Management of Needle Pain and Fear in Autistic Children: Qualitative Perspectives from Caregivers

8th Annual Dr. Benjamin Goldberg Developmental Disabilities Research Day
Introduction:

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Warning: Discussing needle pain & fear
Does anyone in the audience administer needles or help pediatric patients who require needles as part of their care?
Background:

Needle procedures = critical to health

Needle procedures * pain, fear, and distress for children

(McLenon & Rogers, 2019; McMurtry et al., 2015)

Needle procedures are particularly challenging for children labelled with Intellectual & Developmental Disabilities (IDDs), like autism

➢ The fear and pain of children with IDDs is often poorly managed

(Liu et al., 2020; Pascolo et al., 2018; Slifer et al., 2011)
Background: Autism and Needle Procedures

Autism Spectrum Disorder/Autism

- Sensory differences (hypo- or hyper-sensitivity)
- Communication challenges
- Preference for routine/familiarity

(APA, 2022)

High rates of needle fear and phobia amongst autistic children
(Evans et al., 2005; Leyfer et al., 2006)

Autistic children and children with IDDs show increased pain and distress reactions during needle procedures
(Nader et al., 2004; Rattaz et al., 2013; Tordjman et al., 2009; Pascolo et al., 2018)
Objective: Identify what autistic children and their caregivers need to make needle procedures comfortable, and clinical practice guidelines appropriate and actionable for them.

Present Study:

Clinical practice guidelines with evidence-based strategies for helping children cope with needle pain and fear (Taddio et al., 2015; McMurtry et al., 2016)

➢ But remains unclear if these strategies are appropriate for autistic children and their caregivers given their unique needs
Procedure:

20 semi-structured, virtual interviews w/ Canadian caregivers

Hidden slides on demographics

What did we ask about?

Transcribed Verbatim

• Analyzed
• Thematic Analysis

(Braun & Clarke, 2006; 2022)
Qualitative Results:

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Listen to Them

Be Honest With Them

Involve Them in Decisions

Overall, respect agency and control

Respect Their Choices

Speak to Them Directly

Give Them Information

Treat the Child as Autonomous Individual

Theme 1
Quote:

“I was looking around at kind of the neurotypical kids...the doctors were talking to the child... 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.”

- Caregiver 19
Caregivers as Information Hubs

- Knowledgeable/expert about child
- Gathering new knowledge related to needle procedure
- Information about **what to expect** → prepare child
- Sharing information with healthcare providers
  - Pre-communication, planning, collaboration
Environment is Everything

- Sensory (e.g., bright lights, noise)
- Wait times
- Feeling rushed

It’s More than the Poke and Pain

Healthcare Providers as Facilitators of Success

Familiarity and Predictability Matter

- Diversion from routine
- Unfamiliar people, place, equipment

Theme 2
Healthcare Providers as Facilitators of Success

- Get to know the child + build rapport
- Demeanor:
  - Calm, friendly, sensitive/compassionate
  - Forceful, impatient/rushing, frustrated
- Prepared, well-trained, efficient in conducting procedure
- Training and experience with autism
“...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...”

- Caregiver 5
Tailoring Strategies to Child’s Needs

Tailoring of Preparation
- Realistic, concrete
- Customizable resources
- Extensive, in advance

Tailoring of Coping Strategies

Tailoring of Exposure Treatment
- Incorporating rewards
- Increased caregiver involvement

Theme 4
Tailoring of Coping Strategies

- Multiple caregivers present
- Topical anesthetics may be uncomfortable
  - Preparation, coping strategies, selection of method
  - Breathing should be visual and/or interactive
- Distraction
  - Verbal distraction should focus on child’s interest or reward
  - Sensory item, technology, special interest(s)
- Rewards = distract and motivate to participate
"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 talked to him about things that he doesn’t care about, and that makes him go back to the needle."

- Caregiver 1
Conclusions:

Client-centered and individualized approach is critical for autistic children when it comes to needle procedures.

Caregiver-Healthcare provider collaboration and partnership is important.

Future research needed:
- E.g., developing resources
- E.g., examining effectiveness of coping strategies in autism community
Looking for autistic individual to join the research team!

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References

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