

Chapter 14

Listen to us! The voices of young children with pain!

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In this chapter, we explore the experience of both acute and chronic pain among young children and children with cognitive impairments. While acute pain constitute children's primary experience of pain, considerable numbers of young children also live with chronic pain. We will provide more details on PRIME C - an Irish-wide longitudinal cohort, prevalence study which found that a surprising 10% of children between 5-12 years of age self-reported that they have chronic pain. These findings will be related to the importance of intervening early in childhood to avoid disability due to chronic pain later in life. Throughout the chapter, the focus will be on innovative and creative techniques that we have available to give those who are the experts in their own pain experiences, i.e. the children themselves, a voice that can be heard; rather than just relying on parents to provide a proxy report of pain intensity and disability.

Listening to children

Pain is an integral part of children's (i.e., young people under 12, pre-adolescent) everyday life. Receiving effective pain management is key for developing adaptive responses towards painful situations. As pain is an inherently subjective experience, it is crucial caregivers have a full understanding of how children's pain expressions evolve throughout development, characterised by increased verbalisation skills, in order to provide effective pain management (Craig 2009).

How do we access children to gain an understanding of their perspectives in relation to their pain experiences? *'To hear children's voices, a method is required that values subjectivity, enhances empowerment and allows us to enter the respondent's world of meaning and belief'* (Coyne et al. 2006:21).

Giving children a voice in their pain experience with integrity and professionalism respects their rights and dignity (Kilkelly and Donnelly 2006). This voice can be given in various ways, but a particularly strong method, both in research and practice, is using qualitative approaches to listen to the child's narrative of pain. The advantage of qualitative methods is that they encourage freedom of expression, thereby giving children a voice and agency (Carter 2004). Their strength rests in leaving

participants' perceptions intact, while generating rich, detailed and valid data (Bender and Ewbank 1994). It has also been argued that, when conducting research, qualitative methodologies make it easier to create relaxed and trusting spaces to work in (Hyde and Howlett 2004). Building trust with children is particularly relevant in the clinical context and can be facilitated through adopting qualitative methods of pain assessment, so that the healthcare professional becomes less distanced and passive (Carter 2004). If the methods are flexible enough to take account of differences in age, personalities, context and preferred forms of communication (Coyne et al. 2006), adults can then glimpse the world inhabited by children (Greene and Hill 2005). In this chapter, we will provide some examples of how qualitative methods can be used to assess children's pain by giving them a voice. Before we explain these methods, we will first provide more details on the prevalence of acute and chronic pain among young children, how it impacts on them and the role parents play in these pain experiences.

Prevalence of acute pain experiences in young children

The majority of childhood pain experiences represent acute pain, defined as pain of a relatively brief duration, with a sudden onset and an apparent aetiology such as everyday bumps and scrapes, medical procedures or illness (Cummings, Reid, Finley, McGrath, and Ritchie 1996). Most prevalence studies have focused on school-aged children (9-13 years of age) and adolescents (13-18 years of age), revealing an average 3.5 incidence of acute pain per month, with headaches being the most frequently reported and bothersome type of pain (van Dijk, McGrath, Pickett, and Van Den Kerkhof 2006). Moreover, girls tend to report higher levels of pain compared to boys and the overall prevalence of pain has been found to increase with age (Perquin et al. 2000).

Nevertheless, evidence indicating that pain is prevalent among younger children is accumulating. In their observational study of everyday pain in pre-schoolers attending day-care, Fearon and colleagues (1996) observed that young children (3-7 years of age) experience a painful event approximately every three waking hours. Using the Pain Experience Interview, a reliable epidemiological tool to assess the prevalence of pain in children, McGrath and team (2000) found that 5-7 year olds reported on average eleven acute trauma or disease pain experiences (e.g. cut finger, toothache, chest pain), which varied widely in terms of intensity and affect. As with the school-aged sample, headaches were very common in this age group, with a prevalence of 43.2 per cent (McGrath et al. 2000).

Beyond these everyday acute pain experiences, this age group is also subjected to a large variety of medical interventions that might be painful, such as immunisations and blood draws. In Ireland, for example, the Health Service Executive's (HSE) National Immunisation Office recommends six vaccinations for babies before the age of fourteen months, two additional vaccinations at five years of

age, and a further four vaccinations for children aged twelve years (HSE 2013). Pain resulting from needle-related procedures is usually mild, but can be associated with significant levels of fear (Taddio et al. 2009; Taddio et al. 2012), therefore effective pain management is crucial.

