

Making Needle Procedures Comfortable for Autistic Children: Caregiver Perspectives

by

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ABSTRACT

MAKING NEEDLE PROCEDURES COMFORTABLE FOR AUTISTIC CHILDREN:

CAREGIVER PERSPECTIVES

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Autistic children are at increased risk for having difficulty undergoing needle procedures. While clinical practice guidelines (CPGs) are available, little is known about how to make needles comfortable and CPGs appropriate for autistic children. To address this gap in the research, a convenience sample of 20 caregivers of autistic children were interviewed about the appropriateness of CPGs for their child. Interview transcripts were analyzed using descriptive statistics and Reflexive Thematic Analysis. Results underscore the importance of child autonomy and external factors, such as the environment, on children's comfort. Results also indicate that tailoring of preparation and coping strategies is required to meet the needs of autistic children. Overall, findings support that a patient-centered and individualized approach is imperative to make needles comfortable for autistic children. Recommendations for healthcare providers and caregivers are provided. Results can contribute to developing CPGs that are more appropriate for autistic children and their caregivers.

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1 Introduction and Literature Review

Needle procedures, such as vaccines and venipunctures, are common throughout childhood and are associated with pain, fear, and distress for most children (Jacobson et al., 2001; McLenon et al., 2019; McMurtry et al., 2015). Needle fear ranges from mild to clinically significant phobia, characterized by significant distress and avoidance of needles (McMurtry et al., 2015). Fear and pain have a bi-directional relationship, such that needle pain can lead to higher needle fear and higher needle fear can lead to more painful needles. In the short-term, poor management of needle fear and pain leads to negative needle procedure experiences, such as the child experiencing distress, pain, and increased risk of injury (McMurtry et al., 2015). In the long-term, children who develop high needle fear and/or endure painful needles are more likely to develop chronic needle fear and later avoidance of healthcare (McLenon et al., 2019; McMurtry et al., 2015). Additionally, caregivers may delay or avoid pediatric needle procedures due to their child's distress (Jacobsen et al., 2001). Children with autism spectrum disorder (autism) are at increased risk for developing high needle fear and having difficulty undergoing needles for several reasons, such as individual differences in underlying sensory function and communication challenges.

Autism is a neurodevelopmental disability diagnosed in about 1 in every 66 Canadian children aged five to 17 years (Ofner et al., 2018). Autism is characterized by persistent challenges in social interaction and communication and restrictive and repetitive patterns of behavior and interests (American Psychiatric Association [APA], 2013). Inflexibility, including rigidly sticking to routines, and sensory sensitivity, including negative or intense responses to sensory input, are also common features (APA, 2013). Identity-first language is used throughout this thesis (i.e., autistic child), which aligns with the views of disability culture advocates and disability studies scholars (e.g., Dunn & Andrews, 2015) and the preferences of most participants in the present study.

Contrary to classical reports, it is a misconception that autism is associated with reduced sensitivity to pain (Moore, 2015). In response to venipuncture, for example, autistic children have shown elevated, not reduced, physiological and facial pain reactions and longer-lasting behavioral pain reactions compared to their neurotypical peers (Nader et al., 2004; Rattaz et al., 2013; Tordjman et al. 2009). Differences in how autistic individuals express pain may have led to misconceptions about their pain sensitivity and can also lead to ineffective pain management (Liu et al., 2020). Due to difficulties with verbal communication, some autistic children may express their pain non-verbally, such as through behaviors or facial expressions (Liu et al., 2020; Muskat et al., 2015). These non-verbal signals may be more subtle than verbal signals, which can lead to poor detection and management of autistic children's pain (Messmer et al., 2008). Additionally, some behaviors that autistic children may exhibit to signal their pain and/or fear, such as aggression, fleeing, and physical resistance, can be problematic (Evans et al., 2005; Shabani & Fisher, 2006). These behaviors during needle procedures may be harmful for children and healthcare providers (HCPs) and may also be poorly managed by using strategies like restraint or sedation, which can exacerbate pain and fear (Braff & Nealon, 1979; Salvatore et al., 2021; Slifer et al., 2011).

Autistic children have also been found to exhibit higher rates of medical-related fears compared to their neurotypical peers (Evans et al., 2005) with needle fear being most common (Leyfer et al., 2006). Sensory sensitivities are thought to make autistic children susceptible to associating their aversive sensory experiences with objects or situations, leading to fear, anxiety, and/or phobia (Muskett et al., 2019). In a typical clinic setting for a needle procedure, there is likely to be florescent lights, smells from cleaning supplies, unfamiliar people and environments, and potentially loud noises, such as other people crying in the waiting room. For autistic children with sensory sensitivities and/or a need for routine and predictability, these social-environmental conditions could exacerbate their needle-related distress. Finally, many HCPs lack experience and training with autistic individuals (Liu, 2020; Davignon et al., 2014) and

some hold stigma or misconceptions about autism (Salvatore et al., 2021), which can lead to sub-optimal care.

Given the above-described risks for autistic children having difficulty undergoing needle procedures, it is critical that effective strategies for treating needle pain and fear are available for this population. There are clinical practice guidelines (CPGs) on managing children’s pain and low-to-moderate levels of fear during needle procedures (see Table 1; Taddio et al., 2015) and for treating high needle fear in children (McMurtry et al., 2016). The strategies in these CPGs were not designed specifically for autistic children and are described below before discussing potential autism-specific considerations.

Table 1. Strategies for Managing Pediatric Needle Pain and Low-to-Moderate Fear

Strategy	Age Range	Before, During or After Procedure
Process strategies		
Educate clinicians about pain management.	All ages.	Before.
Educate caregivers about pain management.	All ages.	Before and on day of.
Educate child receiving needle about what will happen, how it will feel, and how to cope.	All ages.	Mostly before.
Caregiver present.	Children 10 years and younger. For older individuals, their preference.	During.
Pharmacologic Strategies		
Topical anesthetics to manage pain.	All ages.	30 to 60 minutes before.
Physical Strategies		
Sit upright.	Children 3 years and older. Younger children can sit on caregiver’s lap.	During.
Avoid restraining/holding down child.	All ages.	During.

Psychological Strategies		
Provide neutrally worded verbal signal of impending needle insertion, such as “here we go” or counting down.	All ages.	Immediately before needle insertion.
Do not provide repeated and uninformative reassurance (e.g., “you will be okay”) or false suggestion (e.g., “it won’t hurt”).	All ages.	Before and during.
Breathing interventions paired with toy distraction during procedure.	Children 3-12 years.	During.
Distract the child.	All ages. Type of distractor depends on age and preferences.	During.
- Video, music, and verbal distraction.	Children aged 3-12 years.	During.
- Directed video distraction and directed or undirected toy distraction.	Infants and children under 3 years.	During.

Note. Strategies taken from (Taddio et al., 2015).

High levels of needle fear are unlikely to dissipate without treatment and can interfere with the effectiveness of the coping strategies in Table 1 (McMurtry et al., 2015). Exposure treatment is recommended for treating high needle fear in children (McMurtry et al., 2016), which has also shown effectiveness in the pediatric autism population (e.g., Grider et al., 2012; Slifer et al., 2011; Shabani & Fisher, 2006). Exposure treatment involves exposing a person to the feared stimuli or situation in a gradual and controlled manner (McMurtry et al., 2016). An exposure hierarchy is created by listing the order of exposure steps for the child to progress through, working from the least to the most fear-inducing situation (see example in Appendix A). Over time, the child learns that their fear is unlikely to cause serious harm and that they can cope with their distress (McMurtry et al., 2016).

