**Introduction:**

This presentation is titled: Let’s Listen: What do Caregivers Have to say About Reducing Their Autistic Child’s Needle Fear and Pain?

I'd like to thank the Autism Scholars Award for supporting this research as well as the Pediatric Pain Health and Communication Lab directed by my supervisor Dr. Meghan McMurtry.

My name is Olivia, and my presentation will focus on needle fear and pain in the Autism population. This topic may be distressing to some, so please disengage as needed and as a reminder, you can use your personal space as needed during my presentation.

The visual elements in my presentation are mostly for aesthetic purposes, rather than being critical to understanding. You can find my presentation and script through the conference Website, including ALT text for any visuals used.

Please email me at odobson@uoguelph.ca if you have any follow-up questions or comments.

**Background:**

First, I will introduce needle pain and fear.

As we know, needle procedures like vaccines and blood draws are critical to maintaining health and all children deserve accessible and comfortable healthcare.

For most children, needle procedures are associated with fear and pain (McMurtry et al., 2015).

Children labelled with Intellectual and Developmental Disabilities may be at particular risk because their pain is often ineffectively managed (Knoll et al., 2013). Non-adherence with (Slifer et al., 2011) and poor uptake of needle procedures, compared to neurotypical population (O’Neill et al., 2019) is also common in youth with developmental disabilities.

So why are needles difficult for Autistic youth in particular?

1. Specific phobias, which involve extreme fear and anxiety, are prevalent in the Autism population and in particular, medical-related fears and phobias are common (Evans et al., 2005; Leyfer et al., 2006).

2. Sensory sensitivities and

3. Communication challenges can make tolerating needle procedures more difficult (Taghizadeh et al. 2015; Slifer et al., 2011; Liu, 2020).

4. Needle procedures often involve unfamiliar people, equipment, and environments, which may be difficult for Autistic youth who often have a need for routine and predictability (Boada & Parellada, 2017; Slifer et al., 2011).

5. Many healthcare professionals are not familiar with Autism, which can lead to sub-optimal care (Liu, 2020) and many people may hold the misconception that Autism is associated with hyposensitivity or indifference to pain (Moore, 2015).

6. Finally, compared to the neurotypical population, the pain of Autistic individuals may be expressed behaviorally or facially rather than verbally, which can lead to poor management of their pain (Messmer et al., 2008). It is also common for Autistic youth to externalize their pain and fear, such as by kicking or fleeing (Evans et al., 2005; Shabani & Fisher, 2006; Wolff & Symons, 2013) and such behaviors may be poorly managed through strategies like restraint or sedation (Braff & Nealon, 1979), which can exacerbate pain and fear and can be traumatic (Shabani & Fisher, 2006; Slifer et al., 2011).

Additionally, unmanaged needle pain and fear can lead to both short and long-term consequences. There is a good evidence base for the neurotypical population, which has led to clinical practice guidelines for managing needle pain (Taddio et al., 2015) and high levels of fear (McMurtry et al., 2016). What we don’t know is what caregivers and their Autistic child experience during needles and whether our existing practices and resources are actionable for them (Davit et al., 2011).

That brings me to the objective of this study, which is to begin to address the gaps in the literature, by identifying what caregivers and their Autistic children need to have comfortable and accessible needle procedures.

**Sample and Method:**

We chose the method and sample with this objective in mind.

The procedure involved me conducting virtual and semi-structured interviews with 20 Canadian primary caregivers of Autistic youth. Interviews were transcribed verbatim and then analyzed by me.

We chose to speak with caregivers as an initial needs assessment since caregivers are not only an informative source about their child’s needs, but also play a key role in supporting their child through painful procedures and as a liaison between their child and clinicians. In terms of the 20 caregivers who made up our sample, 2 fathers and 18 mothers were included, most of whom were from Ontario (15 from Ontario) and there was one from Quebec, one from New Brunswick and one from Nova Scotia. Caregiver age was 41 years on average.

The children who were being discussed had an average age of 10 years and ranged from 4 to 17 years old.

Most children were said to communicate verbally (14 participants in total), but one quarter (4 participants in total) communicate solely non-verbally and two of the children who use verbal communication lose this ability when anxious.

Most were males (14 males and 6 females) with a high level of needle fear as assessed by a fear rating out of 10 and several follow up questions. Specifically, 18 had high needle fear, one had moderately high needle fear and one had low levels of needle fear. The average needle fear rating out of 10 where 10 is the most possible fear was 8 out of 10.