Consequently, early childhood represents a critical developmental stage in the child's life for shaping future pain management skills. In particular, these acute pain experiences in young children provide opportunities for children to gain an understanding of what pain is and how to manage pain. While the field of paediatric pain research has been largely dominated by investigations of how young children deal with medical pain (i.e. due to immunisations, blood draws), everyday bumps and falls are more frequent and experienced with varying intensities. Furthermore, medical procedures are quite disconnected from the family's normal environment. Taken together, exploring children's responses to everyday painful events might provide a better insight into development of children's typical pain management skills (Fearon et al. 1999). For instance, Fearon and colleagues (1999) found that coping strategies for these pain experiences gradually developed as children gained in independence; older children relied less on adults to provide help and demonstrated more engagement in protective behaviours such as holding and self-quieting.

It is crucial to gain a better understanding of pain during early childhood, as the nervous system is still developing and therefore highly responsive to noxious stimuli (Schwaller and Fitzgerald 2014). In support of this assumption, stressful events in early childhood (including painful events such as surgery and needle procedures), especially when occurring repeatedly, were found to induce long-lasting changes in pain processing (Schwaller and Fitzgerald 2014) and can be a predisposing factor in developing chronic pain later in life (Burke, Finn, McGuire, and Roche 2016).

Prevalence of chronic pain experiences in young children

While acute pain constitute children's primary experience of pain, considerable numbers of young children also live with chronic pain, regardless of the aetiology. Chronic pain can be described as continuous pain that lasts longer than it should, i.e. three months, or, as frequent recurrent pain with a minimum duration of 3 months, often without a clear biomedical cause (American Pain Society 2001). The meta-analysis of King and colleagues (2011) reported a prevalence of paediatric chronic pain between 11-38 per cent, with higher prevalence in girls and older children. Headache (8-83 per cent), abdominal pain (4-53 per cent) and musculoskeletal pain (4-40 per cent) were the most frequently reported and investigated types of pain (King et al. 2011). Chronic pain can substantially interfere with children's daily functioning as manifested by impaired sleep patterns, and worse academic, physical, and social functioning (Gauntlett-Gilbert and Eccleston 2007; Konijnenberg et al. 2005; Logan and Scharff 2005; Logan, Simons, Stein, and Chastain 2008; Long, Krishnamurthy and

Palermo 2008). Moreover, the experience of chronic pain seems to persist in a considerable proportion of children and adolescents (Perquin et al. 2003) and may be predictive of long-term pain complaints and pain-related disability in adulthood (King et al. 2011). Interestingly, findings by McGrath and colleagues (2000) revealed that chronic or recurrent pain often start in early childhood: recurrent headache on average began around 6.8 years of age, and arthritic pain similarly started on average around 6.4 years.

Importantly, while chronic pain is less common than acute pain in normal developing children the reverse appears to be true for children with a cognitive impairment. Cognitive impairment is generally regarded as having a noticeable and measureable difficulty in remembering, learning new things, concentrating and/or making decisions, all of which influence pain expressions (Hadjistavropoulos et al. 2011). Breau et al. (2003) identified higher rates of pain prevalence in children with a cognitive impairment (aged 3-18) with 35-52 per cent of children experiencing pain at least once a week. Contrary to pain in children without cognitive impairments, the cause of the pain was mainly related to a chronic illness. For example, a new Irish study has found one in fifty children with Down syndrome have juvenile arthritis. This four-year project – undertaken at UCD School of Medicine in partnership with clinicians in Our Lady's Children's Hospital Crumlin and supported by Arthritis Ireland, Down Syndrome Ireland and the National Children's Research Centre – found that children with Down syndrome are 18-21 times more likely to suffer from the debilitating disease than children without Down syndrome (Arthritis Ireland 2017). The pain experienced due to a chronic illness in these children was also more severe in intensity and duration compared to accidental pain or pain related to a medical procedure (Breau et al. 2003). Given the vulnerability of children with cognitive impairments due to their limited verbalisation skills, it is important to gain a better understanding of and appropriate assessment of their pain.