1.1 Potential Considerations for Managing Needle Pain and Fear in Autistic Children

There are likely special considerations for using the existing CPGs to manage needle pain and fear in autistic children, but this has not been examined in the literature. For example, topical anesthetics (TAs) may be difficult to use with autistic children who may have sensitivity to touch. For autistic children, it may be helpful to practice with TAs prior to application for a real needle procedure (Grider et al., 2012; Slifer et al., 2011). Additionally, since autistic children tend to benefit from predictability and routines, preparation before a needle procedure is likely a particularly important strategy for them and their caregiver(s). Videos (Boada & Parellada, 2017) and visual tools like Social Stories may be helpful to prepare autistic children for what to expect during exposure treatment (Davit et al., 2011) and a needle procedure (Taghizadeh et al., 2015; Taghizadeh et al., 2019). Social Stories are visual stories that guide a person through the steps of a situation by describing appropriate behaviors and environmental information (Spencer et al., 2008). As part of preparation, learning about what sensory experiences to expect may also be especially important for autistic children given that their sensory sensitivities may contribute to their fear and discomfort (Cohen, 2008; Jaaniste et al., 2007). Further, it may be important to accommodate the sensory needs of autistic children by modifying the procedural environment, such as reducing noise and offering privacy (Davignon et al., 2014; Salvatore et al., 2021; Taghizadeh et al., 2019).

Albeit limited, research on exposure treatment for needle fear in autistic children has found it to be effective and highlights the importance of using positive reinforcement, such as praise or tangible items, to motivate the child's progress (Davit et al., 2011; Grider et al., 2021; Shabani & Fisher, 2006; Slifer et al., 2011). Additionally, increased parental involvement has been a helpful modification to exposure treatment for the phobias of autistic children (Ollendick et al., 2020). Caregivers have also guided at-home exposure treatment for their autistic child's needle fear (Davit et al., 2011).

Therefore, autistic children may benefit from their caregivers being heavily involved in and/or leading exposure treatment for their needle fear.

2 Study Objective

Autistic children are at risk for having difficulty undergoing needle procedures and developing high needle fear, which if unmanaged, can lead to both short- and long-term health consequences (McMurtry et al., 2015). There are CPGs for managing pediatric needle pain (Taddio et al., 2015) and treating high levels of needle fear (McMurtry et al., 2016) in the neurotypical population. However, it remains unknown whether these CPGs are appropriate for autistic children and their caregivers. Our objective, which guided the qualitative analysis, was to **explore caregiver perceptions of what is needed for needle procedures to be comfortable and clinical practice guidelines to be appropriate, actionable, and accessible for them and their autistic child**. Given the dearth of research on this topic and the exploratory nature of the work, hypotheses were not developed or tested.

3 Methods

3.1 Procedure

3.1.1 Recruitment, Screening and Sample Size

This study was approved by the University of Guelph Research Ethics Board (21-06-039). Invitations to participate in a virtual interview were posted online in ~25 Facebook groups oriented towards caregivers of autistic children. Caregivers were selected for the interviews since they are not only an informative source about their child's needs, but also play a key role in supporting their child through painful procedures. Interested caregivers contacted the principal researcher (PR) via email and were then invited to attend a screening call. During screening, the PR: 1) described the objective of the study and what participation would look like, 2) asked questions about

inclusion criteria, and 3) asked questions to aid purposive sampling. All interested caregivers met the inclusion criteria of speaking English, living in Canada, and having a child between the ages of four and 18 years with a diagnosis of autism from a healthcare provider. Purposive sampling was used to ensure that the sample represented at least some caregivers with a child with high needle fear and with a child who communicated non-verbally. Near the end of recruitment, the PR preferentially selected two interested caregivers with a child who communicated non-verbally. After screening, caregivers were invited to schedule a tentative interview date, pending their review of the consent form.

Following the advice of Vasileiou et al. (2018), a sufficient range for sample size was estimated a priori by the PR based on factors intrinsic to this study, including the narrow objective and use of purposive sampling, which can help to maximize the 'information power' within a sample (see Malterud et al., 2016). A sample size of 12-20 was expected to be feasible to obtain and large enough to capture a breadth of caregiver perspectives, but small enough to maintain a narrow scope focusing on a participant-oriented analysis of the data (Sandelowski, 1995). Data collection began in October 2022 amidst the COVID-19 pandemic, including vaccines being made available for children. Recruitment was terminated in January 2022 when 20 interviews had been scheduled.

3.1.2 Consent, Interviews and Transcription

Participants read a consent form and reviewed several websites describing evidence-based strategies for managing pediatric needle pain and fear prior to their interview. At the beginning of each interview, the PR summarized the consent form, invited questions, and obtained verbal consent to continue with the interview. Using Microsoft Teams, individual interviews (60-90 minutes) were conducted to allow caregivers to share their in-depth and personal perspectives (Gill et al., 2008). The semi-structured interview guide ensured gathering of critical information, while allowing for the pursuit of more detail and unexpected discoveries.

Interviews began with a demographics questionnaire. The interview guide consisted of open-ended questions about, 1) the child's past needle procedures; 2) strategies for managing needle pain and low-to-moderate fear (Taddio et al., 2015); 3) exposure treatment for high levels of needle fear (McMurtry et al., 2016) and 4) potential autism-specific considerations, such as environmental accommodations. Close-ended questions were embedded throughout to gather caregiver ratings of how helpful certain strategies would be for autistic children on a Likert Scale (0 - Not Helpful, 1- Slightly Helpful, 2 - Somewhat Helpful, 3 - Very Helpful, 4 - Extremely Helpful). The PR concluded interviews by thanking participants, inviting questions, and offering a \$25 incentive gift card. The PR interviewed all participants and for some interviews, a research assistant attended to assist with recording of close-ended responses. The PR took brief field notes during and after each interview to aid in later data analysis. Research assistants transcribed the interviews verbatim, which were reviewed for accuracy by the PR (see Appendix C for data security and organization).

3.2 Data Analysis Method

Demographics data and responses to close-ended questions were analyzed using descriptive statistics via SPSS software. Interview data was coded and analyzed using Braun and Clarke's six interactive and recursive steps of Reflexive Thematic Analysis (TA; Braun & Clarke, 2006; 2022; see Appendix B for descriptions of the steps). Analysis was reflexive in that the PR was self-questioning and reflective throughout data analysis, including keeping a reflexive journal. The PR is a clinical psychology graduate student with years of experience working with (clinically and recreationally) and advocating for families with autistic children. The PR's background informed their interactions with participants and interpretation of responses.

The TA process involved the PR systematically assigning pieces of data that are relevant to the research question with a code label and then developing themes by grouping codes into patterns of shared meaning. Themes unify the recurrent perspectives from across the dataset into meaningful concepts (Braun & Clarke, 2006).

A critical realist theoretical framework and an experiential qualitative framework guided analysis. An inductive approach was taken for coding, which occurred at the semantic level. Transcripts were uploaded to NVivo software, which facilitated labelling and organizing codes.

4 Results

4.1 Sample and Demographics

The sample was comprised of 18 mothers who identified as female and 2 fathers who identified as male (*M* age = 42 years). Seventeen families were from Ontario, and the provinces of New Brunswick, Quebec, and Nova Scotia were each represented by one caregiver. The autistic children being discussed in the interviews (*M* age = 10 years, range = 4-15 years) were primarily male (14/20) with high needle fear (18/20). According to caregivers, five children had been diagnosed with an intellectual disability or cognitive delay, six with attention deficit hyperactivity disorder, and three with an anxiety disorder. Caregivers reported that most children (19/20) had sensory sensitivity to touch and/or sound and two children had sensitivity to smells. According to caregivers, their children had an average needle fear level of 8 on a scale from 0 (not afraid at all) to 10 (extremely afraid). Only one caregiver reported that they had high needle fear, and the average self-reported fear level of caregivers was 1.5 on the scale from 0 to 10. Most children communicated verbally (15/20), one quarter (5/20) communicated solely non-verbally, and two children who communicated verbally were said to lose that ability when anxious, such as during a needle procedure. Most caregivers (15/20) and children (12/20) were of White/European decent, but there was also representation of caregivers and children from Asian, Black, and Indigenous ethnic backgrounds.

