

Giving parents a voice in child pain management

It will be no surprise to any parent that the way parents respond to their child in pain has a substantial impact on how the child will experience their pain. Research shows that, throughout childhood and even in adolescence, parents play a unique if not changing role in their child's pain management. In this blog I would like to highlight how this parental role can impact pain management strategies in both acute and chronic pain context.

In addition to this, parents can play an active and invaluable role in managing their child's acute pain experiences. In babies, breastfeeding and skin-to-skin contact can both help a baby to experience less pain during painful medical procedures (see pictures). In addition, providing the child with sucrose, or a sugar solution, right before the painful procedure is effective in reducing the baby's pain.





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When children grow older, new age-appropriate pain management strategies have to be used. Strategies as age-appropriate distraction (e.g. playing a game on a phone or tablet, reading out of a book, listening to music), advising their child to take deep breaths, blowing bubbles, and applying topical anaesthetics before a needle procedure have shown to reduce child's pain during painful medical procedures.

**Playing
games
with
your kids
makes
needles
hurt less.**

#ItDoesntHaveToHurt

ymc It Doesn't Have to Hurt
Prevent Pain Control for Children

However, parents are also an important advocate for their child to receive the most evidence-based pain management during painful medical procedures. Within the academic world, we now have good knowledge on which parental strategies are effective to reduce child pain during acute pain experiences such as immunisations. However, this doesn't necessarily mean that this knowledge reaches parents and health care professionals. It is important that parents and health care professionals are aware of these techniques. To achieve this, we need to use different ways of spreading the information than what we, academics, are used to. Recently, the paediatric pain world has been very active in using social media such as Twitter or YouTube to spread messages to parents directly. A few examples of this are the

- ***Be Sweet to Babies*** YouTube video, developed by Dr Denise Harrison, SickKids, Toronto, Canada: <https://www.youtube.com/watch?v=eLZQsFjngtk>
- ***The Power of Parent's Touch*** YouTube video, developed by Dr Marsha Campbell-Yeo, IWK Health Centre, Halifax, Canada: <https://www.youtube.com/watch?v=3nqN9c3FWn8>
- ***It doesn't have to hurt*** YouTube video, developed by Dr Christine Chambers, IWK Health Centre, Halifax, Canada: <https://www.youtube.com/watch?v=KgBwVSYqfps>

The YouTube videos are part of the 'It Doesn't Have To Hurt series' were so successful that they led to a more wide-spread campaign to increase parent's knowledge on child pain experiences. In order to expand on the YouTube video's and reach a large group of parents, Dr Christine Chambers has been successfully collaborating with the online parenting magazine "The Yummy Mummy Club". Even though this is not the most typical kind of collaboration academics would think of, these are crucial collaborations when trying to reach a wider public! If you're interested in the value and learning more on how to set up these kinds of collaborations, Dr Christine Chambers did a great job in describing this within other blog posts, see for example: <http://www.burness.com/social-media-it-doesnt-have-to-hurt/> and <http://www.cihir-irsc.gc.ca/e/49436.html>. Also have a look at <http://www.caphc.org/blog/> for an overview of the activities that took place in the first quarter of this great initiative.

A critical thing for this new avenue of using social media to reach parents, will be looking at how the effectiveness of these campaigns can be evaluated. How can we make sure that we are reaching and impacting parents? There was a recent, thought-provoking twitter chat on this topic, organised by Health Care Social Media Canada (#hcsma). For those of you who are interested to find out more about this, you can find the Storify of this twitter chat at <http://sfy.co/a0smQ>.

Not only acute pain, but also chronic pain, is common in children. A recent meta-analysis suggested that 11-18% of children report chronic pain experiences (King et al., 2011). Similar numbers were found in a large cohort study in primary school children in Ireland, with 10% of 5-12 year old children reporting chronic pain (PRIME-

C; O'Higgins et al., 2014) or pain lasting more than 3 months. Chronic pain can be quite difficult for a child. It can negatively influence the child's ability to engage in daily activities and their emotional, academic and physical well-being (Gauntlett-Gilbert & Eccleston, 2007; Logan, Simons, Stein, & Chastain, 2008). However, paediatric chronic pain can also have a negative impact on the parents. Parents of a child with chronic pain commonly report high levels of parental stress, anxiety, depressive symptoms, marital problems, restrictions in personal, social and family activities (Palermo & Eccleston, 2009). In other words, their life is changed fundamentally and unexpectedly and is now characterised by the struggle to adapt to a life filled with uncertainty, fear, distress and loss (Jordan, Eccleston, and Osborn, 2007).

This distress in parents can have a negative effect on their child, both directly and indirectly. For the direct pathway, children focus on how parents respond to a situation, as they view their parents as models for how to respond to similar situations. Therefore, if parents show negative emotional responses, children could view this as an example for how to deal with pain. Indirectly, these negative emotions can influence how parents behave towards their child in pain. Parental feelings of distress could result in more overprotective behaviours (e.g. reassuring, stopping their child from engaging in activities that could induce pain). Although parents usually engage in these overprotective behaviours automatically, they are unfortunately associated with more pain, distress and disability experienced by the child (Blount et al., 2008, Claar, Simons, & Logan, 2008).

Consequently, when treating chronic pain in children, it is important to fully include and actively work with the parents as well as with the child. However, very few available treatment options actively involve parents beyond providing parents with general information about pain. A recent overview indicated that including parents in treatment is not only beneficial for the child's experience but also improves the parents' behavioural responses and their mental health (Eccleston et al., 2015). Two examples of online treatment programmes that actively involve parents as part of the child's treatment for chronic pain are:

- *Web-based Management of Adolescent Pain (Web-MAP)*, developed by the team of Dr Tonya Palermo, Seattle's children hospital, USA, which is an interactive and personalized intervention based on cognitive-behaviour therapy for the treatment of paediatric chronic pain.
- *Teens Taking Charge: Managing Arthritis Online*, developed by the team of Dr Jennifer Stinson, SickKids, Toronto, Canada, which focuses on providing children with Juvenile Idiopathic arthritis and their parents with JIA-specific education, self-management strategies, and social support.

Both programmes are showing to be effective in reducing child disability. The intense involvement of parents was of major importance for these programs. I'm then also quite pleased to announce that the Centre for Pain Research at NUI Galway has been able to establish connections with both developers to explore the possibility of implementing these programmes within Ireland. At the moment, there are no dedicated pain management programmes available for children in Ireland and we hope that these online treatment options could fill this gap. Dr Line Caes has

visited the lab of Dr Tonya Palermo in Seattle last year and Dr Jennifer Stinson will be visiting the School of Psychology at NUI Galway in March 2016 in order to kickstart these projects. We are looking forward to tell you more about the outcome of both projects in future blogs!