PRIME C – prevalence, impact, and cost of chronic pain among 5-12 year olds living in Ireland

PRIME C, an Irish-wide longitudinal prevalence study, led by Dr. O'Higgins, found a surprising 10% of children in Irish Primary Schools self-reported that they had chronic pain. Previous research indicated that pain influences children's daily lives, resulting in absence from school, sleep problems, poor school performance, and problems with social activities (Claar et al. 1999; Dick and Riddell 2010; Hainsworth et al. 2007; Palermo et al. 2009). The PRIME C study characterised the nature, extent, impact and cost of chronic pain among 5 -12 year olds. Using cluster-systematic random sampling, primary schools were invited to participate and 3,116 5-12 year olds completed questionnaires in school classrooms, at three time points, one year apart. Questionnaires used

internationally valid psychometric measures to assess a range of quality of life factors and chronic pain indicators among children, with corresponding parental/primary care giver questions, which were completed at home. Data were also gathered on the cost of chronic pain.

Of the children who reported having chronic pain, there was a higher prevalence among girls and older children, similar to other studies among this age group. How pain impacted on them was different depending on the age of the child. Children aged 5-8 years with chronic pain were significantly more likely to feel alone and not get along as well with their parents. Children with chronic pain aged 9-12 were significantly more likely to feel bored, alone, scared, different, and worry about doing schoolwork compared to children without chronic pain. Hence the importance of exploring in more depth how their day-to-day lives were impacted by their pain. This led to the final phase of the study under a Knowledge Exchange and Dissemination grant working participatively with children who have chronic pain and their families (see section on Participative Health Research for more details). On the cost side of PRIME C, childhood chronic pain according to parents/care givers incurred an incremental increase of up to €500 in healthcare costs per year.

One interesting feature of the PRIME-C results, which differed from other studies, was that more of the 12-year-old boys reported pain than girls of the same age, in particular musculoskeletal pain, affecting their ability to participate fully in sports. The large amount of pain noted by boys in their lower limbs may be due to increased intensity of sports activities combined with a decrease in daily physical activity and higher levels of obesity among this age group (Riddiford-Harland et al 2015), resulting in overuse injuries. It has been suggested that this is becoming increasingly common, especially during pubescent growth spurts (Launay 2015). This may reflect the increasing difficulty of fitting physical activity into *'the time-challenged, gender-stereotyped, highly-technologized, cyber-filled lives of today's youth'* (Berger et al 2008:277). This is very pertinent for Irish primary school children where there is a strong affiliation with traditional Gaelic sports such as hurling, camogie and Gaelic football, run under the auspices of the Gaelic Athletic Association (GAA). It is important to highlight that pain in children during sports should not be considered normal, *'It is a warning sign of overtraining, which may require the activity to be modified, reduced or even discontinued'* (Launay 2015:139).

How well children learn to cope with their pain has important health implications. So how were these children coping with their pain? Over 300 children shared their pain stories with researchers during PRIME C data collection. The majority of coping strategies discussed by the children involved reduction in physical activity and distraction, this often involved their withdrawal from interactions with friends, family, physical activities and school, and were reported as having only varying degrees of success in reducing their pain.

This was the first study to explore chronic pain extensively amongst young children in Ireland (O'Higgins et al 2015). PRIME C results suggested that clinicians should explore all aspects of health-related quality of life (HRQoL) for children with chronic pain, leading to improved outcomes and lower long-term costs. Additionally, and according with previous studies, the results revealed the importance of the social environment in this young age group.

In particular, only 50 per cent of the children reporting chronic pain had parents corroborate that their child had chronic pain. These children were older; had more siblings; were more likely to have seen a GP in the last 12 months; had significantly better self-reported school functioning; and had worse self-reported family functioning. Children with chronic pain who reported not telling their parents about their pain explained that it was due to: fear of not being believed; their worries about medical intervention or not being allowed to participate in activities.

'I feel the muscles in my back are very sore, excruciatingly sore. I don't tell my parents because all they do is sort of tease me about needles and stuff'. Boy, age twelve

These children reported that their pain experiences were not acknowledged by parents

'People don't notice my pain, and my parents ignore it'. Boy, age twelve

'I told my parents but they just say it will go away'. Boy, age twelve.

A further twenty-seven parents reported a child with chronic pain, where the child did not report the same. These children were more likely to: attend a DEIS (Delivering Equality of Opportunity in Schools) school; have a father who was unemployed; have a medical card; have a parent who suffered from chronic pain; and have a chronic illness according to parental report. Relative to children who reported chronic pain, these children had poorer parent-reported physical, family and social functioning (Durand, et al. 2016).

'Most of our daughter's pain secondary to her eczema effects our whole family as she has many nights of not sleeping and crying due to pain keeping others awake as a result'. Mother of girl, aged five.

