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Commentary on: A systematic review of self and observer assessment of pain and related functioning in youth with brain-based developmental disabilities.

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Pain is highly prevalent in populations with brain based developmental disabilities [9; 14]. Higher levels of pain in these populations might be a result of a predisposition to particular conditions [15], motor changes that leave individuals at greater risk of injury [12] as well as differences in access to the healthcare systems [4; 5; 13]. Further there may be differences in cognitive processing styles, emotional regulation and the development of social relationships might leave these populations especially vulnerable within the healthcare system [7; 8].

The accurate measurement of pain is critical to ensure the appropriate treatment can be obtained by these populations. However, the majority of measures of pain require the use of language which is complex and built on metaphors to describe the quality of the pain (i.e. McGill Pain Questionnaire, [10]) or require typical verbal communication and magnitude estimation (i.e. [3]). These measures might not be accessible to subsections of individuals with brain based developmental disabilities. Considering measures that have been developed for the measurement of pain based on observer reports (i.e. the FLACC, [16] and Non-Communicating Child Pain Checklist, [2]), these may give a proxy measure of the existence of pain however often these might not be especially accurate at differentiating between pain and distress, further these observations are built on an assumption of pain behaviours anticipated to be present but may not reflect the range of responses that those with brain based developmental disabilities might produce (i.e. freezing in response to pain) [1].

The review by Noyek et al. [11], begins a critical discourse on this topic considering not only how pain has been measured in populations with brain-based developmental disabilities but also where individual differences have and have not been addressed. The limited consideration of individual differences/the psychological health of participants in these studies is of critical concern. Noyek et al., observe here that within acute pain states, only 4 papers measure the Quality of Life in patients with brain-based developmental disabilities and a further 4 consider any fear or anxiety around acute/procedural pain. When presenting studies on chronic pain states, again only 4 measure facets of patients' mental health, although more here do consider Quality of Life (n = 17). Given the number of articles included within this review this shows a neglect of considering these patients individual experiences and in particular the complexity of the impact of pain on the wider health of already marginalised populations.

A further observation here is that even for Cerebral Palsy, which has substantially more research than any other brain based developmental disability, knowledge of pain in these populations is severely lacking in breadth or depth. As established in the review it is clear that there is growth in the amount of literature examining pain in these populations, however progress is still slow. Considering the development of this research it is important that this research takes a co-creation model which ensures that the questions posed by researchers within these developing fields of research address the greatest needs of the populations affected but also that this research is done and discussed in a clear and respectful way. Without this the research will at least be harder for the communities it is supposed to serve to accept and at worst might be wholly unsuitable for their actual needs and may in-fact perpetrate harmful information about these populations.

Where individual differences here were observed these were more likely to be 'functional' responses, either in everyday, social or motor functioning. Although some of this information might be useful or even necessary in some cases it also speaks to one of the challenges for populations with brain based developmental disabilities within healthcare, namely that rather than considering what needs a person might have for optimal outcomes there is a focus on identifying what a person can do. This can also extend to a challenge in the perception that 'functioning' is a static state, for a number of young people being in a state of pain and/or anxiety might make engaging in activities which can

be easily performed on a typical day significantly more challenging (i.e. communication), for this reason the reliance on functional labels might be considered overly reductionistic in many cases [6].

To facilitate this research and the related practice to best support as many people with brain based developmental disabilities it is also critical for researchers to adopt a more imaginative approach of engaging with these populations. Almost all of the research reported here either used standard verbal/written tools, or where the participant did not have access to these tools used an observer report of pain. Development of a wider range of tools which allows individuals to use augmented or alternative communication tools, as well as seeking methods to support people in communicating pain in a way that they can is likely to result in better understanding, measurement and ultimately outcomes. This can be even more clearly seen when considering the nature of the articles which have been published over time. Although the number of quantitative articles increases clearly, there is still very limited research exploring the experiences of pain in CYP with brain based developmental disabilities using qualitative methods. These methods would likely need to use more flexible approaches to ensure that CYP could share their narratives, however without this a critical piece of the puzzle regarding these experiences is missed.

It is clear from this review that the challenges that CYP with brain-based disabilities face with pain are frequent and likely undermanaged and misunderstood. As academic and clinical communities more research is needed to ensure that pain experiences in these populations are better managed and that this is done with these populations and with respect for individuals with the person placed at the centre of this conversation.

Conflict of interest

The author has no conflict of interest in production of this manuscript

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