4.2 Themes

Four themes were created from the data. The first two themes were focused on child autonomy and external factors that impact children's comfort, which speak to what is needed for needle procedures to be comfortable for autistic children. The third and fourth themes addressed what is needed to make existing CPGs appropriate for caregivers and their autistic children, focusing on the key role of caregivers in using preparation as a strategy and caregiver ideas for tailoring strategies to the needs of autistic children.

4.2.1 Theme 1: Treat the Child as an Autonomous Individual

Caregivers expressed that a sense of agency and control is key to their child's comfort with needle procedures.

I knew that the more agency, or like, the more control, she had over what she could control, the better it would be for getting the needle (P04).

Specifically, caregivers suggested involving the child in decisions, such as offering choice of what clothing to wear, what distractor to bring, and/or who comes to support them. Caregivers also suggested respecting their child's agency by postponing the procedure if the child is upset rather than forcing them to undergo the procedure. In line with the patient-centered model of care, giving a patient control over their care was seen as helping to prevent traumatic and promote positive healthcare experiences.

Giving her [child] as much agency as possible, feeling in control as much as possible. Because if she can feel that her choices matter, then she feels that she matters...there was a time when she- we couldn't follow through with the procedure. We didn't get mad of course, we listened, we realized that it was too upsetting for her, so we were like, "that's okay. That's okay, we can try another day, right?" So, making sure that, again, it's not gonna have a negative effect on her is very important... to make

sure that they [needle procedures] are positive, we should be listening to our kids more (P08).

Caregivers expressed that it is problematic to undermine the child's right to autonomy and self-determination, such as by lying to them about the procedure, not listening to them, not speaking to them directly, and/or not giving them information about the procedure and their health. Caregivers shared examples of HCPs contributing to inhibiting their child's autonomy, such as by directing information only towards the parent.

I was looking around at kind of the neurotypical kids...the doctors were talking to the child, "I'm going to do this. And now I'm going to do this. You're going to see this. You're going to feel this." And with my guy, we've got a doctor walking around like this, talking to me. I'm not the one getting the needle...I think that's a big thing, even if a child is intellectually delayed, speaking to the child in a traumatic situation is so important (P19).

The importance of prioritizing the autonomy of autistic children is underscored by this theme, as unfortunately, people may incorrectly assume that a child with a disability is not capable of making their own choices, consenting to care, and understanding information about their health.

4.2.2 Theme 2: It's More Than the Poke and Pain

Caregivers underscored that their children's comfort during needle procedures is associated with more than the needle poke and pain. Many caregivers shared that pain does not appear to be the primary or singular source of discomfort for their child. Rather, it is the entire situation of the needle procedure.

I would say it's not a fear of pain, but the situation and probably the restraining (P20).

Caregivers highlighted three factors that significantly contribute to their child's comfort during needle procedures – the environment, the (un)familiarity of the situation, and the healthcare provider – which have been divided into three subthemes.

4.2.2.1 Subtheme 1: Environment is Everything

The environment was seen as pivotal for autistic children when it comes to needle procedures. Sensory-related features of the environment were highlighted as exacerbating the child's discomfort, including the bright/florescent lights, noise from crowds, smells in the clinic (e.g., cleaning products), and the feelings of being touched, the alcohol wipe, and Band-aids. Caregivers also agreed that patient flow through the clinic is important to their child's comfort. Efficient providers and clinics were described as helpful and appointments were seen as ideal due to children's difficulty coping with wait times, waiting rooms, and lineups. While appointments were said to be helpful to avoid delays, caregivers also shared that the typical appointment time slots may not be long enough for their child and that their child dislikes feeling rushed.

So, having an appointment is good in some ways because then you go straight in. Not having an appointment gives you more leeway, but then if you get the wrong time, you're in this big, long line and then now you've got all this time to like work yourself up. So, I'd say there's like two sides to that. The best-case scenario would be like, walk in and we just like go right in (P15).

More broadly, caregivers described how the clinic setting itself contributes to their child's comfort, including their child being uncomfortable in large, crowded venues that lack privacy. In contrast, caregivers described their child as being most comfortable in child-friendly, as opposed to medicalized, settings and at clinics that are specialized in treating children with special needs.

...we went to our local COVID vaccine clinic, which is in a community center, in a gym so like, long lineups, big open space, echoey, lots of

people, lots of people in masks. They had a private area, which was literally just behind a curtain. It was just my husband and our son and after 20 minutes they had to leave with no vaccine...they were not equipped, they didn't leave enough time, there wasn't enough privacy, so my husband made the decision to just leave with no vaccine... (P02).

Many caregivers even mentioned travelling, sometimes far distances, for their child to receive their needle in a more child-friendly and specialized clinic setting.

I guess it's not just my son, but it's also the staff, the environment that also plays a big role. So, if we were to take my child to a lab, just like in [local city], the experience was very, very different, compared to if we were to take my son to [children's hospital] where the staff is more trained in handling children and especially children with special needs, and the hospital itself is very child friendly. There's like lot of you know, beautiful kids, beautiful wall art and all that. It's just a kid-friendly hospital. So, yeah, there have been many times, especially when he was younger, where we did have to travel all the way to [city of children's hospital] and it is very far for us... (P09).

This subtheme implies that specialized clinics should be available for families and environmental accommodations should be offered in regular clinic settings. Feasible accommodations could make a significant difference for autistic children, such as scheduling longer appointments.

4.2.2.2 Subtheme 2: Familiarity and Predictability Matter

Caregivers described that their child's fear of the unknown exacerbates their needle-related fear and pain. Autistic children were reported to have anxiety related to the unfamiliarity and unpredictability of the situation.

...half his pain is associated with the fear of the unknown and not being in control, and like that is what is increasing his experience of pain. It's not just the physical prick of the needle, it's all of those other things that are elevating his nervous system (P03).

For many children, needle procedures like vaccinations, are relatively rare occurrences (i.e., not daily/weekly/monthly), making them diversions from their routine. Caregivers explained that changing their child's routine to undergo the procedure makes the experience challenging.

I think it's harder for him to kind of be at the appointment and be in the mood for it because he doesn't like to get out of routine. Like he maybe doesn't trust the person that's gonna do it, and everything that's happening around it. Like more than the needle in itself, it's like the experience in general (P11).

Lack of past experience with needles and/or avoidance or long gaps between needle procedures were reported to contribute to the child's needle-related anxiety. It is likely that as the child experiences more (positive) needle procedures, they can better predict what to expect in the future, relieving some of their anticipatory anxiety. To maximize predictability for their child, caregivers suggested strategies like creating a consistent 'needle procedure routine,' bringing a familiar support person, and bringing familiar comfort items.

We [caregivers] tend to think a lot about if something is unpredictable, right? Trying to bring as much consistency to alter that environment. So, what's consistent? Mom and dad are both there reassuring her [child], she can bring her favorite books... you can bring your favorite [toy]... we travel with a knapsack, so in there we have our other things. So, even the knapsack itself is something she's familiar with (P08).

Additionally, caregivers described their child's improved ability to cope with needles when the HCP and setting are familiar to them. If the clinic setting and staff are unfamiliar to the child, then caregivers recommended visiting the clinic before the procedure or arriving early on the day of to provide the child with time for familiarization.

The dentist does what they call, "happy visits..." they go in, they [healthcare providers] show the child everything without actually anything happening to the child... Like if the child was able to go in and sit down on a chair and like see everything and then come back at a later date, and say, "Okay, remember how we went and did that? And you know, nothing happened. Today we're gonna go in and actually get your bloodwork done" (P18).

While it is impossible to make all aspects of a needle procedure predictable, this subtheme indicates that there are certain practices that can help to improve autistic children's comfort by increasing their sense of familiarity, such as not avoiding needles and creating a routine.

4.2.2.3 Subtheme 3: Healthcare Providers as Facilitators of Success

HCPs were described as playing an important role in the child's comfort during needle procedures, beyond whether the child is familiar with the HCP. Prepared and well-trained HCPs were seen as facilitating successful needle procedures.