Those children who did not report chronic pain but whose parents did were reported by parents to have impaired functioning across domains. The few children whose parents confirmed their report of chronic pain appeared to engage in more effective coping strategies.

'She knows she can control the pains by understanding them. Work in progress!' Mother of girl, age nine.

Taken together, these findings suggest a strong discordance between parental and child reporting with respect to chronic pain in this young age group. This discordance has important implications for their pain management, given that children are highly dependent on their parents for help and care, and further stress the need for all caregivers to actively listen to children's perspectives to avoid negating the child's sense of agency.

The role of the caregiver responses and reliance of parental proxy reports

A strong evidence base highlights the important role of the environment, particularly parental responses, in understanding childhood pain. This is particularly true for children with cognitive impairments whom, due to limited verbal capacities, rely heavily on caregivers for appropriately advocating their needs with respect to effective pain management (Solodiuk and Curley 2003). Despite this heavy reliance on caregivers for help and care, evidence reveals a lack in confidence in healthcare professionals to undertake pain assessment in children with cognitive impairments (Carter, Simons, Bray and Arnott 2016; Malviya et al. 2005). The *Social Communication Model of Pain* is a well-recognized theoretical model illustrating the key role of pain expressions in understanding how caregivers respond to a child's pain and how these caregiver responses can in turn impact on the child's pain experiences (Craig 2009).

The Social Communication Model of Pain

The social communication model of pain (SCM), based upon Rosenthal's (1982) model of non-verbal communication, takes into account non-verbal as well as verbal pain communications. Both are key in providing effective pain management attuned to the child's needs. The model recognizes three important steps in the process of communicating pain. The first, step A, entails the sufferer's (i.e. the child's) internal experience of pain, which is encoded in expressive pain behaviours (step B). The observer (i.e. caregiver) needs to decode the child's expressive behaviour in order to draw inferences about their pain (step C). The behavioural responses of the observer, based upon the inferences the observer draw, may, in turn, have an impact upon the child's pain experience (step A) and pain expression (step B; Hadjistavropoulos et al. 2011). Detecting, interpreting and responding to the pain of others can have important implications for the recovery or survival of the person in pain, which is especially relevant in the context of paediatric pain.

Non-verbal behavioural expressions, such as facial pain expressions, crying and protective behaviour, are the main repertoire of young infants to communicate pain (Hadjistavropoulos et al. 2011). With increasing age, non-verbal behaviour gradually expands with other means of communication, such as verbal expression of pain (Craig and Korol 2008). It is important to acknowledge, though, that non-verbal pain expression remain the main form of pain communication

amongst children with cognitive impairments. While children with cognitive impairments show large individual differences in their pain expression according to their mobility, developmental level, clinical condition, and verbal abilities (LaChapelle 1999), common pain behaviours seem to fit within the following categories: vocal behaviour, eating/sleeping, social behaviour, facial expressions, activity, body and limbs, and physical signs (McGrath, Rosmus, Canfield, Campbell, and Hennigar 1998).

Of the various possible expressions of pain, facial pain expressions and pain verbalizations have been found to be among the most salient in communicating pain to others. The clarity, intensity and type of pain expression are important for accurate decoding by observers and can impact observers' inferences and related behavioural response (Hadjistavropoulos et al. 2011). For instance, these pain expressions are crucial for observers to make estimations about the child's pain intensity, which in turn is considered an important determinant of caregiving responses such as pain control. Indeed, findings have indicated parent and health care professionals' estimates of child pain influence decisions regarding pain medication; with pain underestimations contributing to lower level of comfort among parents to administer pharmacological analgesics (Maimon, Marques, and Goldman 2007; Pillia-Riddell and Racine 2009). Higher pain estimates, on the other hand, have been linked to more health care usage by children (Janicke, Finney, and Riley 2001). Hence, being attuned to both verbal and non-verbal pain expression by any child is a crucial first step in giving them a voice in their pain management.

