

Animating children's pain research: using arts-based approaches to disseminate knowledge and mobilise emotions

by Bernie Carter (FRCN 2009)



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Across more than 20 years I have undertaken research and scholarly work focusing on children's pain (Carter 1994, 2020), with a particular focus on the assessment of pain in children with profound cognitive impairment (PCI) (Carter et al, 2002, 2016, 2017). However, research is not just about writing bids and doing the research; increasingly, it is about translating findings into action.

This article focuses on how I have tried to make change happen based on the evidence of my own and other people's research. The specific trigger is a longitudinal qualitative study in which eight mothers of children with

PCI shared stories of their experiences of learning, enduring, knowing and advocating for their child's pain. The research itself is modest – small scale and regional – yet it is one of very few studies to address the issue.

In a separate article, the perspectives of clinicians, collected during the same study, are reported (Carter et al 2016). Long after the study was finished, I knew it was not finished with me. This article reflects on how I have continued to walk with the stories from this study. This article has its roots in my earliest work but is most recently connected to an article published in 2017. The link to that article and its abstract are provided below.

Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives

Abstract

Children with profound cognitive impairment (PCI) are a heterogenous group who often experience frequent and persistent pain. Those people closest to the child are key to assessing their pain. This mixed methods study aimed to explore how parents acquire knowledge and skills in assessing and managing their child's pain. Eight mothers completed a weekly pain diary and were interviewed at weeks one and eight. Qualitative data were analysed using thematic analysis and the quantitative data using descriptive statistics. Mothers talked of learning through a system of trial and error ('learning to get on with it'); this was accomplished through 'learning to know without a rule book or guide'; 'learning to be a convincing advocate'; and 'learning to endure and to get things right.'

Experiential and reflective learning were evident in the way the mothers developed a 'sense of knowing' their child's pain. They drew on embodied knowledge of how their child usually expressed and responded to pain to help make pain-related decisions. Health professionals need to support mothers/parents to develop their knowledge and skills and to gain confidence in pain assessment, and they should recognise and act on the mothers' concerns.

Citation

Carter B, Arnott J, Simons J et al (2017) Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Research and Management*. 2017, 25:14920. doi: 10.1155/2017/2514920

Link

www.hindawi.com/journals/prm/2017/2514920

Introduction and background

Children with profound cognitive impairment (PCI) (or profound and multiple learning disability) are children whose severe learning disability and other disabilities significantly impact on their ability to communicate (National Health Institute 2018). Many children with PCI are fully reliant on their parents and caregivers to care for their complex health and social care needs. Children with PCI are a diverse group, both in terms of their underlying condition (for example, cerebral palsy, neurodegenerative and metabolic disorders) and the range of comorbidities they experience (for example, perceptual disorders, physical impairments, and respiratory and feeding problems) (Bottos and Chambers 2006).

Typically, children with PCI have a high burden of pain that increases across their lifetime. They can experience pain from a wide range of sources, some specifically related to their underlying condition (for example, gastro-oesophageal reflux, muscle spasms) or their treatment (for example, suctioning, venepuncture) as well as the more commonplace pains of childhood (for example, earache). Considering the frequency, range and burden of pain that many children with PCI carry, it is of particular concern that their pain is often both poorly managed and under-assessed and undertreated (Valkenburg et al 2012, Cascella et al 2019).

Children with PCI display a heterogeneity of response to and expression of pain; this partly reflects the child's particular comorbidities and motor development disabilities (Pivalizza and Pivalizza 2008) and the effect these may have on their behavioural and physiological responses (Breau and Camfield 2011). This can result in a 'perfect storm', with some children with PCI receiving inadequate assessment and treatment (Genik et al 2017) while experiencing frequent, persistent, and significant pain (Breau et al 2003, Jayanath et al 2016). The situation of this group of children troubled me a lot 20 years ago. It continues to trouble me today. Their situation remains an invidious one.

Influence and impact

Although children with PCI are a diverse group, they share the characteristic of being unable to self-report their pain. With the 'gold standard' of self-report no longer available, the landscape of pain assessment

is shifted to one which relies on other, less certain, strategies. Part of the problem is that when clinical uncertainty is high (Carter et al 2016), and clinician knowledge is low (Genik et al 2017), which it often is when caring for children with PCI, clinicians do not always recognise parents' expertise and experience. Consequently, parents face challenges advocating for, and convincing clinicians of their child's pain.

Day in, day out, year in and year out, parents attend to their children's pain, developing a 'sense of knowing' of their child's pain. They develop a deep and intrinsic knowledge of how their child usually expresses and responds to pain; their knowledge arises from a genuine, authentic form of experiential and reflective learning. Clinicians, despite a developing evidence base and validated pain tools, report navigating uncertainty in relation to assessing and managing the pain of children with PCI (Carter et al 2016).

Despite my own efforts and those of a relatively small band of other researchers and practitioners in the field, only limited pockets of pain-related change have occurred for this group of children over the past 20 years. There have been important advances in the development of validated pain assessment tools (Breau et al 2002, Hunt et al 2004, Malviya et al 2006), but they are not consistently embedded in practice (Yamada et al 2017). Even in 2020, there is still only a 'small, slow moving body of pain research' (Genik and McMurtry 2020) for this population of children.

It was against this context of slow change and progress that I assessed my best efforts. I had undertaken research and managed to attract small pockets of funding to support the research. I had worked with parents, practitioners, educators, and charities. I had published, been cited, written books and been invited to present the findings at conferences, workshops and study days in hospitals, hospices, community settings and universities in the UK and internationally.