...we can prepare so much but really if they [healthcare providers] don't have their stuff together, that's where the issues are going to happen. I can prepare him, I can do all this, and if I can get there and it's a disorganized mess, if the people don't understand autism, if the people are not sympathetic... the kid will blow up... (P05).

Well-trained HCPs were said to facilitate positive experiences by answering questions and facilitating the use of coping strategies. Additionally, caregivers described the

benefit of providers being trained in and understanding of working with autistic patients. Caregivers also reported their child to be more comfortable when the HCP gets to know about the child's interests and needs and builds rapport with them.

So that the child can make a little bit of a connection with the healthcare professional because it is a stranger for him. So, if there [is] any healthcare professional talk with the child before the procedure, then it will make a good connection between them, and after that connection, then [if] the healthcare professional touch[es] the child, maybe the child may not feel that bad (P12).

Furthermore, the impact of the HCP's demeanor on the child's comfort was emphasized. Caregivers valued qualities like calmness, patience, friendliness, and sensitivity, while it was said to be unhelpful to act forceful, impatient, or frustrated towards the child. Many caregivers even mentioned their autistic child's ability to perceive the demeanor of the HCP.

I've seen like body language and people who are not patient with kids. And with my son, he's very receptive of that. He can pick up on that very quickly... like if he knows someone is being pushy, like rushing him... or being rude or not being compassionate, then yeah, he gets more upset (P09).

This subtheme provides tangible advice for HCPs about how they can promote more comfortable needle procedures for autistic children, such as by getting to know the individual child. It may also be helpful for clinics to provide staff with training in working with autistic children since caregivers highlighted that even limited training in this area could facilitate more positive experiences for their child.

...people who provide needle procedures, just them having maybe a little more training on especially the sensory issues that kids on the spectrum might have. They might not even know what like sensory processing

disorder is... Just a tad, little bit of training could help them to be more sensitive, which some already really are, but then some aren't. That can really make a difference in everyone's experience (P03).

4.2.3 Theme 3: Caregivers as Information Hubs

Caregivers described themselves as hubs of information, such that they seek and obtain information, which they pass on to their child and HCPs. To gather information, caregivers reported doing research and communicating with HCPs and other caregivers. Caregivers described the benefits of gaining information about coping strategies to support and advocate for their child. Information about what to expect for the procedure helps caregivers to prepare their child, including by discussing the procedure, answering questions, and creating and using educational resources, like Social Stories.

So, the caregivers will research the information a lot and then we'll have all that information in our brains, and then when we're going through the Social Stories, for the...child, if she asks questions, we have the answers to reassure her.

So, more information is always best because it's good for us [caregivers] to know so we can kinda prepare [child's name] as well, right? And if there's stairs or a ramp that we need to use, we can talk about that...So, I would say the best tools are more information (P08).

Caregivers also described themselves as the experts on their children. Caregivers highlighted the importance of them sharing advice about working with their child with HCPs before the procedure and the HCPs taking their lead during the procedure. Pre-communication and pre-planning between HCPs and caregivers were seen as especially important and many caregivers noted that they find it helpful to disclose their child's special needs to the HCP:

...one of us talks to the nurse and says, "he's on the spectrum, here's our history, here's his history, this is what you need to be aware of (P05).

Pre-needle communication between caregivers and HCPs also offers an opportunity for caregivers to ask questions and gather the information that they need to prepare their child. Critically, caregivers agreed that the benefit of pre-needle communication depends on how receptive the HCP is.

So, that's why I think if you don't involve parents, then you're bound to fail with autistic kids because they are all different, and they all have individualities, right?... I usually call them [clinic] beforehand. I usually email them and let them know [about child's needs]. Some listen and some don't. The ones that don't, regret not having listened, the one's that do, it's the best way (P06).

Caregivers described how when providers are receptive and responsive to collaboration with caregivers, the procedure runs smoother and more individualized care can be delivered.

...we had kind of an intake conversation of what we could prepare, what [child] dislikes, likes. That sort of thing...it saved me from having a mental breakdown about it to be quite frank. They were so great, and so wonderful, and followed up after, like on the phone. And everything that we talked about prepping, they did.

So that was big, that prep before and the personalized service, if you will, of the experience...(P16).

Caregivers clearly play key roles in gathering information and preparing their child and HCPs for a needle procedure. Caregivers indicated that they can be supported in this role by having relevant information more easily accessible to them, such as being available at clinics. This theme also supports that the preparation of

caregivers and HCPs before an autistic child's needle procedure may need to be more collaborative than may typically be necessary.

4.2.4 Theme 4: Tailoring Strategies to Child's Needs

Caregivers believed evidence-based strategies for managing needle pain and fear are helpful for their child, but noted that tailoring strategies for preparation, coping during the procedure, and exposure treatment for high needle fear to their child's needs would enhance appropriateness; these subthemes are explored below.

4.2.4.1 Subtheme 1: Tailoring of Child Preparation

Caregivers provided special considerations for preparing autistic children for needle procedures, including the benefit of offering resources in multiple formats for those who learn in different ways. The importance of offering visual-based modalities for preparing children was emphasized, such as Social Stories, videos, and visual schedules or calendars.

One strategy is that we can use the visuals, because with the autistic children, they are very visual people. So, you can show them the pictures, in the form of PECS [picture cards] before any event or incident that is going to happen in their life. So, if you show those pictures, they might understand that "this is going to happen with me," then it will create a less stress on their mind (P12).

According to caregivers, it is critical that the focus of preparation for autistic children is what to expect and why the needle procedure is important. Preparation for the sensory experiences that the child can expect to encounter should also be incorporated. Specifically, caregivers suggested preparing the child for what to expect through Social Stories, videos, and role playing.

...we would practice kind of like the "they're gonna poke you, and then they'll rub it, and then they'll put a Band-Aid on it." And going through

those steps like obviously not putting a needle, but putting the syringe against him, pushing it, so he kinda feels that pressure. And I think for most of these kids, that's pretty critical.

I think the smells, and the feelings, like the antiseptics before, like having him more clearly understand that [be]cause I was telling him that they're gonna wipe it. I probably should've gotten a cotton ball and put something wet on it. I do think that that is very helpful for these guys...like I know for him, he needs to know like step-by-step like what are you doing and why (P19).

Caregivers also reported on the timing of preparation; specifically, not beginning to prepare the child for the needle procedure too early, because this could exacerbate anxiety, or too late, because the child needs adequate time to prepare. Additionally, caregivers noted that the preparation must keep their child engaged, such as by including interactive features, technology, or their special interests. Caregivers also noted that their child would not comprehend the information if it were too advanced or abstract. Caregivers shared that their child required highly concrete, realistic, and accurate preparation, because otherwise they would not connect the preparation to their real life. For example, the pictures in visual resources and medical tools used for role play should be as true-to-reality as possible.

We give kids like play needles and syringes, but everything is in the form of a toy, and when you give it to them as a toy, and then [later] they see the real thing, there's no connection...Especially autistic kids where sometimes their imagination is not there (P10).

Furthermore, caregivers indicated that the more specific an educational resource is to their child's situation, the more effectively their child can apply the information to themselves. Consistent with this, caregivers emphasized that resources should be customizable and individualized for children's unique needs.

Give me a bank of 30 different images and let me create the Social Story because not only does he have autism, but he has this mild intellectual disability, so like there's certain pieces of information or certain language that he wouldn't understand, so there needs to be like that tailoring of the Social Story (P02).

This subtheme implies that autistic children benefit from education about what to expect, and their preparation may be more effective if it is: 1) visual-based and/or offered in multiple formats, 2) focused on what will happen and why, including sensory experiences, 3) concrete and realistic, 3) engaging, and 4) customizable and individualized.

4.2.4.2 Subtheme 2: Tailoring of Coping Strategies

Existing coping strategies for managing needle pain were generally seen as beneficial for autistic children, but caregivers suggested methods of tailoring to enhance appropriateness. Caregivers endorsed that parent presence during the needle procedure is helpful but highlighted that support from multiple caregivers may be preferable.