Most (12 out of 20 children) were of a White-European ethnic background, but there was also representation of Asian, Caribbean, Indigenous, and Black, backgrounds.

**Data Analysis:**

How did we analyze the open-ended interview responses?

Thematic Analysis was used as a method for identifying, analyzing, and reporting themes AKA patterns within data (Braun & Clarke, 2006; Morse & Field, 2005).

Given the dearth of research on this topic as well as the exploratory nature of the work, **no specific hypotheses** were developed regarding participant perspectives. Therefore, I took an inductive, meaning data-driven, approach to analyzing the data. I also used a reflexive approach where I, the researcher, was self-questioning and reflecting by using a reflexive journal throughout the process.

I followed Braun and Clarke’s steps for Thematic Analysis (2006), referencing their up-to-date guide (2022).

The process involves **1. Familiarization with the data** by reading and re-reading interview transcripts, **2. Coding** by systematically reviewing and sorting the data, then assigning important pieces of data with a code label; this involves one coder and is subjective and I used semantic/explicit coding, which stays close to the data, and **3.** Lastly, I searched for **themes** across the codes by clustering codes into patterns of shared meaning.

Analysis began around January of 2022 and Thematic Analysis is a lengthy process involving reflexivity and ongoing refinement of themes before finalizing analysis. I am currently still searching for and refining existing themes.

**Findings:**

So, let’s discuss some findings!

There are three sub-themes that fit under the overarching theme called, **“Generic Doesn’t Cut It.”** There was a pattern of caregivers expressing that the generic or mainstream way of doing things is not inclusive of Autistic children, including 1. generic resources, 2. medical environments, and 3. coping strategies.

This is the first sub-theme, which is a pattern of caregivers expressing that educational and preparation resources are not a “one size fits all.” Existing resources were said to be geared towards the mainstream neurotypical audience, while lacking consideration of special needs.

Some examples of codes that were clustered under this theme are:

* The need for social stories and visual options.
* The need to consider sensory concerns.
* The need for more detailed information about what to expect since Autistic children often need extensive preparation for a new experience.
* Also, the need for customizable resources and resources in multiple formats/modalities for people learn in different ways.
* And since generic resources don’t always meet their child’s needs, caregivers also said they do their own research and create their own resources.

Looking at some quotes that exemplify this theme, one parent said: “Most of the needle information that I have received applies to neurotypical situations, right, so like kids that are not Autistic” … “you almost read that and it’s like, “Ha ha,” tried that, been there, that’s not going to work, right?”… “You know it fits the majority, but it’s not- there’s really nothing that’s actually geared towards the audience that matters to me.”

Another said: “There’s no touching on routine, keeping it the same. I didn’t see agency either…to be honest I noticed that it just didn’t seem to have like a disability lens.”

“We also use social stories…and in a lot of the documentation that I read, that you sent me…I don’t believe social stories were actually mentioned.”

The second sub-theme is caregivers expressing that mainstream hospitals and mass vaccine clinics are not Autism friendly. This theme is called Medical Environments are not Autism-friendly.

Some example codes under this theme are things like:

* The typical cold medicalized environment.
* Large, crowded venues.
* Not allowing appointments and having wait times, waiting rooms, and lineups.
* The typical time slots allotted also may be an issue if the child needs extra time.
* Further, all the sensory aspects of the environment like the typical antiseptic-y smell of hospitals, florescent/bright lights, and loud noises such as babies crying, can be disturbing.

These things may not be a big deal for most children but can add to fear and anxiety for Autistic children.

The third sub-theme is that generic coping strategies for managing needle pain and fear may need accommodations to be appropriate for Autistic children. This theme is called, “Coping Strategies may Need Accommodations.”

Codes about several practices/strategies were clustered together as the strategies were said to require special considerations:

* For example, sensory sensitivities and waiting for it to work can make topical anesthetics more challenging for Autistic youth.
* Concerns with using breathing were also noted, such as the child not understanding the technique and/or needing a visual component.
* And while distraction and rewards were said to be generally helpful, generic ways of using these strategies may not cut it. Caregivers urged not assuming that their child has the same interests and preferences as other NT children their age when trying to distract or reward them.
* Caregiver presence is already a recommended strategy, but Autistic children seem to benefit from greater support with multiple caregivers present and working together and with the providers.

