



Pain Awareness in Autistic Adults: Conceptualizing an Overlooked Dimension of Pain Experience

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Autism

- Autism refers to complex neurobehavioral and neurodevelopmental conditions.
- Sensory features are defined as one of four restricted/repetitive behavior diagnostic criteria:
 - “An apparent indifference to pain/ temperature”.

(American Psychiatric Association, 2013)



Pain

- Previous literature:
 - Scarcity of knowledge regarding pain perception (Allely, 2013; Moore, 2015).
 - Focused on
 - pain thresholds.
 - pain sensitivity.





Welcome to a Journey



Quantitative



Qualitative





The Current Study- Aim

To explore:

- How autistic adults experience pain awareness
- How challenges in this process affect participation, well-being, and healthcare interactions



Methods

- **Qualitative study:** phenomenological approach.
- 15 autistic adults
 - Participants: Inclusion criteria:
 - Adults - age > 18.
 - Level 1 ASD.
 - Normal verbal performance and intelligence.
 - Proficiency in the Hebrew language.
 - **Exclusion criterion:** Any chronic pain diagnosis.



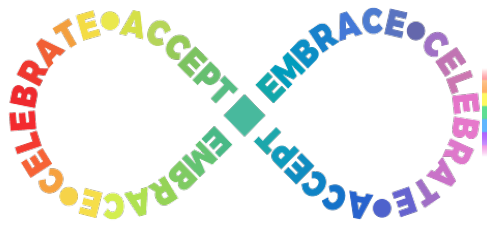
Methods

- **Setting:**
 - Face-to-face, in-depth interviews.
 - Zoom videoconferencing software.
 - 60 to 90 min.
- **Research tools:** Interview guide.
- **Analysis:** Deductive thematic analysis.



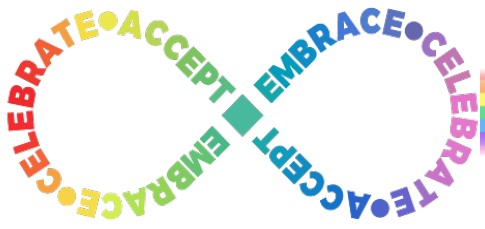
Results: 5 themes

- Pain recognition
- Pain characterization
- Pain interpretation
- Pain expression
- Pain-related interactions



Pain recognition

- Refers to realizing that a bodily sensation is pain.
- The most fragile and delayed stage of the process.
- Pain recognition was frequently described as vague, slow, and effortful, rather than immediate or automatic.



Pain recognition-

“I was restless, and my family asked what was wrong. Only when my mom put her palm on my forehead and said I had a fever did I realize that something hurt.”

(R.N, 24)



Pain characterization

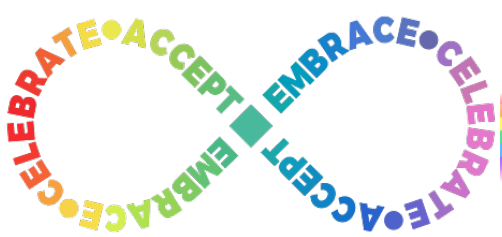
Participants reported uncertainty in identifying pain features:

- Pain intensity
- Location
- Quality
- Temporal features
- Factors that modulated pain.



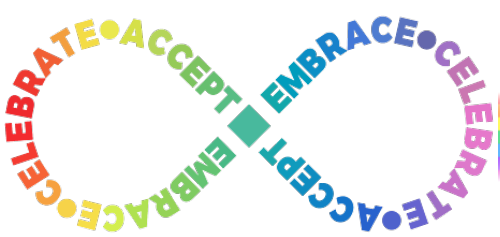
Pain characterization

“It’s hard for me to explain or define if the pain is burning, sharp, or anything like that. I feel it’s a language I don’t understand and don’t know how to use.” (N.M, 28)



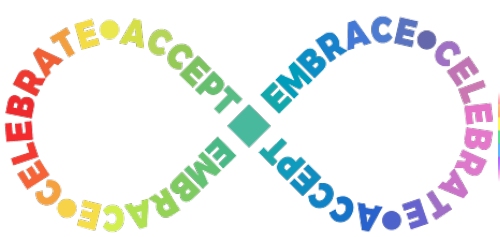
Pain interpretation

- Participants described substantial challenges in integrating multiple physical sensations into a coherent pain experience:
- Making sense of pain and understanding what it means.
- An active cognitive process rather than an intuitive bodily response



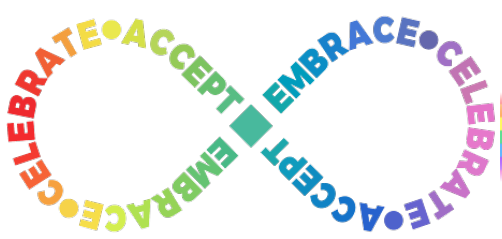
Pain interpretation

“My leg got caught in the train exit gate and broke. I fainted from the pain... I couldn't connect between the gate, the distortion in my leg, and the terrible pain I was feeling... Only when my father explained that my leg had been caught, that it broke, and that now I was in pain because of the fracture, only then did I understood what had happened.” (O. G, 23)



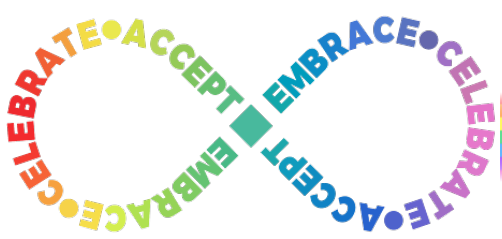
Pain expression

- Challenges in expression of pain (behaviorally and verbally).
- Sometimes it is expressed bodily only- restlessness, withdrawal or unusual movements
- Pain expressions did not always align with conventional expectations.