I personally feel like both the parents have to go because it gets extremely stressful when one person goes to handle this chaos because it gets really overwhelming... both of us have to be available to go together for this (P09).

Caregivers described topical anesthetics (TAs) as being helpful for managing their child's needle pain. Although, it was reported that the wait time for TAs to become effective and the child's sensory sensitivities can complicate the use of TAs.

So, we bought the patch for her, and we put it on her arm, and she freaked out because she didn't want something stuck to her arm... the sensory feeling of like a patch stuck to her arm, really, really disturbed her

and she wanted to rip it off all the time, right?... She really, really disliked the numbing feeling... (P06).

Many caregivers suggested that use of preparation and coping strategies as well as strategic selection of TA application method may make TAs more appropriate for autistic children. Additionally, caregivers suggested that if a breathing technique is used, then it should include a visual and interactive/guided component. Some caregivers also noted that autistic children may have unique preferences for positioning and movement during the needle procedure, such as standing or pacing, which should be accommodated.

Caregivers described distraction as a helpful coping strategy that may be most effective if it involves a sensory item, technology, or the child's special interest(s). Also, concerns were raised about the effectiveness of verbal distraction for children who communicate non-verbally and/or when the topic is not focused on the child's interests or a reward. While small talk about generic and age-appropriate topics may distract neurotypical children, caregivers urged against assuming the child's preferences and interests when trying to distract them.

Usually, if I can get him to talk about something that he enjoys, if I can start off that way, then it goes well, right? So, for the Covid vaccine, when we got in there, I already started talking to him about his favorite show, and that started the conversation with the nurse about what his favorite song was, and it went well. I did not do so well when I tried to get him the flu shot, and I let the pharmacist talk to him first. That was a mistake... they [pharmacist] talked to him about things that he doesn't care about, and that makes him go back to the needle. Like he's thinking about the needle, right? (P01).

Additionally, contingent access to a reward, such as a preferred item or quality time, was commonly mentioned as a strategy that caregivers use to facilitate the

success of their child's needle procedure. Overall, this subtheme indicates that caregivers perceive evidence-based coping strategies to be helpful for their autistic children, including distraction and TAs. However, caregivers and HCPs should consider how standard practices can be tailored to individual children's needs, such as tailoring distraction to the child's interests and preparing the child for using TAs if they have sensory sensitivities.

4.2.4.3 Subtheme 3: Tailoring of Exposure Treatment

Caregivers generally reported believing that exposure treatment would be beneficial for reducing their child's high needle fear. Additionally, caregivers tended to describe themselves as good candidates for guiding exposure treatment because they know their child best, are familiar to the child, could take their time, and could apply the practice exposure to the real needle procedure.

I think we know our kids, like I know my kid, I know what's going to make her tick, I know what's going to set her off... and I'm a familiar person, so it's better for me to do it, then to have someone else do it because I know her. There's just that comfort in that knowledge. And I would be the one going to that appointment with her anyways. So, then I would be walking through all of these steps on the day of, like "oh yeah, we rocked this before," "we did this before, remember that?" "we did that" (P04).

However, some caregivers highlighted that they would want support from a professional and/or that caregiver level of education may be a barrier to leading exposure treatment. Additionally, some caregivers mentioned that they do not have the time or energy to invest in guiding exposure treatment and that distractions at home may get in the way of administration. On the other hand, caregivers highlighted ways that they could be supported in guiding casual role-play exposure and exposure treatment for their child, such as being given a written guidance, examples of exposure hierarchies, and advice on handling potential problems.

I want to know troubleshooting. What to do if you ran into a problem with one of the steps, what to do if you found it was actually increasing their anxiety? I guess I would want some resources for the “what if’s” not so much the carrying it out. Because I think once we had all the steps, like properly outlined or decided what those steps are, I think that would be fairly straight-forward to do. It would be more just like, “okay well we did this and now she reacted this way, so now what do I do?” (P04).

It was also commonly suggested to utilize existing support workers for exposure treatment and to provide caregivers with an exposure ‘toolkit’ with needle-related materials.

If they had mailed me a kit: here’s a Social Story, or here’s 30 images, create your own Social Story, here is a Band-aid, an alcohol swab, a cotton ball, and here’s a real needle. And maybe instead of like the metal needle, maybe there’s a piece of plastic to show the size of what the needle is because some are thicker than others. Like here’s the exact objects that are going to be used. All of that would be so helpful rather than me having to run around to a pharmacy to try and find it (P02).

Caregivers were concerned that their child would refuse to engage with and/or have a negative reaction to exposure treatment, such as exhibiting externalizing behavior. Administering rewards was suggested as a potential solution to a child’s reluctance to engage with exposure.

I think in general reinforcers are really good to help with certain things because in general autistic children are a little bit like, what’s the point? What’s in it for me? Kind of very straightforward and they don’t see that what’s in it for you is you actually reduce your fear and it’ll help you for the rest of your life kind of thing. That’s too abstract. They don’t understand it.

So, it's easier to motivate them with something tangible in the moment, that's easy to obtain, you know? (P17).

Additionally, caregivers indicated that exposure treatment should be individualized for each child, including the exposure steps and pace of treatment. Consistent with this finding, caregivers suggested using visual tools that are specific to the child to facilitate their participation, such as tracking progress on a visual map. Therefore, strategies like incorporating the caregiver in administration, individualizing the treatment, using visuals, and administering rewards could enhance the appropriateness of exposure treatment for needle fear in autistic children.

4.3 Caregiver Helpfulness Ratings

The following ratings were gathered to supplement the qualitative results presented above. Consistent with the qualitative results, caregiver ratings of the helpfulness of preparation strategies (see Figure 1) reflect the utility of visual-based preparation, including via video modelling and visual tools. In contrast, most caregivers rated written resources as not helpful for their child and web-based resources to be somewhat helpful. Also consistent with qualitative results, ratings support the usefulness of caregivers learning about coping strategies, and while caregivers generally endorsed the helpfulness of their child learning about coping strategies, the value of children learning about what will happen and receiving sensory-related information and exposure was more strongly emphasized by the ratings.

