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ORIGINAL RESEARCH

# Development and feasibility testing of a Pain Neuroscience Education program for children with chronic pain: treatment protocol


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**Abstract**
*Background:* Current treatment for adults with chronic pain often includes Pain Neuroscience Education (PNE) to make people understand the nature underlying their pain and thus provides a clear rational for a biopsychosocial approach. Despite recommendations to use Pain Neuroscience Education as well in children with chronic pain, a specific program, tailored to children aged 6–12 years is lacking.
*Objectives:* The aim of this study was to develop a Pain Neuroscience Education program for children with chronic pain and test its feasibility.
*Methods:* First the internet and scientific literature was searched for sources (e.g., books, videos, etc.) that might be supportive in teaching children about the neurophysiology of pain. Based on this content, we developed a Pain Neuroscience Education program for children, 'PNE4Kids', which was tested for feasibility in three groups of healthy children ($n = 18$; 9 girls and 9 boys) aged between 6 and 12 years old.

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*Results and conclusions:* This paper provides both scientists and clinicians with a specific program to explain the neurophysiology of pain to children with chronic pain, since it is past high time to use a modern neuroscience approach in this vulnerable population. Further research should examine the effectiveness of this developed PNE4Kids program on pain-related outcomes in children with chronic pain.

Registration number: NCT02880332 (https://clinicaltrials.gov/ct2/show/NCT02880332).


## Background

Chronic pain, generally defined as continuous or recurrent pain episodes lasting more than 12 weeks, is a very distressing and debilitating problem in children and adolescents. Previous epidemiological research suggests median prevalence rates of 11–38% for children with chronic pain.[1] The most occurring chronic pain types in children are headache, abdominal pain, back pain and musculoskeletal pain.[1] Persistent pain periods mainly affect the children's school attendance and participation in recreational activities, possibly leading to academic impairments and social exclusion.[2,3] Even worse is children's greater predisposition to develop chronic pain into adulthood.[4] Considering these disadvantages, children suffering from chronic pain should be treated as fast as possible and in the most optimal way. As such, research regarding the most efficient and affordable strategies to treat this population should be advocated.

### Non-pharmacological interventions for the management of chronic pain in children: state of the art

The existing literature on pain management in children with chronic pain encourages a multidisciplinary approach involving physical therapy and psychological interventions.[5] Landry et al.[5] reported that (1) daily aerobic physical exercise, (2) a progress to sports-specific functional activities and (3) education on pacing and consistent activity level should be prescribed for all children with chronic pain, irrespectively the pain condition.[5] In the past, psychological interventions often included relaxation therapy, sleep and stress management.[5]

Up to recently, research from the psychological field favours the use of behavioural or cognitive behavioural therapy (CBT) for many chronic pain conditions in children (chronic headache, recurrent abdominal pain and juvenile idiopathic arthritis and fibromyalgia).[6] CBT focusses on the development of personal coping strategies, which help patients to solve current problems and change unhelpful patterns in cognitions (e.g., thoughts, beliefs, and attitudes), behaviours, and emotional regulation.[6] A systematic review conducted by Fisher et al.[7] confirmed its effectiveness in reducing pain intensity in children with chronic pain conditions, such as juvenile idiopathic arthritis, musculoskeletal pain, headache and recurrent abdominal pain.[7] Despite its beneficial effects, adherence to CBT is rather low.[8] More specifically, negative attitudes and beliefs regarding the recommended intervention were considered to be the most frequently cited reasons for quitting treatment among non-adherents.[8]

Although CBT for children often includes some educational information on pain before teaching them accurate coping mechanisms, it is often based on the role of cognitions in 'fuelling' pain and the paradigm that pain is 'unavoidable', supporting the need for accurate coping, rather than explaining the underlying biological mechanisms of pain.[9] When patients' beliefs about pain as an accurate marker of tissue damage are not addressed during education, treatment aimed at changing the patient's attitudes and behaviours might be counterintuitive[10] and seems to lose its positive effects in the long-term.[9] Therefore, in addition to the current existing CBT approach, children might benefit from supplementary treatment including an explanation about the neurophysiology of pain.[11]

### Pain Neuroscience Education: promising (but unexplored) intervention in children

Pain is conceptualized as a biopsychosocial process, thus requiring interventions targeting the underlying neurophysiology of chronic pain in its totality. Primarily this means teaching patients about the function of pain, how pain originates, which changes occur when pain becomes chronic, and the role of ones' thoughts, feelings, behaviours, environmental and social factors etc. in the origination and sustenance of pain. This initial and crucial educational part, termed Pain Neuroscience Education (PNE), makes people understand the nature behind their pain and thus provides a clear rational for a biopsychosocial approach, thereby increasing the likelihood that an appropriate cognitive and behavioural response will follow.[12] This enables patients to integrate this understanding into their everyday live (i.e. their beliefs, attitudes and behaviours) and subsequent treatment.[13] This innovative education style has shown to be effective in various adult chronic pain populations, by changing their pain beliefs and by improving the patients' pain coping strategies and health status.[14,15] To date, no study examined the effectiveness of PNE in children with chronic pain. Although, one might presume its relevance in this particular population, based on the following reasons.

