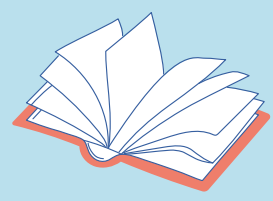


Caregiver Perspectives on Making Needle Procedures Comfortable for Autistic¹ Children

BACKGROUND:

- Needle procedures, like vaccines, are critical to our health and can be especially challenging for autistic children
- Clinical practice guidelines (CPGs) are available for managing children's needle pain and fear, but these guidelines and associated strategies may not meet the needs of autistic children



GOAL OF THIS STUDY:

To gather caregiver perspectives on what is needed for needle procedures to be comfortable and CPGs to be appropriate and actionable for them and their autistic child.

PARTICIPANTS:

- 20 caregivers (18 mothers, 2 fathers) of autistic children aged 4 to 18 years old
- 18/20 caregivers reported their autistic child has high needle fear



PROCEDURE:

- Virtual, individual interviews
- Discussed strategies from CPGs
- Interviews were analyzed using thematic analysis - a way to describe themes in what caregivers say

THEMES FROM INTERVIEWS

Treat the Child as an Autonomous Individual

- ✓ It is important to listen to autistic children and speak to them directly
- ✓ Involve them in decisions/offer choices and respect their choices
- ✓ Provide them with honest information

"I knew that the more agency, or like more control, she had over what she could control, the better it would be for getting the needle (P4)."

It's More Than the Poke and Pain

3 Subthemes

1. Environment is Everything
 - E.g., noise, patient flow through clinic
2. Familiarity and Predictability Matter
 - E.g., fear of unknown people and environment, bring familiar items
3. Healthcare Providers as Facilitators of Success
 - E.g., helpful to be patient and trained in working with autistic children

"...half his pain is associated with the fear of the unknown and not being in control, and 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 (P3)."

Tailoring Strategies to Child's Needs

3 Subthemes

1. Tailoring of Child Preparation
 - E.g., visual resources, prepare for what to expect, prepare well in advance
2. Tailoring of Coping Strategies
 - E.g., accommodate for sensory needs, distract using child's specific interests
3. Tailoring of Exposure Treatment
 - E.g., involve caregivers, use rewards

"...you almost read that and it's like, 'haha, 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 (P6)."

Caregivers as Information Hubs

- ✓ Caregivers are experts on their child's needs and gather new knowledge to prepare everyone for the needle procedure
- ✓ Caregivers benefit from communicating with clinic/healthcare providers in advance

"...we had kind of an intake conversation... They [healthcare providers] were so great, and so wonderful, and followed up after, like on the phone. And everything that we talked about prepping, they did (P16)."

TAKEAWAY MESSAGE:

Caregivers and their autistic children require a child/family-centered and individualized approach for needle procedures to be comfortable and CPGs to be appropriate for them.



NEXT STEPS:

Developing resources for managing needle pain and fear that better meet the needs of autistic children and their caregivers.

Email Olivia with any questions/comments:
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THANK YOU!
to all caregivers who participated!



¹ Identity-first language (i.e., autistic) is used in this infographic as this was the preference of most participants in this study and aligns with the advice of autistic self-advocates.