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EDITORIAL

Special issue on pain and intellectual and developmental disabilities

Children with Intellectual and Developmental Disabilities (IDD) represent a diverse group with conditions that begin during the developmental period and are associated with physical, learning, language, behavioral, and/or intellectual-based impairments. These impairments also frequently impact day-to-day functioning, generally lasting throughout a person's lifetime.[1] Because of the work of pioneering researchers in the field, pain is now understood to be a common and complex occurrence for children with IDD.[2] Indeed, under certain circumstances and contrary to historical beliefs, children with IDD compared to typically developing peers may actually be more sensitive to pain[3] and demonstrate greater pain evoked potentials.[4] Children with IDD also undergo more frequent and more invasive painful medical events[5] and are more likely to experience chronic pain compared to typically developing peers.[6,7] Unfortunately, children with IDD are also more likely to have limitations in their ability to communicate about their pain effectively, which impacts their ability to effectively utilize self-report pain assessment measures or advocate for their own pain relief.[8] Caregivers may be apt to underestimate the pain of their children with IDD[9,10] or may have difficulty communicating their concerns to their healthcare providers. As a result, pain is often missed or under-recognized as well as poorly or undermanaged.[2] Despite this well-documented clinical problem, research on pain in this population has been slow-moving and wrought with challenges. Indeed, children with IDD are often excluded from pain research, and any research including this population has many associated ethical and logistical challenges. In our opinion, the most significant outcomes from research to date include (a) evidence documenting the problem of pain as a significant challenge for children with IDD and (b) the development of valid and reliable observational pain assessment tools. Despite the development of the tools, however, there remains an extensive knowledge-to-practice gap in terms of using the assessment tools across home, respite, and clinical settings. As a field, we need to address these practice gaps as we also pursue scientific efforts to inform pain management approaches for children with IDD. We are encouraged by recent work; for example, a pain assessment toolbox and clinical practice points specific to pain in children with physical disabilities were developed and disseminated,[11,12] pain education programs have been developed for caregivers and tested for effectiveness,[13-15] and while still severely limited, studies are starting to emerge focused on understanding pain management approaches in this population.[16-20]

This special issue features important and diverse research spanning pain prevalence, assessment, and management in children with IDD. We are also pleased to highlight a knowledge mobilization project focused on impacting care and the human experience.

This special issue begins with an invited narrative commentary where Carter and colleagues describe how they harnessed the power of storytelling to create awareness around pain in children with IDD.[21] Using their multidisciplinary expertise (qualitative researcher, writer, animator) and in collaboration with parents, a short video was created to powerfully capture and illuminate the lived experience of parents caring for a non-verbal child with IDD and chronic pain. The final product educates in a way that academic literature simply cannot—with profound emotion and human connection. The commentary describing the creation of this product is informative to anyone working to create impactful knowledge mobilization products that call for action to elicit change.

Next, Andersen and colleagues present the protocol for their large-scale international survey quantifying pain prevalence, burden, and pain management practices in children with cerebral palsy (CP).[22] In this study, mothers' and fathers' perspectives are invited as well as the child with CP's self-report (when able) and siblings serve as controls. The CPPain program, including the survey described, was developed in close collaboration with users, including individuals with CP and their families. This foundational work aims to inform the development of interventions to support better assessment and management of pain in clinical practice around the world.

As noted above, communication of pain for children with IDD can be a challenge. Fitzpatrick and colleagues describe how three children with autism spectrum disorder (ASD) with intellectual disability undertook training to use a pain scale and to request their preferred pain relief strategies.[23] Pain communication training could be an important part of understanding and reducing challenging behaviors in children with ASD who have ongoing pain.

There has been a paucity of research studies broadly exploring pain treatment approaches in IDD, and even less is known about the utility of non-pharmacological interventions. Ostojic and colleagues report a mixed methods study assessing the acceptability and feasibility of using a biofeedback-assisted relaxation training as an intervention for chronic pain management in children with CP.[24] This pilot study highlights the ways in which biofeedback—used via an iOS application—was feasible and beneficial as noted by both children and their parents.

To conclude the special issue, Boyer and colleagues characterized pain in the context of orthopedic surgery in children with CP.[25] While the intent of orthopedic surgery is to have a positive impact on function and pain, pain before and after surgery has rarely been

reported in CP. Pain prevalence and orthopedic outcomes were documented retrospectively and factors that predicted pain at 1-year follow-up were identified. This study emphasizes the importance of attending to chronic pain before surgery to improve pain and functional outcomes.

These five papers, originating from around the world, report on innovative approaches to understanding the complexities of pain in children with IDD. Initiatives like the International Association for the Study of Pain (IASP)'s 2019 global year of pain in the most vulnerable as well as IASP's new Special Interest Group on Pain and Intellectual and Developmental Disabilities (PIDDSIG) and this current special issue with Paediatric and Neonatal Pain are all examples of recent momentum to bring attention to pain and IDD. These initiatives, among others, aim to mobilize researchers and healthcare providers to work together and with children with IDD and their families to generate clinically relevant knowledge and ultimately to ensure that knowledge improves the lives of children with IDD.

Chantel C. Burkitt[1,2]
Lara M. Genik[3,4,5]

[1]*Gillette Children's Specialty Healthcare, Saint Paul, Minnesota, USA*
[2]*Department of Educational Psychology, University of Minnesota, Minneapolis, Minnesota, USA*
Email: cburkitt@gillettechildrens.com
[3]*University of Guelph, Guelph, Ontario, Canada*
[4]*Vanier Children's Mental Wellness, London, Ontario, Canada*
[5]*Archways Centre for CBT, London, Ontario, Canada*

ORCID

Chantel C. Burkitt https://orcid.org/0000-0002-1250-181X
Lara M. Genik https://orcid.org/0000-0002-4337-2926

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