The impact of caregiver's pain management responses on the sufferer's pain have been well documented in young children, mainly in the context of procedural pain. Specifically, parental protective responses (e.g. reassuring, comforting the child and providing empathic comments) have been associated with more pain and distress experienced by the child (Blount, Devine, Cheng, Simons, and Hayutin 2008; Manimala, Blount, and Cohen 2000; McMurtry, McGrath, Asp, and Chambers 2007; Racine, Riddell, Flora, Taddio, Garfield, and Greenberg 2016). While parental engagement in coping-promoting behaviour (e.g. distracting the child, using humour, and commands to engage in deep breathing and relaxation) in response to child pain is associated with less pain and distress and more use of adaptive coping strategies by children (Blount et al. 2008; Manimala et al. 2000). Despite being related to increased child distress, an observational study on parent's naturalistic behaviour during immunisations (Lisi, Campbell, Pillai Riddell, Garfield and Greenberg 2013) revealed soothing behaviours to be the most frequent behaviour parents engaged in. Furthermore, parental behaviours during vaccinations at pre-school age (4-6 year-olds), have been found to be a stronger predictor of child distress in anticipation of the vaccination than the child's own behaviour during previous vaccinations (Racine et al. 2016). While the exact mechanisms underlying these bidirectional influences between child and parent remain unclear (e.g. do higher levels of child

distress induce more parental protective behaviour or vice versa), these findings highlight the importance of considering childhood pain experiences as social events. Not only have parents a significant impact on their child's pain, due to on-going development of verbal and cognitive abilities across childhood, parents are often used as proxies for their child's pain experience.

Parent/caregiver reports as a proxy for child pain experiences

While self-report of pain is considered the gold standard for pain assessment, this might not be feasible for pre- or non-verbal children, such as children with a cognitive impairment. Consequently, parental or caregivers report of their child's pain is gathered to gain an in-depth report of the child pain experience. However, the accuracy of caregiver report may be limited, with evidence revealing underestimation is common (Hadjistavropoulos et al. 2011). For instance, focus groups with nurses revealed that discordance between child pain behaviour and parent proxy report is one of the barriers to nurses providing effective pain management (Twycross and Collis 2013). This discordance in reporting might be due to the variety of factors that influence parental proxy reports of pain. Beyond reliance on child pain behaviours, parental reports of their child's pain intensity are also influenced by their own worries about the child's pain, with higher parental worry related to more parental reports of child pain and distress (Caes, Vervoort, Devos, Verlooy, Benoit, and Goubert 2017; Racine et al. 2016). Parental report might be the only way to get an insight into children's pain experience for pre-verbal children, but this proxy reporting is often continued in pre-schoolers (von Baeyer, Jaaniste, Vo, Brunson, Lao, and Champion 2017) despite the ability of children as young as 3 years old to understand and communicate their pain (Jaaniste et al. 2016).

While cognitive developmental requirements for reporting on pain experiences need to be considered, especially when the pain is currently not present (see Jaaniste, Noel, and von Baeyer 2016 for a detailed overview), it might be more appropriate to rely on child self-report where possible (von Baeyer 2014). To support this self-report in younger ages, we need to be more creative in finding appropriate ways to give the child a voice.

How can young children share their experiences?

Adapted self-report scales

The use of the well-validated Faces Pain Scale – Revised (Hicks, von Baeyer, Spafford, van Korlaar, and Goodenough 2001) for children aged 5 years and older to report on their pain intensity might not be suitable for pre-schoolers due to the tendency of selecting only the first or last item of scales (von Baeyer et al. 2017). Consequently, based upon a systematic review of self-report measures of pain used pre-schoolers, von Baeyer and colleagues (2017) concluded that there is limited validation of

existing self-report tools for use in pre-schoolers and recommended a 2-step approach with simplified scales (e.g. reduced response options) in this age group. This two-step approach entails first asking the child a binary yes-no question on whether they are in pain, followed by a 3-point scale conveying mild, moderate or severe pain in case the answer to the first question is 'yes' (von Baeyer, Chambers, Forsyth, Eisen, and Parker 2013; von Baeyer et al. 2017). Mixed results have been found to date with this simplified, two-step approach. While it significantly improved pain reports in 3 and 4 year olds for hypothetical pain (von Baeyer et al. 2013), recent validation efforts within a clinical context was only successful in providing evidence for validity in 4 year olds undergoing a venepuncture, not for 3-year olds (Emmott et al. 2017). Further research is needed to establish the most suitable self-report technique for pain in pre-schoolers. For instance, combining the binary yes-no question with observational pain assessment might be a more reliable pain assessment in verbal children younger than 3 years (Emmott et al. 2017).