When children (with chronic pain) do not understand the origin of their pain, they might develop inappropriate pain beliefs, sustaining the vicious circle of chronic pain.[16] Indeed, inappropriate pain beliefs such as pain catastrophizing might aggravate a child's functional disability.[17] In addition, adolescents with chronic pain seem to mediate their inappropriate pain beliefs by passive coping strategies.[18] Pain coping and pain beliefs might be positively addressed by PNE.[14,15] Moreover, since previous findings indicate that a better understanding of the nature of the illness results in improved patient outcomes,[19] PNE should be provided to children.

Secondly, emerging empirical inquiry suggests that central sensitization might be present in children with chronic pain.[20] Several studies report signs of secondary hyperalgesia in children with juvenile fibromyalgia and juvenile idiopathic arthritis.[20] In the latter population, Cornelissen et al.[21] found altered detection thresholds in response to thermal, mechanical and vibration stimuli. In children with migraine and recurrent abdominal pain, different cortical nociceptive processing was found.[22,23] Given that the presence of central sensitization has been identified as a predictor of poor therapy outcome in adults,[24–26] we advocate that targeting the processes underlying central sensitization is an important consideration in children with chronic pain as well.

Based on the understanding that parental beliefs about the aetiology of the child's pain influences the child's pain outcomes,[27] parents should be involved in PNE for children as well. Indeed, research findings support the importance of giving parents information about their child's pain, especially before actual treatment is started.[28] Besides, many parents of children with chronic pain seek numerous specialists in their determination to find an organic reason for their child's pain. They are not willing to accept that their child's pain might exist without any organic tissue damage. In fact, during this never- ending search, they are not at any time taught about the awareness that pain and tissue damage are not synonymous; their child's pain might be disproportionate to tissue damage and can even be reported without it. On the contrary, it also occurs that parents consider their child's pain as something imaginary or unreal, which might result in ignorant behaviour.

For the reasons outlined above, the application of PNE in paediatrics seems warranted. However, in accordance to the review of Robins et al.,[29] no studies were found examining the use of PNE in children. Previous studies investigating educational programs (e.g. psychoeducation) mainly focused on pain management rather than teaching people about the biological processes underlying pain. Some studies examined the effect of pre-operative pain education for children. For example, Crandall et al.[30] investigated the value of pre-operative pain education in children who needed a tonsillectomy. It did not affect the children's post-operative pain level or anxiety level, however, children's perceptions of pain education were promising; they reported that pre-operative pain education is useful to learn about pain. Again, these educational interventions did not include any explanation about the biological processes underlying pain, but were rather based on an explanation about the surgical procedure and subsequent pain management.

Hence, the potential of PNE has not been explored in children with chronic pain, and given the previously indicated need for PNE in the child population, we developed such a PNE program (PNE4Kids) adapted to the specific population.

## Development of a Pain Neuroscience Education program for children (PNE4Kids)

The program development occurred in several stages, each of which are described below.

### First step: shaping the content of the PNE4Kids

The first step comprised searching the internet for all kinds of sources (e.g., books, videos, etc.) that might be supportive in teaching children about the neurophysiology of pain. Most published books about pain in children include some explanation about the neurophysiology of pain, but have been directed towards parents of youth with chronic pain.[29] Even though these books might be useful for parents in providing them valuable insight to help their child manage chronic pain, the PNE content still not matches a child's cognitive capacity.

Yet, one book, '*Cuentos Analgesicos*' by Cubas,[31] appeared valuable in developing PNE4Kids.[31] The book explains pain neuroscience mainly to pain practitioners and parents, including fairy tales about the neurophysiology of pain at the end of the book, which can be used to explain pain neuroscience to children. Each story was built to explain a specific pain concept, term or manifestation that might occur when suffering from (chronic) pain. For example, one fairy tale explained secondary hyperalgesia, another story explained the influence of pain memories on pain experience, etc. Although useful for therapists and adults (i.e., parents) to comprehend pain, most stories are too complex for the child to understand and translate it to their individual pain problem. Besides, it is anticipated that the process of reading out and explaining each story to the child would be too time consuming for its application in clinical practice.