I had written lay publications, reports, and contributed to pain guidelines. I had lobbied, presented evidence at parliament, been chair of the RCN Pain in Children Group, and been awarded my Fellowship of the Royal College of Nursing (FRCN) based on my work on pain. Despite all this, the message was not getting through as strongly as I had hoped. I was not making change happen in the way I wanted it to.

Acknowledgement

The research work that underpins the 'Developing a Sense of Knowing' paper was undertaken with Dr Janine Arnott (now Reverend Arnott), Dr Joan Simons from the Open University and Professor Lucy Bray from Edge Hill University. All things are possible when you work with great people, and these are three of the best

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RESOURCES

Communicating Lily's Pain
www.tinyurl.com/Lily-Pain
30Bird
www.30bird.org
Mister Munro
www.mistermunro.co.uk
WellChild
www.wellchild.org.uk

Like other researchers, I turned to arts-based methods as a synergistic knowledge-translation strategy (Rieger and Schultz 2014). I determined to work differently, and in the past three years I have worked with children and young people, parents, people with chronic pain, dancers, performers, illustrators, graphic designers, writers, creative directors, sound installation experts, trainee vicars, a contortionist, teachers, the general public, and many more.

Current and future relevance

I homed in on using creative methods and the arts as a means of communicating research knowledge, conveying evidence-based information, symbolising experience, generating discussion, provoking meaning-making and different ways of knowing. Other researchers, aspiring to similar outcomes, have created beautiful and evocative work, such as exhibitions on menopause (Carpenter et al 2019), dementia (Bartlett 2015), and open heart surgery (Lapum et al 2012). Like these other researchers, I have discovered the rewards and the perils of using the arts; the arts can disrupt in unpredictable ways over which the researcher has little control (Bartlett 2015).

Landmarks on my journey include the creation of an immersive soundscape installation, exploration of somatic practice, poetry, creative explorations at festivals of science and a resource called 'Communicating Lily's Pain'. Each of these elements has been powerful in further shaping my understanding of children's pain and in creating opportunities to stimulate new dialogue and engagement. Each has given new opportunities to engage with people and to share findings from my research and to try and shape thinking and practice. Like Carpenter et al (2019), I believe and have evidence that these approaches have helped to stimulate learning, dispel myths, spur dialogue, and increase empathy.

Serendipity played a role at the outset of this journey; a chance meeting resulted in an introduction to Rob Young, a writer and artist and generally inspirational individual. I shared the (anonymised) stories of the parents and clinicians and both my passion for and frustration about changing people's hearts and minds about children's pain. Rob instinctively grasped the essence of what needed to be conveyed and we started to work together in earnest.

Our initial project was as artists in residence at 30Bird, a company that works with artists,

practitioners and scientists to create new interdisciplinary art forms and performances. In this project, I was the scientist/academic and Rob was the artist. During a one-week residency we were given space, time and a vanishingly small amount of funding to create a performance. We had few rules, some amazing guidance from the director Mehrdad Seyf, and we were both pushed out of our comfort zones. We created an immersive sound and light installation called *The Mother Of All Pain*. This installation consisted of an authentic soundscape composed of the voices of parents, members of the public and from YouTube videos of parents supported by WellChild (a national children's charity).

The soundscape was projected through speakers on the arms of a giant 4.5 metre mobile (an upscaled version of a mobile that might hang over a child's cot). The installation was performed in a blacked-out studio with the only lighting being tiny LED lights attached to the speakers on the mobile's arms; as the mobile spun, an evocative and otherworldly mix of light, dark and overlapping words was created.

At its first performance, its impact was visceral. Every performance since has provoked a similar response; people have cried, felt the need to talk to us, shared stories about their own pain and expressed concern for the children and their families. This response has occurred regardless of whether the audience has been the general public, practitioners, pain specialists, people with pain, or parents of children with PCI. However, the aspects of the installation that meant it was powerful (for example, blackout, ceiling rigs, technical audio support) mitigated against it being easily presented at conferences or in hospitals. Although it can be adapted, the experience is not the same. These limitations meant I needed a way to try and make the essence of the experience available to more people.

The Mother Of All Pain is the inspiration for *Communicating Lily's Pain*; its DNA is evident in pretty much every aspect. However, *Lily's Pain* is a much more practical distillation of the research findings than is evident in some of the other arts-based adventures. *Communicating Lily's Pain* is a resource that aims to help parents and health professionals assess pain in children with PCI. Every step of the way has been collaborative and informed and shaped by parents, professionals and artists with relevant expertise and experience, including the brilliant team at MisterMunro.

The animation takes the story of one child, Lily, and her mother. The script is drawn directly from quotations from the research and the voice-over is performed by a parent. Condensing research findings accurately, authentically and precisely into a tiny script and generating images, the tone, style and pacing of the animation was both incredibly challenging and rewarding.

Evaluation and feedback from clinicians and parents and the wider public has revealed that its impact potentially outweighs all of my other books, articles, presentations and so on. It is immediate, accessible and has 'mobilise[d] emotion' (Bartlett 2015). The information sheets are important aspects of the resource, but the most powerful element is the animation itself.

My sense is that arts-based approaches to knowledge translation and dissemination

are a key component for researchers to consider. Determining the effectiveness of art in communicating research is not without challenge, although there are methods for thoughtful evaluation (Rieger and Schultz 2014). Arts-based approaches are not appropriate for all research; they are not easy, and they require commitment to working and thinking in a different way to the ones we are traditionally trained to work in.

Lapum et al (2012) observe that researchers who engage with arts-based approaches are 'not merely marked, but re-shaped'. I would agree with this. I know that my thinking, understanding and ways of working about children's pain assessment have been re-shaped; I am hoping that engagement with the work I have been involved in producing has re-shaped the people it has touched.

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