Observational assessment

For preverbal children and children with cognitive impairments, the gold standard is observational assessments such as the The Face, Legs, Activity, Cry, and Consolability (FLACC; Voepel-Lewis, Merkel, Tait, Trzcinka and Malviya 2002). The FLACC is a reliable, valid, and clinically useful tool, providing a comprehensive pain score on a scale from 0-10 based on 5 pain behaviours typically observed in children with cognitive impairments: facial pain expressions, legs activity, general activity level, crying, and difficulty in comforting or consoling the child (Voepel-Lewis et al., 2002). Each of these behaviours are scored on a scale from 0 -2 according to their intensity and added up to create a score ranging from 0-10 that is translatable to the traditionally used numeric rating scale (NRS) for pain intensity (Voepel-Lewis et al. 2002). The FLACC has also recently been revised to account for the individual differences in how children with cognitive impairments express their pain (rFLACC). The rFLACC harnesses parents' unique knowledge about their child by allowing them to add specific pain behaviours unique to their child to each section of the coding scheme. For instance, this individualisation revealed that for some children with cognitive impairments, a lack of expression, crying or responsiveness are key indicators of pain (Malviya et al. 2006). Despite representing the child's voice indirectly, this development of the rFLACC reflects and recognizes the need to give agency to children independently of their verbal capacities.

Participative Health Research

Going beyond the sole reliance on pain intensity, creative options exist to gain more in-depth perspective of the child's pain and impact on daily life by using participatory paradigms. Deeper insights into children's views and experiences can give adults better understandings of the reality for

children, rather than ideas tempered by memories of childhood, when we rely on proxy adult reports (O'Higgins and Nic Gabhainn 2010). Participative Health Research (PHR) is a particularly useful way to understand the health and wellbeing of children, in the present tense. It does this by providing children with opportunities to show their unique point of view and competencies, and to use their perspectives and experiences to shape the research topics, research methods, and the interpretation and reporting of the findings (Gibbs et al. 2017). PHR with children is a rights-based approach, consistent with the United Nations (1989) Convention on the Rights of the Child (Lundy and McEvoy 2012), in Ireland's the National Children's Strategy (2000) and the National Strategy on Children and Young Peoples' Participation Decision Making 2015-2020 (2015). PHR acknowledges children as capable social actors who have their own views and agency while supporting safe spaces for children's participation and is inclusive of different levels of communication skills (Gibbs et al 2017). It creates conditions for children's empowerment, encouraging their contributions on issues that are relevant to their own lives, as well as their community (Kellett 2010).

Essentially, PHR seeks to undermine power relations in the production of knowledge (Nieuwenhuys 2004). Empowerment, by dissolving the power hierarchy, involves engaging participants in the research process in order to maximize equity. It differs from power balance in that it can be seen as *'the end result of participative practices where each participant has control and/or influence over the issues of concern to them'* (Barry1996:2). The possibility of empowerment for those involved is one of the key elements of participatory research approaches (Bowd et al. 2010). However, researchers need to acknowledge they may not actually *'know what would be empowering for others'* (Gore 1992: 63). Cross did investigate longer-term consequences as the process unfolded over time and provided evidence that the ways in which children felt participatory research processes to be empowering, and the extent to which they engaged with them, were shaped by the power constraints which children continue to experience (and of which some are aware) within their own lives (Cross 2009). Researchers' argument that children are competent as research participants (Alderson1995; Alderson and Morrow 2004) works once one accepts that children's competence is different from, and not necessarily of lesser value, than that of adults (Kellett 2005). Empowerment is possible if researchers make the effort to communicate and accept participants as equals; as the experts in their own lives.

Hence, the choice of method of representation during the Knowledge Exchange and Dissemination phase of the longitudinal cohort study of the prevalence, impact and cost of chronic pain among 5-12 year olds living in Ireland (PRIME C) was considered carefully in order to enhance the communication between children and the adult researcher. An important point is that children cannot be reduced to a *'homogenized group of others'* (Schafer and Yarwood 2008:123); age being a significant factor in their differences, experience and maturity being another. Methods need to be both

appropriate and acceptable to the group of children involved (Hill 1997); *'even methods that are defined as participatory can be disempowering and excluding for respondents if used with the wrong group, in the wrong situation or the wrong way'* (Boyden and Ennew, 1997:83).

