ efforts to find the balance between dealing with their sensory challenges and struggles on the one hand and enjoying social life as well as maintaining their intimate relationships on the other.

Sensory sensitivities also shape autistic persons’ friendships preferences of the type of person to befriend or not to befriend. For example, participants frequently voiced

a preference for interacting with people with certain smells or tone of voice (Helen), or a preference for socializing with friends who share similar difficulties, like other neurodivergent people. As appeared from the data, autistic people embody their friendships in a different range of physical activities that answer their physical and emotional needs, and which make them feel even more related to others who enact and embody friendship in similar ways. This can also explain preference for having neurodivergent friends who, as some participants believed, share similar experiences of difficulties including but not limited to sensory challenges. A preference for interacting with and befriending autistic or neurodivergent people was also found in prior studies in which autistic adults described feeling more comfortable interacting with other autistic persons (over neurotypicals) (Milton & Sims, 2016; Morrison et al., 2020).

Moreover, difficulties in auditory and information processing contribute to participants' feeling of social exclusion and marginalization. The inability to track with a group conversation, to hear and be heard, as Jolie and Linda clearly demonstrated, complicate social communication and hinder the initiation of intimate relationships with others. The interaction of sensory difficulties with communication explains autistic individuals' emerging habitus of less talking and more doing (e.g., participation in structured activities, playing video or board games etc.). The way autistic people embody friendship by "doing" things with others as opposed to "talking" makes the whole interaction more comfortable and even pleasurable for many autistic individuals. This is supported by other studies that showed a preference among autistic people for participation in structured social activities because they require less verbal communication (Chan et al., 2023; Müller et al., 2008). This finding might help explain the limited reports of closeness, intimacy, and sharing talk in autistic individuals' experiences of friendship (Bauminger-Zviely & Kimhi, 2017; Petrina et al., 2014) and add evidence to previous research that suggested a link between unusual sensory sensitivities and communication difficulties in autism (Lane et al., 2010; Watson et al., 2011).

In Lai et al. (2011) research, female autistic adults displayed more sensory sensitivities and symptoms compared to males, and in Walsh et al. (2018) report, lower visual and auditory oversensitivity was reported by trans and non-binary autistic participants compared to those who identify themselves as women and men. In the current study, no significant gender differences were found in relation to sensory experiences and sensitivities. Due to the small number of participants in this study, future research will be needed to examine the influence of gender on autistic individuals' sensitivities and reactions to sensory stimuli.

Contrary to old views on autism as a "basic desire for aloneness" (Kanner, 1943, p. 249), the findings in this research reflected a real desire for social interaction and relationships in autism despite significant sensory impacts on autistic persons' ability to function or even exist in certain social spaces. Therefore, the current research supported previous findings that showed that autistic people desire and do have social relationships (Brownlow et al., 2015; Fernandes et al., 2016; Pecora et al., 2016; Ryan et al., 2021; Strunz et al., 2017; Turner et al., 2017). However, by showing how sensory and environmental aspects affect social interaction and socialization in autism, this study illuminated one more layer of difficulties that makes social interaction and the maintenance and formation of relationships in autism more challenging.

In short, this current study pointed to the importance of sensory aspects in autistic people's social experiences. It examined how autistic individuals experience sensory stimuli—auditory, visual, and tactile—and how their perception of these stimuli impacts their behavior, their interactions with others, and their everyday activities. By adopting diverse sensory, communicative, and social coping strategies, autistic people constantly adapt their previous sensory and social experiences to particular social and physical environments. This produces common sociability patterns and preferences among autistic people, which reflect the balance autistic individuals seek between the stress of social interaction and the desire for it.

Accordingly, this study highlighted the need for greater awareness of sensory phenomena in understanding autistic individuals' daily and life experiences. The continual medical, clinical, and educational focus on the mental processes and cognitive aspects of autistic people's lives had contributed to a neglect of the sensory and physical aspects that underpin communication and social interaction in autism. In the case of sociability and relationships, this study illuminated the perceptual grounding of experience and of social relationships and how they construct sociability and friendship patterns among autistic people. By giving specific attention to the sensory dimensions of autistic persons' experience and by highlighting the need for an ethnography that is more attuned to these dimensions, this study addressed the need identified by Solomon (2010) for a deep examination of the perceptual aspects of autism. By illuminating embodied and sensory aspects, this study suggested adopting a framework that views autism not merely as a mental condition, but also as a physical condition which is comprised of both bodily actions and dispositions.

Implications

This research not only contributed theoretically but can also have significant practical implications. It underscored the importance of considering physical and environmental factors and their impacts on the daily and social lives of autistic individuals. Adopting this view could enhance the development of more effective services and supports for autistic individuals and their communities. Specifically, the findings can help designing intervention plans aimed at improving social interaction and reducing barriers, including sensory and environmental factors that contributed to meltdowns and stress in autistic individuals. Additionally, recognizing autistic individuals' desire for social interaction and focusing on external influences on their social abilities can help promote a more inclusive view of autism, potentially reducing stigma and the widespread misinterpretation of autistics as asocial, and encouraging meaningful social engagement.

Limitations and future research

This research has several limitations. First, the findings cannot be generalized to all autistic individuals, as the study included only those with adequate social and communication skills for self-expression. Future research should use alternative data collection methods to include other autistic groups, such as nonverbal individuals, to better understand sensory experiences across all autistic groups. Second, despite efforts to include diverse participants, the study did not fully represent all social groups from the recruitment area, particularly missing autistic participants from First Nations and other Indigenous groups, who make up a significant portion of BC's population. Third, the small study population was limited to the Lower

Mainland of BC, making the findings specific to that region. Studies examining autistic experiences in different cultures and areas could provide valuable cross-cultural insights. Finally, the COVID-19 pandemic restricted face-to-face observations and interactions with participants. Future studies should include more observational data from in-person interactions in various settings and contexts. Longitudinal research is also needed to examine how sensory experiences and perceptions evolve with age and changing life circumstances.

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