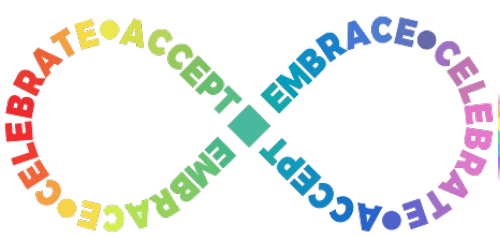
Pain expression

“Once the doctor said, ‘You don’t look like you’re in pain.’ I thought, how can I look like it? I just told you that I am.”
(P.G, 21)



Pain related interactions

- Pain-related interactions emerged as both a challenge and a resource.
- It plays a central role in shaping how pain is expressed, interpreted, and ultimately understood and managed by autistic adults.



Pain related interactions

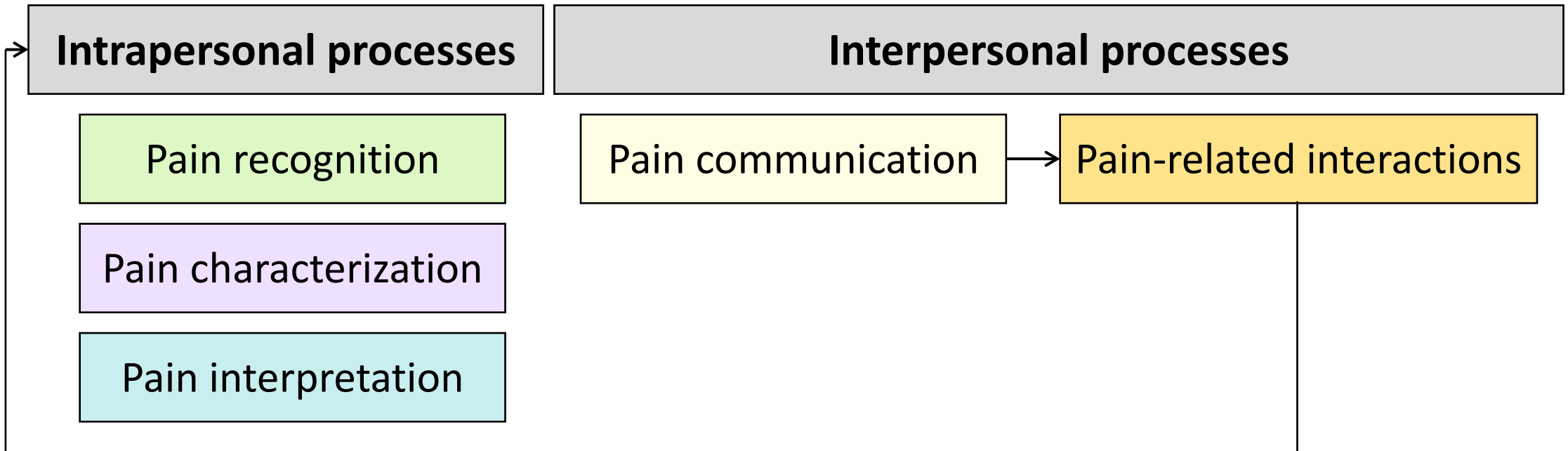
“When I tell the doctor I’m in pain, I always feel I need to prove it. He asks many questions that I don’t know how to answer, and then he looks doubtful.” (P.G, 21)

“I’m an adult, but without my father there, I don’t feel safe to talk about my pain. Alone, they don’t listen to me.” (N.L, 28)



Discussion

Pain awareness





Discussion

Pain awareness is a core aspect of pain experience among people with autism

Pain awareness difficulties affect their self-understanding and ability to communicate their pain

Since people with autism cope with challenges expressing their pain, they get less treatment under pain conditions

Pain awareness should be better addressed in future studies and in clinical interventions



With Thanks To...

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- The participants in this study for devoting their time and sharing their experiences with open hearts.





Thank you for listening!

Related papers:

- Kalingel Levi, M., Schreur, E., Granovsky, Y., Bar-Shalita, T., Fogel, Hoffman, T., and Gal, E. (2023). “When I’m in pain, everything is overwhelming”: Implications of pain of adults with Autism on their daily living and participation. *Frontiers in Psychology*, 13, Article 911756.
- Kalingel Levi, M., Graanovsky, Y., Bar-Shalita, T., Weissman-Fogel, I., Hoffman, T., & Gal, E. (2025). Development and validation of the pain awareness scale. *The Journal of Pain*, 164(7), 1123–1131.