In relation to the strategy of distraction, one parent said: **“**I’ve had that happen where someone tries to distract him, like “oh look it’s spider man”, and I’m like, “yeah, like we don’t watch that.”

And in relation to using topical anesthetics, this parent said: “like if we have to get there early and now he’s got to wait, he doesn’t do well with waiting.”

Similarly, a parent said: **“**Every other kid is gonna want you know, like a little gift, or little sticker or whatever, he’s not interested.” And they also shared this quote: “I think there’s something a lot of providers have to stop doing in general is to ask Autistic kids about school and their friends from school because sometimes they don’t have friends at school…”

Another theme was identified based on caregivers expressing that the reason that needle procedures are so difficult for their child is about **more than the needle poke and pain itself.**

For example, children’s fear also comes from things in the environment, sensory concerns, uncertainty and fear of the unknown, and getting out of their routine. Interestingly, many caregivers highlighted that the ***pain*** is not the biggest concern that their child has.

One parent said: “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.”

Another parent said: “Maybe he’s kinda okay, but then you arrive and there a lot of other circumstances that for other kids is normal, but it can set him up to be like…his levels of stress are going to be higher. Like if there’s too many people, people are talking too much, or noise, or sometimes you go to the clinic and there’s babies crying, so all this- these things are…kind of setting the mood for him to get his stress levels higher and higher.”

Moving on to a new theme. Caregivers also highlighted various concepts that centralize around the theme of **treating the child as an autonomous individual**. By autonomous, we mean having the freedom to govern yourself and control your own affairs. Examples of codes that were clustered together to form this theme include things like listening to the child, respecting their agency, being honest them with the needle or proceeding if they’re showing extreme signs of distress, giving them information about their health, not ambushing them, and offering them with choices/including them in decisions related to the procedure.

Highlighting this theme, a parent said: “Agency is huge… For instance like, “Do you want to sit in this chair? Or do you want to sit in that chair?” Or like, “Do you want to sit on dad or mum’s lap?” Or whatever the case, just giving her as much choice and agency every step of the way.”

Another participant said: “…it could take away some of the anxiety over what’s happening to give him that kind of, "my choice" attitude.”

As an example of respecting the child’s wishes, here is a quote from someone else: “The nurse who was administering the needle said, “Do you want me to just go ahead and do it?” and I was like, “No.” Like, she wanted to just disregard, you know, what my daughter was- how she was acting and feeling and I was like, “No, no, we’ll come back and do this another time.” There was no way I was gonna let her do that, just like, give her the needle and whatever.”

Finally, I will share this quote that highlights the importance of giving the child information about the procedure just like you would for any neurotypical individual: “She is fantastic, and when you get there, she explains things to him, not like he is just a silly little boy, you know? Like she explains things like, “So, this is going to happen like this, and that,” and “once you get it done” and I think for him, it’s very important to kind of have the information of what’s going on.”

**Implications:**

Today, we discussed three themes that were identified from the interviews and these findings have several implications.

The themes reveal important ways that generic practices are just not cutting it for families with children who have special needs.

It is already known that adjustments to service delivery can create more equitable access to healthcare (Edwards & Northway, 2011). And consistent with the present findings, previous research has documented useful adjustments such as increased parental involvement, control given to the Autistic child, incorporating special interests, and environmental accommodations, when treating Autistic patients (Moree & Davis, 2010; Ollendick et al., 2020).

 This image shows a doctor's office from Columbia Memorial Health that has clouds painted on the walls and a blanket and an iPad ready sitting on the medical chair. The room is friendly and welcoming. 


Above are two images of Autism-friendly medical environments that exemplify thinking outside of the box to meet children’s needs.

From this study, we have a better understanding of the additional factors that we should be considering in order to make needle procedures more accessible to Autistic children, such as offering them choices, preparing them with individualized resources, and trying to reduce environmental stressors as much as possible.

As for conclusions and future directions, 1. these parent perspectives are important to hear, 2. there is a clear avenue for future research to examine the effectiveness of strategies for reducing needle fear and pain in the Autistic population, and 3. another future direction, which is likely to be the avenue for my research, is developing resources that can be individualized and better meet the needs of Autistic children and their parents.

Ultimately, these findings can contribute to improving needle procedures for children with Autism, which is a critical issue both during and after a global pandemic.

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Thanks for listening! Any questions? You can email me with questions and comments at this email address odobson@uoguelph.ca