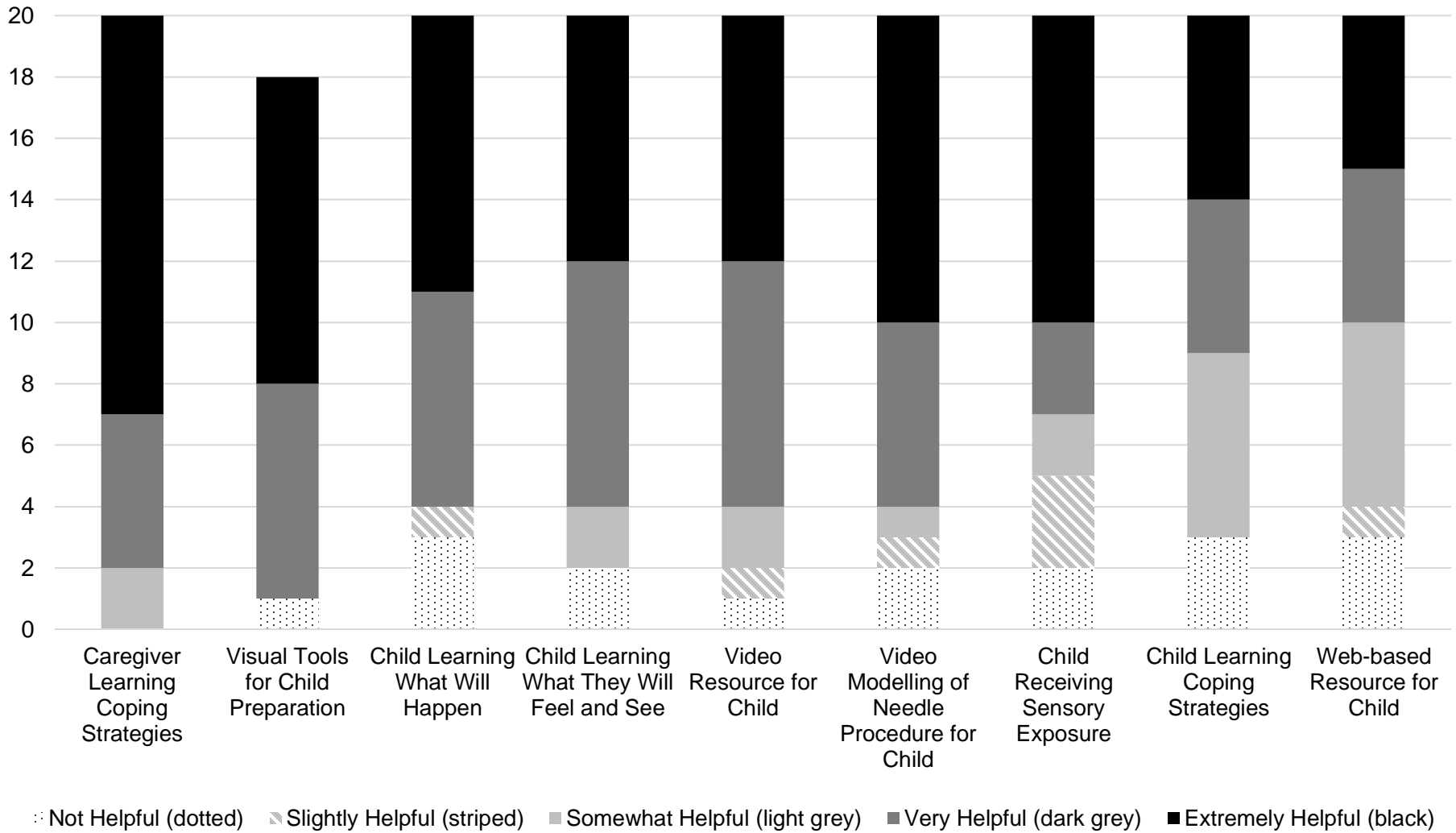


Figure 1. Caregiver Ratings of the Helpfulness of Preparation Strategies (ordered from left to right by most to least frequently endorsed as “very/extremely” helpful).

Note. Two caregivers were not asked to rate the helpfulness of preparation via visual tools because they reported that their child does not use visual tools.

Consistent with the qualitative results, caregiver ratings of the helpfulness of coping strategies (see Figure 2) support that many of the strategies from CPGs are perceived as helpful for autistic children, including distraction, topical anesthetics, sitting upright, and having a caregiver present. Although, caregivers generally indicated that a verbal signal of impending procedure, breathing techniques, and verbal distraction are not helpful. Considering the qualitative results, these strategies may require tailoring to be appropriate for autistic children, such as verbal distraction being tailored to the child's interests. Caregivers endorsed giving children more control by making choices as extremely helpful, which is consistent with the theme about child autonomy. Ratings were also consistent with the qualitative advice from caregivers to provide rewards for exposure treatment and after a needle procedure. Finally, dimmer lightening and quieter environments were primarily endorsed as being extremely helpful, aligning with the subtheme about the impact of the environment on children's comfort.

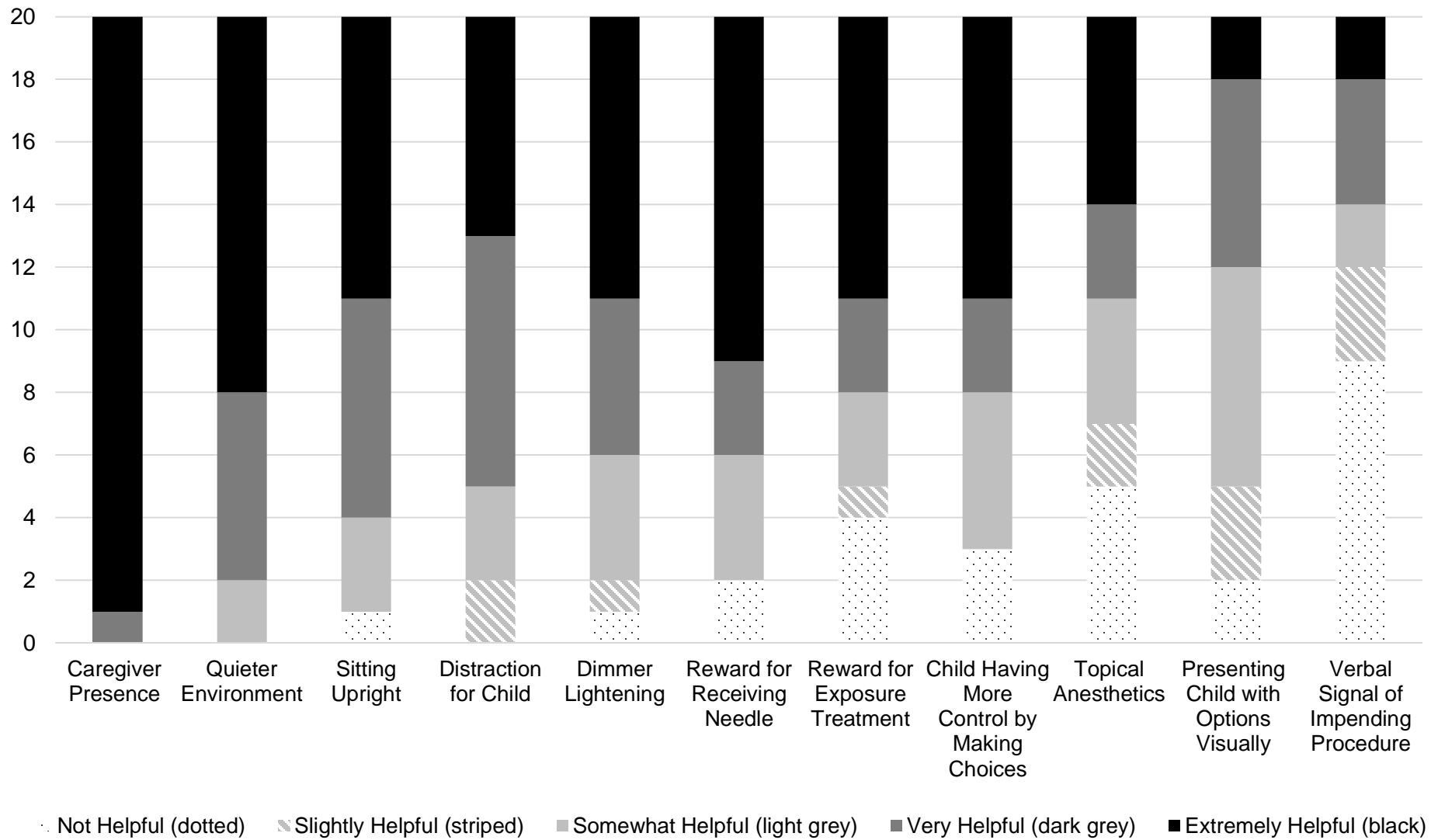


Figure 2. Caregiver Ratings of the Helpfulness of Coping Strategies and Rewards (ordered from left to right by most to least frequently endorsed as "very/extremely" helpful).

5 Discussion

This study sought to explore caregiver perspectives on how needle procedures can be made more comfortable and CPGs more appropriate, actionable, and accessible for them and their autistic child. Table 2 presents potential solutions for needle-related challenges that may be faced by autistic children and their caregivers. The references in Table 2 represent previous literature that aligns with the recommendation provided based on the present findings. Table 2 is followed by a discussion of how the themes created align with extant literature and together, indicate the need for a patient-centered and individualized approach to care.