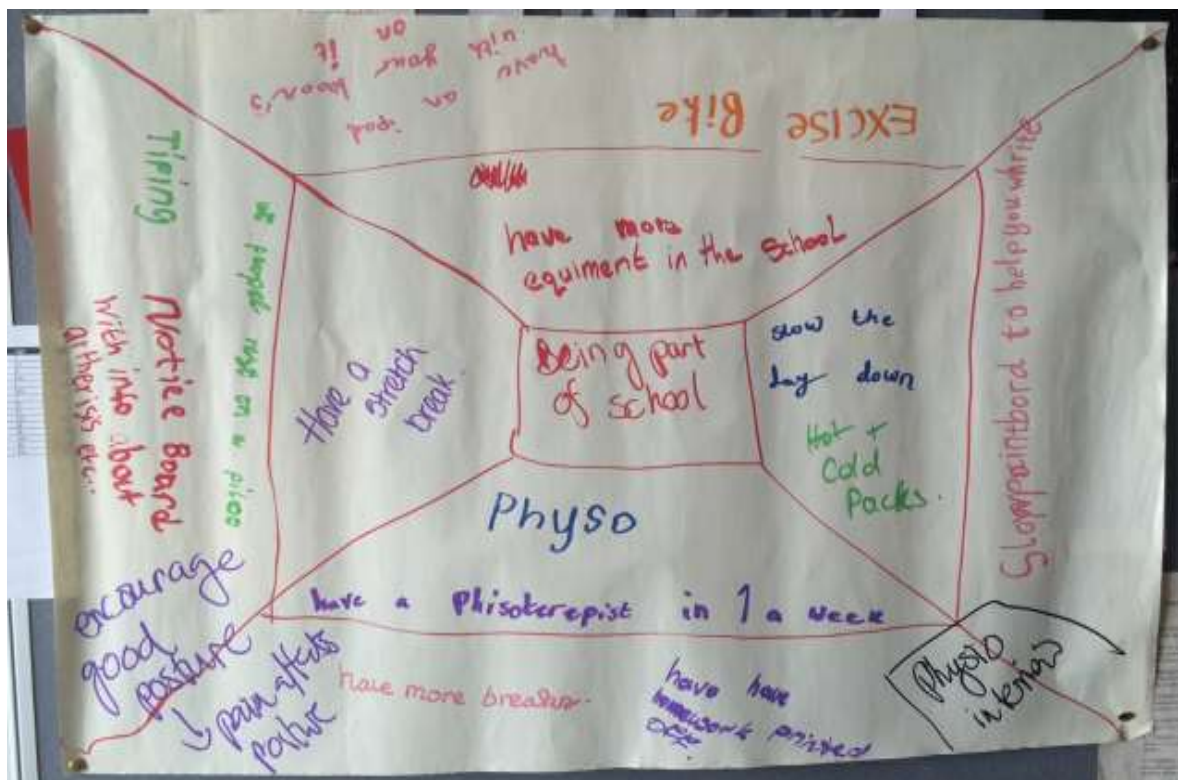
Knowledge Exchange and Dissemination phase of PRIME-C as an example of PHR

The value of adding PHR as a further layer to the PRIME-C study became clear as the children shared their pain stories, which made us aware that not only were children not telling adults about their pain but, when they did tell their teachers, the reaction from staff in the primary schools was not necessarily the best. For example, children reported that they were told to drink water and/or put their head down on their desks, or wait away from their classmates for someone to take them home, so isolating and differentiating them from their peers.

These findings stimulated the researchers to work together with the children to explore how best to create an intervention for teachers to raise awareness of paediatric chronic pain and possibly more effective management strategies. A first step in this approach was to invite 15 children (aged 5-11; 13 girls and 2 boys) who live with chronic pain due Juvenile Idiopathic Arthritis and their families to a PHR workshop. The workshop turned into a picnic on a sunny Saturday afternoon in Dublin; chosen as a central location. In this way, we overcame one of the challenges of working with children out of the school setting, i.e. securing parental consent and acquiescence to transport their children to an event. The PHR workshop involved asking our young participants individually to share their perceptions on issues that affect them on a daily basis either with drawings or words on pieces of coloured paper, without any input or direction of the researchers. This first step is crucial, as from past experience and with a commitment to work with 'the experts' (i.e. the children living with chronic pain), researchers' and adult ideas may well be different from the lived reality. Working in two small groups, the children collated all their ideas into themes by playing a variation of the snap card game (all the individual ideas were dealt out by the youngest member of each group face up – to increase saturation with all the ideas from the other children - thus piles of similar issues generated and each pile labelled by the children). They all discussed and chose the most important area that they then explored in more detail as: *'being part of school life'*. With that issue in the centre, they developed a 'Web of Ideas' about how best to support children with chronic pain to participate more fully in primary school life (See figure 1). Throughout the activity, all decisions were fully controlled by the children, with minimal direction or input from the researcher.

