How can we better assess pain in autistic patients? A scoping review

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Background

- Autism is a lifelong condition characterised by social and communicative differences and restricted, stereotyped behaviours and interests[1]
- 'Atypical' displays of pain behaviours such as reduced guarding of painful areas has been interpreted as hyposensitivity to pain[1]
- Differences in communication styles of autistic individuals may result in clinicians misinterpreting pain expression[2]
- Increased restrictive, repetitive or self-injurious behaviours are often indicative of undiagnosed pain[3]
- Sensory differences may result in difficulty localising pain[4]
- These factors has led to poorer health outcomes, later presentations of disease and under-management of pain in autistic individuals[3]

Project aim

To better understand how to assess, manage and prevent pain in autistic individuals

Method

- Articles focusing on pain discourse or assessment in autistic individuals of all ages were eligible for inclusion
- Articles solely focusing on pharmacological pain management were excluded
- French articles were translated by the UQ School of Languages

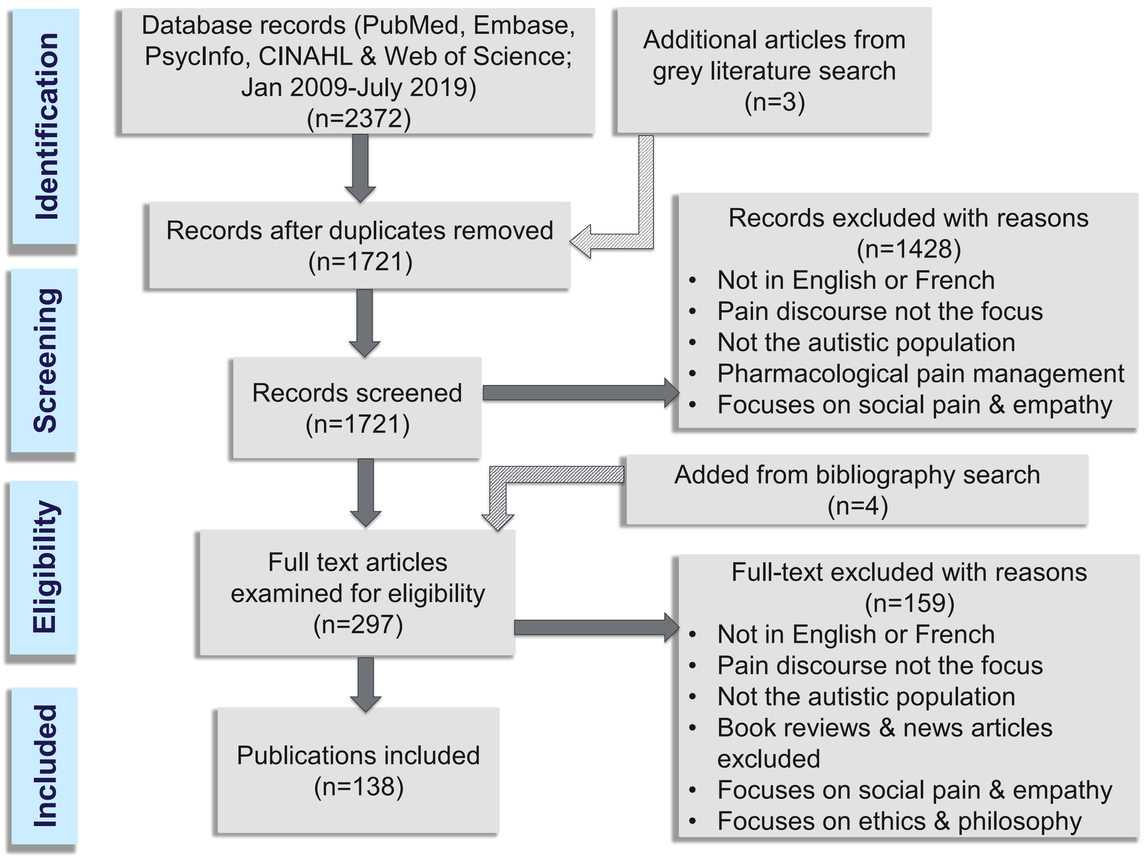

Figure 1: PRISMA flow chart of study selection process

Results

Pain sensation: Notions of hyposensitivity to pain are refuted

Pain assessment: The literature emphasised the importance of observational tools

Role of self-report: Not enough is known about the role of self-report in this population

Barriers to pain management: Stress and anxiety, poor self-efficacy and poorly managed associated problems exacerbate the experience of pain

Tools for pain assessment

- For the paediatric population, the Non-Communicating Child Pain Checklist Revised (NCCPC-R) was most commonly recommended
- For adults, the Non-Communicating Adult Pain Checklist (NCAPC) and the Pain and Discomfort Scale (PADS) were recommended
- Newer pain scales such as the French ESDDA scale[5] or the modified NCCPC for autism[6] show promise in clinical practice

Recommendations

Based on the findings of the scoping review, we recommend the following strategies to improve pain assessment and management for autistic individuals:

1. Increased training and awareness for clinicians, focusing on assessing and managing pain in autistic individuals
2. Improved communication of pain by adopting alternative communication strategies such as sign language and visual aids
3. Increased use of validated pain assessment scales
4. Reducing anxiety by providing autism-friendly environments and improving predictability in the healthcare setting
5. Treating associated problems such as disrupted sleep, disturbed eating and internalising symptoms
6. Future research should focus on strategies to improve self-reporting of pain

Next Steps

- Findings will be used to inform a training resource and tool for GPs that will include information about autistic pain expression, strategies to talk about pain with autistic patients and links to existing resources.
- This will be embedded within primary care clinical pathways for use by GPs around Australia.

References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders.* 4th ed (text revision). Washington, DC: American Psychiatric Association; 2000.
2. Moore DJ. Acute pain experience in individuals with autism spectrum disorders: a review. Autism. 2015;19(4):387-99.
3. Saravane D, Mytych I. Pain and autism. Douleur et Analgesie. 2018;31(3):137-48.
4. Oueriagli Nabih F, Benali A, Kachouchi A, Adali I, Manoudi F, Asri F. Perception de la douleur chez les enfants autistes (étude prospective de 40 cas) [Pain perception in children with autism (prospective study of 40 cases)]. Neuropsychiatrie de l'Enfance et de l'Adolescence. 2016;64(1):52-7.
5. Mytych I, Mercier C, Da Silva S, Ducreux E, Saravane D. Expression de la douleur dans les troubles du spectre autistique. Douleurs : Évaluation - Diagnostic - Traitement. 2018;19(6):255-7.
6. Dubois A, Michelon C, Rattaz C, Zabalia M, Baghdadli A. Daily living pain assessment in children with autism: Exploratory study. Res Dev Disabil. 2017;62:238-46.

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