

Pain in Autistic Children: Interviews with Child-Parent Dyads.

B. Donaghy*, H. Poole, B. Rosser, M. Failla & D. J. Moore
School of Psychology

Any enquiries contact: B.E.Donaghy@2016.LJMU.ac.uk

Introduction

- When described through their defining characteristics, both autism and pain have an overriding sensory element. For example, pain as an unpleasant sensory experience (Raja et al., 2020), and the American Psychiatric Association (2013) listing hyper- or hypo-reactivity to sensory input as a trait of autism.
- Therefore, as pain is a sensory experience itself, it might be expected that autistic people would experience pain differently than neurotypical peers.
- However despite these clear overlaps and a high prevalence of paediatric chronic pain cases involving autistic children, research understanding pain experience in autistic children remains sparse.
- This study explores pain experiences of autistic children and young people (CYP) from both the autistic CYP's and their parent/guardian's perspective to address knowledge gaps in how autistic children understand their pain and seek care from others.

Method

Online Questionnaire

Participants each completed a bespoke questionnaire collecting:

- 1) Key demographics (i.e. age and gender, and pre-existing conditions)
- 2) Information for interviews -
 - 2a) Identification of pain scenario for interview
 - 2b) Interview format adjustments (i.e. keep cameras off and not discuss certain topics)



Online Interview

Dyads were interviewed separately on the participating autistic CYP's experience of pain.

- Topics included:
- 1) Pain importance
 - 2) Pain description
 - 3) Pain behaviour
 - 4) Cognitive pain states
 - 5) Emotional pain states



Preliminary Themes

A total of 7 dyads have participated, with a further 3 dyads recruited but not yet participated. *Therefore current themes are preliminary.*

The ability to "mask" in social situations such as school becomes increasingly difficult when in pain

Pain Behaviour

Often used as an indicator of pain intensity. I.e. vomiting when pain intensity is highest

Often used as a source of pain relief through distraction. I.e. watching a comfort tv show

Use of intensity during a previous pain experience to describe current pain intensity

Pain Description

Use of simile's to describe pain quality
"...someone's like hammering my head..."

Autistic CYP often don't speak to their healthcare professionals due to a lack of trust and use of confusing medical jargon

Trusting Relationships

Autistic CYP often only disclose their pain to those they know well/frequently interact with i.e. parents or SEN teachers

Conclusions

- In medical settings, the use of pain behaviours and indicators of pain intensity may be more useful in understanding the pain experience of an autistic CYP
- Healthcare professionals must build a trusting relationship with autistic CYP before expecting an autistic CYP to freely disclose their pain. In the meantime, communicating with an autistic CYP parent to understand the autistic CYP experience of pain would be most useful to appropriately implement useful pain management
- Whilst this study provides some understanding of pain in autistic CYP, further research must be conducted to build on the results presented here gaining a deeper understanding of the challenges autistic CYP may face.

References