Table 2. Summary of Needle-related Challenges and Potential Solutions

<p>Feeling lack of control and/or agency</p> <ol style="list-style-type: none">1. Caregivers should involve child in decisions and offer choices (Freedman et al., 2019).2. HCPs should provide child with information and speak to them directly (<i>Taghizadeh et al. 2019</i>).3. Caregivers should be honest with child and avoid false suggestion (Taddio et al., 2015).4. HCPs and caregivers should respect child's choices and feelings, including not forcing or ambushing them with the needle (Taddio et al., 2015; <i>Salvatore et al., 2021</i>).
<hr/> <p>Distressing medical environment</p> <ol style="list-style-type: none">1. HCPs/clinics should adapt the medical environment to meet child's needs, such as offering dimmer lighting or a quiet room away from crowds (<i>Davignon et al., 2014</i>; <i>Muskat et al., 2015</i>; <i>Salvatore et al., 2021</i>; <i>Taghizadeh et al. 2019</i>; <i>Wilson & Peterson, 2018</i>).2. Caregivers can encourage child to adaptively cope with sensory input, such as via distraction, self-stimulating behaviors, or use of special equipment like noise-cancelling headphones.3. HCPs/clinics should offer child privacy (Gold et al., 2020; McMurtry, 2020).4. HCPs/clinics should offer families sensory-friendly and accessible spaces (<i>Taghizadeh et al. 2019</i>).
<hr/> <p>Challenges with timing</p> <ol style="list-style-type: none">1. HCPs/clinics should allow appointments to avoid prolonged standing, delays, wait times, waiting rooms, etc. (<i>Davignon et al., 2014</i>; Gold et al., 2020; McMurtry, 2020; <i>Muskat et al., 2015</i>; <i>Taghizadeh et al. 2019</i>).2. HCPs/clinics should accommodate extra time to avoid rushing families (<i>Davignon et al., 2014</i>; <i>Muskat et al., 2015</i>; <i>Taghizadeh et al. 2019</i>).

Challenges with unfamiliarity, unpredictability, and/or diversion from routine

1. When possible, caregivers should select a familiar clinic with familiar HCPs (*Johnson et al., 2014*).
2. HCPs/clinics should allow families to have a ‘happy visit’ to introduce the child to an unfamiliar clinic and staff prior to their needle procedure (**Kupzyk et al., 2019*).
3. HCPs/clinics should allow families to arrive early for familiarization on procedure day.
4. Caregivers should create a ‘needle procedure routine’ with which the child can become familiar.
5. Caregivers should facilitate bringing familiar items from home and people to support the child (*Johnson et al., 2014*; **Kupzyk et al., 2019*).
6. Caregivers can remind child of routine restoration and return to regular routine as soon as possible.

Difficulties with healthcare providers (HCPs)

1. HCPs should be knowledgeable about conducting the needle procedure and coping strategies (**Taddio et al., 2015**).
2. HCPs should have training/experience in working with autistic children (*Bultas, 2012*; *Davignon et al., 2014*; **Kupzyk et al., 2019*; *Muskat et al., 2015*; *Salvatore et al., 2021*; *Taghizadeh et al. 2019*; *Wilson & Peterson, 2018*). Caregivers may wish to seek clinics with staff who have such training.
3. HCPs should exhibit sensitivity, understanding, patience, and friendliness (*Muskat et al., 2015*; *Taghizadeh et al. 2019*).
4. HCPs should not exhibit annoyance, frustration, or force towards the child.
5. HCPs should build rapport and trust with the child (**McMurtry, 2020**).

Child requiring individualized care

1. HCPs and caregivers should communicate/collaborate in advance to plan for needle procedure and discuss child’s individual needs (*Davignon et al., 2014*; *Johnson et al., 2014*; **McMurtry, 2020**; *Taghizadeh et al., 2015*; *Taghizadeh et al., 2019*).
2. HCPs and clinics should be flexible/open to accommodating the needs autistic patients and modifying standard practices (*Muskat et al., 2015*; *Salvatore et al., 2021*; *Taghizadeh et al. 2019*).
3. Caregivers should have access to customizable and individualized educational resources.
4. Educational resources should be offered in various formats/modalities (*Boada & Parellada, 2017*).

Caregiver burdened with preparing others

1. HCPs should be receptive to collaboration with caregivers and treat caregivers as the expert on their child (*Bultas, 2012*; *Muskat et al., 2015*; *Taghizadeh et al. 2015*; *Wilson & Peterson, 2018*).
2. HCPs should assist caregivers in gathering information about coping strategies (**Taddio et al., 2015**) and what to expect, so that they can prepare their child for the procedure (*Davignon et al., 2014*).

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3. HCPs should take the caregiver's lead during the needle procedure, such as following how to interact with the child (*Salvatore et al., 2021*).
 4. Educational resources and information should be accessible and easily digestible for caregivers.
-

Child has unique preparation needs

1. Caregivers should use visual-based methods of preparing their child for the procedure, including videos, Social Stories, and visual calendars/schedules (*Boada & Parellada, 2017; Daly et al., 2010; Johnson et al., 2014; Muskat et al., 2015; Taghizadeh et al. 2019*).
 2. Caregivers should focus child preparation on what will happen and why (**Cohen, 2008**; *Jaaniste et al., 2007).
 3. Caregivers should involve preparing for sensory experiences into child preparation, such as role-playing wiping the arm with an alcohol swab.
 4. Educational resources and information should be concrete, realistic, and specific to the child.
 5. Educational resources and information should be engaging, such as involving an interactive component, technology, and/or the child's special interests.
 6. Caregivers should not introduce preparation too early, since this could increase anxiety, but also not too late, which may not allow for sufficient processing time for the child (**Cohen, 2008**).
-

Child requiring extra support

1. HCPs/clinics should allow the child to have multiple caregivers attend the needle procedure with them (*Taghizadeh et al., 2019*) and/or support workers.
-

Breathing techniques not being effective

1. HCPs and caregivers can make the breathing interactive, visual, and/or guided.
-

Child has unique distraction needs

1. Caregivers and HCPs should avoid verbal distraction unless it is about child's interests or reward(s).
 2. Child may benefit most from a distractor that is a sensory item, specific to their special interests(s), and/or involves technology (*Johnson et al., 2014; Taghizadeh et al., 2015; Taghizadeh et al., 2019*).
-

Challenges related to topical anesthetics (TAs)

1. Caregiver should prepare the child before use of TAs, such as by exposing them to the products (*Grider et al., 2012; Slifer et al., 2011*).
2. Caregivers should facilitate coping strategies, such as distraction, while applying TAs.
3. Caregivers and HCPs can strategically select the TA application method depending on the child's preferences (e.g., patch vs. cream/gel) and seek faster-acting options.
4. Caregivers can refer to TAs as something familiar to the child, such as calling the patch a Band-aid.
5. TAs may not be appropriate if the child has severe sensory aversion to topicals and is not highly concerned about the pain.

Reluctance to undergo needle procedure and/or needle-related exposures

1. Caregiver or HCP can provide reward(s) after the needle procedure and/or for progress towards the needle (**Cohen, 2008**; *Johnson et al., 2014*; *Salvatore et al., 2021*; *Wilson & Peterson, 2018*).
2. Caregiver or HCP can provide reward(s) for engaging in casual exposure to needle-related stimuli and/or for progressing through steps of exposure treatment (*Davit et al., 2011*; *Grider et al., 2021*; **Kupzyk et al., 2019*; *Shabani & Fisher, 2006*; **Slifer et al., 2011**; *Wolff & Symons, 2013*).
3. Caregiver or HCP can use visuals to track and celebrate child's progress towards goal.

Challenges with exposure treatment

1. Incorporate visuals into exposure treatment, such as a token board and visual schedules to track rewards and progress (*Burton et al., 2017*; *Ollendick et al., 2020*).
2. Autistic children may be most comfortable with exposures occurring at home and with their caregivers guiding the exposures (*Ollendick et al., 2020*; *Davit et al., 2011*).
3. Caregivers may have challenges locating materials for exposures, so a 'tool kit' of items should be made accessible to families.
4. Caregivers may not be familiar with guiding exposures, so they should be provided with a how-to-guide, ideas for problem-solving, and guidance from a professional.

