

Communicating Pain: the challenge of pain assessment in children with profound cognitive impairment.

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Pain assessment is something that every nurse caring for children will need to undertake, yet it is something that is not always done effectively, and some children are more at risk of poor pain assessment than others.

Assessing typically developing children's pain can be challenging and children are susceptible to sub-optimal pain management (1-3). Many factors such as the child's gender (4), whether they are pre-verbal (5) and whether their pain is acute or chronic, can be influential. It is also clear that assessment is influenced by the perspective of who is undertaking the assessment, so self-report of pain by children can differ from that of their parents/carers or healthcare professionals, with healthcare professionals often underestimating pain (3).

Assessing pain in some groups of children, such as children with special needs (6) or children with cerebral palsy (7), can be seen as additionally challenging. Assessing the pain of children who are so profoundly cognitively impaired that they are unable to self-report their pain, as they lack the capacity to either verbally communicate or purposefully communicate their pain through other systems, is highly complex and challenging (8, 9). Children with profound cognitive impairment are a heterogeneous group who are at particular risk of experiencing pain (10); often experiencing a higher number of nociceptive and neuropathic pain episodes compared to their healthy peers and sometimes experiencing significant daily pain that impacts on their lives (1, 11, 12). This pain arises from the interplay between their underlying condition and their range of comorbidities; this complicates both assessment and management (13).

Children with profound cognitive impairment are therefore completely reliant on their parents/carers, and on their healthcare

professionals for effective assessment and management of their pain. Studies show that, despite robust and validated tools being available (14), many healthcare professionals lack confidence in their ability to assess and manage pain in this group of children (9, 15).

However, whereas healthcare professionals acquire their skill set and knowledge through a reasonably established curriculum (lectures, books, learning from more experienced clinicians) and across a range of children, parents acquire knowledge through experiential learning about their own child and with little professional input (8, 9). Although studies have demonstrated that parents of children with profound cognitive impairment often develop knowledge and skills experientially (8, 15) and are generally accurate in assessing their child's pain (10), other evidence shows that some may underestimate the intensity of their child's pain (16).

This informal curriculum in which parents learn from their child can work well until something happens which challenges their knowledge, skill set and confidence. This may result from their child's existing pain increasing in intensity or a new source of pain developing. In these circumstances the situation can overwhelm the parents'/carers' resources and they turn to healthcare professionals for additional expertise, insight and intervention (8). However, confronted with the complexity of the child's, often unique, health care needs and idiosyncratic behaviours, healthcare professionals may experience uncertainty as they perceive their usual 'road map' for pain assessment to be inadequate (9). 'Teasing out' pain cues and unravelling whether the child is in pain, what is causing it, and how best to treat the pain, is not simple. In such situations, collaborative working between the parents/carers and healthcare

professionals, based on mutual respect and acknowledgement of each other's expertise and potential contribution, is likely to create optimal circumstances for effective pain assessment and subsequent management. However, this may not always happen.

Having talked to many parents/carers within practice and during research interviews, it is clear that they value healthcare professionals who pause and listen to what they are saying and do not dismiss their ideas, concerns or 'gut feelings'. They value healthcare professionals who respect their unique knowledge about their child but do not expect them to know everything. They appreciate healthcare professionals who accept that trying to put their child's pain into words is tricky and that it can be a struggle to find a meaningful way of communicating their child's pain.

Nurses working as clinicians, managers, educators, leaders and researchers all have an obligation to ensure that they contribute effectively in whatever way they can to ensuring that pain assessment and management is optimal. Although the existing evidence-base about pain assessment in children with profound cognitive impairment is relatively small, it is robust and it offers clear direction. Despite none being ideal, we should be assessing their pain using specific, validated tools (10, 14) such as the Paediatric Pain Profile(17), the revised-Face, Legs, Activity, Cry, Consolability (r-FLACC) tool (18), and the Non-Communicating Children's Pain Checklist-Revised (NCCPC-R)(19). All of this needs to be done in dialogue with the child's parents/carers.

In my role as a researcher with strong links to clinical practice, and with years of listening to both parents and professionals wanting to

improve pain assessment, I realized that one way I could help was to find new ways of disseminating research findings. I wanted to reach out and inform parents and healthcare professionals about the issue and I wanted to do this in a collaborative way. On this dissemination journey I have been involved in working with dancers who choreographed my findings. This work has been performed in public. I have also worked with a writer/artist and director to create an audio-visual installation which has been performed in a theatre and at science festivals. This installation has been adapted for presentation at conferences. I have also worked with illustrators and animators to create a freely available resource, 'Communicating Lily's Pain'.

'Communicating Lily's Pain' includes an animation which is now online <https://www.edgehill.ac.uk/communicatinglilyspain/>. Work is ongoing to create information sheets and teaching materials. The whole of the animation is based on parents' words, and parents and professionals were involved throughout its creation. In two minutes, this animation distills the essence of much of my own pain research and reflects the core messages from other pain researchers. 'Communicating Lily's Pain' aims to inform parents of children with profound cognitive impairment and professionals working with this diverse group of children, as well as informing the wider public. It aims to act as a trigger for conversations; to help parents feel less alone and to provide professionals with insight into what parents need from them. In its own small way, I hope that this resource will stimulate conversations about pain, encourage more critical thinking, and help bring about change.

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