Figure 1: Web of Ideas

The ideas identified by the children became the basis of an awareness raising exercise lead by the children. The children on our PHR picnic decided to make videos to illustrate how chronic pain impacts on them and some ideas on how to improve their ability to 'be part of school'. Using their



parents' phones, they went to work. This process is still on-going, with work currently focused on finalising this educational and awareness-raising video for teachers and primary schools. We plan to release the video on YouTube for all the families involved in the project and a wider audience including the thirty-nine schools involved in the PRIME-C study.

Using the video as a starting point, we will then work with primary schools, principals and teachers, to create guidelines on how to proactively best support children who live with chronic pain to participate, as fully as possible, in primary school life. The guidelines will then be circulated to all primary school principals with the expectation that each school will adopt and adapt them to suit their own community context. It is known that 80 per cent of academic achievement is due to the teacher-child interaction (Thackore 2016). If children with chronic pain can remain engaged within the learning environment with the support of their primary teachers, then their potential to thrive and fully participate in post primary school will be enhanced.

While these examples on PHR reflect the usability of listening to children's narratives within a research context, this technique has also been proven valuable in accepting children as active agents within their clinical pain management. Carter (2004), provided an excellent overview of how to use this narrative approach in clinical settings.

Creative techniques

Other ways of creatively involving children using arts-based techniques have been developed and evaluated. While the application of these approaches is limited in the context of pain, they show promise in offering children a voice, especially non-verbal children (Carter and Ford 2013). Such techniques accommodate to children's skills, capacities, experiences, and interests and include photo-elicitation, poems, performances, collages, as well as drawings. An example of using photographs on a large scale was during the development of Child Indicators of Wellbeing. Children across Ireland identified indicators of their own wellbeing. Using disposable cameras, children were asked to take pictures of 'What makes you well' and 'What keeps you well'? Other groups of children then categorized the photographs and a final group of children created a schema of these themes. This process created Ireland's Child Wellbeing Indicators and highlighted how important pets are in many children's lives (Sixsmith, Nic Gabhainn, Fleming and O'Higgins 2007). The main aim of these techniques is to expand the way children express themselves, while appreciating that not everything has to be channelled through words. All these techniques tend to reduce the power imbalance between children and caregivers/researchers by supporting the child's agency (Carter and Ford 2013).

Examples of applying this to the context of pain can include making a collage of worst pain events or drawing your worst headache on a postcard and address this postcard to someone important to the child. These techniques are in their infancy and need further exploration with respect to their reliability for both research and clinical purposes; Carter and Ford 2013 provide an overview of practical tips concerning these creative techniques.

Conclusion

In conclusion, within this chapter we aimed at providing an overview of the prevalence of both acute and chronic pain in young children, from birth up to 12 years of age, as well as highlighting the importance of supporting and listening to the voices to these young children. While children are highly dependent on their parents for help and care, and parental responses to pain influence the child experiences, gaining the child's own perspective is of crucial importance for effective pain management. Discordance between parent proxy and child self-report might pose a difficulty for healthcare professionals, but are important to further explore in more detail as they can reflect an important underlying issue (e.g. high parental proxy reports might reflect heightened levels of parental worries).

Furthermore, continued development and implementation of creative techniques, beyond the reliance on self-reports, are pivotal to gain a better insight of young children's pain and are of importance to empower young children and children with a cognitive impairment to share their experiences. Using creative methodologies to listen to children are particularly appropriate in this young age group as it matches with their usual ways of communication (i.e. drawings, pictures) while their verbal skills continue to develop and improve (Caes and Jordan 2017).

Gaining a better understanding of pain experiences in young children by giving them a voice will also facilitate the development of more age-appropriate tools to assist these children in learning adaptive ways to cope with pain. This is of importance as learning adaptive pain management techniques early on in life, might promote resilience when faced with pain and thereby prevent continued disability, due to pain, in later childhood, adolescence and even adulthood.

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Glossary

Cognitive impairment is generally regarded as having a noticeable and measureable difficulty in remembering, learning new things, concentrating and/or making decisions.

Pain-related disability or impaired functioning refers to how pain impacts on everyday activities, including sleep patterns, school, physical, mental, social and family life.