Note. **Bolded** references = needle-specific, but not autism-specific (e.g., general to pediatric or developmental disabilities). *Italicized* references = autism-specific, but not needle-specific (e.g., general to medical or hospital visits). Underlined references are autism-specific and needle-specific. References with a * are neither autism-specific (e.g., general to developmental disabilities) nor needle-specific (e.g., general to medical or dental procedures).

Taken together, the present results underscore that caregivers and their autistic children require a patient-centered and individualized approach to be taken for needle procedures to be comfortable and CPGs to be appropriate for them. Caregivers in this study emphasized that individualization of educational information is required to meet their child's needs, which applies to the use of recommendations from this study, which will not apply in the same way for all autistic children. According to caregivers, each autistic child has unique preparation needs, meaning that resources will be most appropriate if the content and format is customizable. Another way that caregivers suggested individualizing autistic children's needle procedure care was accommodating the environment to meet their sensory needs. Similarly, environmental accommodations

have been reported to be important by caregivers and HCPs in the context of autistic children's hospitalizations and medical care more generally (Davignon et al., 2014; Muskat et al., 2015; Salvatore et al., 2021; Taghizadeh et al. 2019; Wilson & Peterson, 2018).

Autistic children were also reported to benefit from individualized strategies to increase their sense of familiarity and routine in relation to needle procedures, such as bringing familiar comfort items from home. Similarly, unpredictability has been noted as a challenge by caregivers in relation to autistic children's hospital care (Johnson et al., 2014; Muskat et al., 2015). A suggestion from caregivers that aligns with the patient-centered care model is giving the child agency and control related to the needle procedure. Consistent with this finding, children have reported benefitting from having more control over their vaccination experience by making choices (Freedman et al., 2019). Making needle procedures more predictable for autistic children may subsequently increase their sense of control because they know what to expect.

Individualization and a patient-centered approach also appears to be critical for preparation, coping strategies, and exposure treatment to be appropriate for autistic children. Caregivers indicated that preparation before an autistic child's needle procedure should involve communication between caregivers and HCPs about the child's needs, which facilitates the HCP in providing more individualized care. Research on the hospital/surgical care experiences of autistic children has similarly emphasized the importance of proactive communication between HCPs and caregivers (Davignon et al., 2014; Johnson et al., 2014; Taghizadeh et al., 2015; Taghizadeh et al., 2019). Child education was also recommended by caregivers to focus on what to expect, which relates to the finding that predictability is important for autistic children.

While caregivers tended to indicate that the strategies from CPGs (McMurtry et al., 2016; Taddio et al., 2015) are helpful for their child, tailoring of coping strategies and exposure treatment was suggested to better meet the needs of autistic children. For example, verbal distraction may not be effective for an autistic child unless it is tailored

to their interests. Furthermore, caregivers highlighted how intervention for high needle fear should be individualized, such as by tailoring the exposures and pacing to the child's needs and using visual tools that the child is familiar with to facilitate their participation.

6 Strengths, Limitations and Future Directions

This study is the first to explore caregiver perspectives on how existing CPGs for managing needle pain and fear can be made more actionable for autistic children and their caregivers. Caregivers provided a plethora of ways that needle procedures can be more comfortable for them and their autistic children. The results can contribute to the tailoring of CPGs for managing needle pain and fear to better meet the needs of autistic children and their caregivers, which should be a future research avenue.

The recommendations provided above should be interpreted with caution given that the results reflect the perspectives of a single sample of Canadian caregivers. The sample's generalizability is also limited by caregivers primarily being of White/European descent and living in Ontario. While caregiver perceptions of the helpfulness of CPG strategies for their child were obtained, this study cannot speak to the objective effectiveness of the CPGs for autistic children. Given autistic children's increased risk of having difficulty undergoing needle procedures, examining the effectiveness of coping strategies for this population is an important step for future research. A multi-method approach is recommended, including self- and parent-report of child pain and fear, behavioral observation, and qualitative approaches.

7 Conclusion

While strategies from CPGs for managing needle pain and fear were generally endorsed as being helpful for autistic children by their caregivers, the present results support that patient-centered and individualized care is critical for autistic children when it comes to needle procedures. There are special considerations for promoting the comfort of autistic children during needle procedures, such as the impact of the

environment, and tailoring is required for preparation, coping strategies, and exposure treatment to meet the needs of autistic children. This study provides practical recommendations for HCPs and caregivers to help autistic children overcome the challenges that they may face in relation to needle procedures and improve their outcomes and experience. The recommendations from this study also likely apply more generally to minimizing needle-related pain, fear, and stress-related responses, particularly for individuals with high needle fear (Gold et al., 2020; McMurtry et al., 2016; Taddio et al., 2015). For example, communication and planning with staff prior to a needle procedure would likely be helpful for any patient who is highly fearful of needles, even if they are non-autistic. As well, medical environments, like mass vaccine clinics, can be distressing for anyone and it is generally considered best practice for the environment of needle procedures to avoid potential stressors like lack of privacy, crowds, and prolonged wait times (Gold et al., 2020; McMurtry, 2020; Taddio et al., 2021). Furthermore, the findings from this study may apply to treating non-autistic children who have similar special needs, such as social-communication and sensory challenges.

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APPENDICES

Appendix A. Example Needle-fear Exposure Hierarchy

Step	Exposure	Fear Rating /100
1	Looking at a picture book about needles	10
2	Sitting in the clinic waiting room	15
3	Playing with toy needle procedure equipment (e.g., toy syringe, bandages)	25
4	Giving a doll or stuffed animal a needle	30
5	Looking at real pictures of needles	40
6	Watching an adult hold a real needle	50
7	Holding a real needle in their hand	60
8	Watching a video of someone else getting a needle	75
9	Rehearsing all steps of a needle procedure, except insertion	80
10	Allowing someone to touch, but not insert, a needle to the skin on their arm	90
11	Receiving a real needle injection	100

Note. Example of a needle-fear exposure hierarchy for a child with high needle fear (0 rating = no fear; 100 rating = most fear possible).

Appendix B. Brief description of steps of Reflexive Thematic Analysis

Steps	Description
Familiarization with the data	Reading and listening to the interviews several times to familiarize myself with the content. Re-reading transcripts and actively searching for content related to the research question.
Generating initial codes	Systematically searching through interview transcripts for data related to the research question. Relevant excerpts from the interviews are extracted and assigned a code label to simplify the meaning of the excerpt. The codebook was revised several times before moving on to the themes stage.
Developing themes	Themes are developed inductively from the coded data by identifying collections of codes that cluster together around a pattern of shared meaning. Themes represent recurrent ideas from across interviews that are related to the research question.
Reviewing themes	Themes are reviewed, revised, and refined through returning to raw and coded data to verify that the themes represent coherent patterns from the data.
Defining and naming themes	The final set of themes are defined (i.e., what the themes represents and why it is relevant) and assigned names.
Producing the report	The themes are presented in a written report.

Note. From Braun & Clarke, 2006.

Appendix C. Data Security and Organization

Interviews took place on Microsoft Teams and the meeting settings were tailored to maximize privacy. The PR and research assistant were located in a secure and private room for all interviews. All interviews were recorded and after each interview, the recordings were automatically sent to the Microsoft Teams OneDrive, which only the PR could access. The same day as the interview, the PR transferred recordings from the OneDrive to the encrypted and password-protected electronic server housed by the University of Guelph and permanently deleted the recordings from the OneDrive. All study data was saved to this server, which is only accessible to personnel in the PR's research Lab, including the director, graduate students, and select undergraduate students. Research assistants in the PR's Lab transcribed the interviews verbatim and the recordings were deleted from the server once the transcriptions were completed and checked for accuracy. Identifiable data, including the recordings, master list with participant contact information, and documents tracking consent and incentives, were further protected by restricting access to the folders containing these documents to only the PR, Lab director, and research assistants involved in transcribing. Completed transcripts were uploaded to NVivo software that was hosted on the PR's Lab server.