The most optimal way to develop PNE4Kids would be to start from the existing adult PNE, which is based on the book '*Explain Pain*' by Butler and Moseley.[32] It includes a description on how the nervous system interprets information from tissues (i.e. muscles, organs, joints, etc.) through peripheral nerve sensitization, central sensitization, synaptic activity and brain processing. Secondly, it explains how pain experiences in response to (or in absence of) nociceptive input can be modulated by neural activation, either upregulation or downregulation.[33] Throughout the education sessions for adults, many metaphors are used to explain the complex matter in a comprehensible way, e.g. the metaphor of the burglar alarm.[32] Still, challenging neurophysiology terms are used and adults are presumed to have basic understanding of the human body. As a result, the adult PNE content had to be adapted to a child's cognitive capacity and world. Intensive brainstorm sessions with experts (physical therapists; psychologists and researchers) in PNE education for adults and parents, but also with a primary school teacher and an expert from the Royal Belgian Institute of Natural Sciences, both experts in educating children about science, and with

parents of children between 6 and 12 y, led to a first draft of the content for children.

### Step 2: feasibility testing of the PNE4Kids content

Once drafted and before testing the PNE4Kids in a pilot study (Clinical Trials Identifier NCT02880332), we wanted to ensure that the PNE4Kids content was tailored to children aged 6–12 years. Therefore, section 1 of the PNE4Kids content was evaluated in two groups of healthy children ($n = 12$; 6 girls and 6 boys), aged 9–10 years from a primary school (Asse, Belgium). The PNE4Kids session was delivered in a to the child familiar (class)room, before noon and lasted approximately 40 minutes. Both sessions were recorded on videotape and sent for feedback to three experts in PNE (clinical as well as research expertise) in adults ($n = 3$). The individual expert's comments and suggestions were discussed among the experts and the following improvements were made; (1) the terminology used during the PNE4Kids session was further simplified and (2) the duration of the session was shortened to 30 min to avoid a decrease in the children's attention. Afterwards, the PNE4Kids session was evaluated a third time in the youngest group of interest; children aged 6–7 years from a childcare facility (Asse, Belgium).

## Pain Neuroscience Education program for children or 'PNE4Kids'

The PNE4Kids program contains three sections: The first section addresses the nociceptive system and its function, divided in subsections each consisting of a specific neurophysiological pain concept (i.e., the nervous system anatomy, nociception and nociceptive pathways, up- and down-regulation of the nervous system). The second part encloses an explanation about adaptations in the nociceptive system following persistent pain (including increased sensitivity of the central nervous system). The third section addresses the translation and application of the PNE4Kids content into the patient's everyday life and subsequent treatment.

To ensure interaction between therapist and child, an interactive board game was developed and used throughout the educational session (Fig. 1). In addition, the use of specific neurophysiological terms (e.g., action potential, nociception, etc.) was avoided by replacing them with a specific entity, recognizable to the child (for example, the 'spinal cord' was called 'the elevator of our body'). To enhance the children's comprehensibility, only one metaphor is used during PNE4Kids. More specifically, 'the nociceptive system', which functions as a defense mechanism, is compared to 'the army', that protects human beings in real life situations. The detailed content and material that were used during PNE4Kids, is available on http://www.paininmotion.be/PNE4Kids.[b] Table 1 summarizes the differences between adult PNE and PNE4Kids.

[b] URL is already active on our website, but our webmasters still need to add the content. The webpage is under construction.

**Figure 1** Application of the interactive board game during PNE4Kids The brain, spinal cord and nerves are removable board pieces. The interactive board game presented in this paper, is intellectual property of the Vrije Universiteit Brussel.

**Table 1** Adaptations of adult Pain Neuroscience Education (PNE) to PNE4Kids.

| Adult PNE | PNE4Kids |
|---|---|
| Supporting material during PNE session: PowerPoint presentation, educational booklet | Supporting material during PNE session: interactive tool (board game), videotape, drawings and educational booklet |
| One-on one session | 1 therapist, 1 child and parent involvement |
| Detailed explanation | Simplistic explanation during board game; specific neurophysiological terms replaced by an appropriate allegory |
| Pain concepts explained by using different metaphors and stories | Pain concepts explained by using a coherent story throughout board game (e.g., in terms of army) |

## Conclusion

The effectiveness of PNE in several adult chronic pain populations raised the question whether PNE might also gain positive results in the treatment of children with chronic pain. To the best of our knowledge, no PNE material tailored to children aged 6–12 years exists, neither did any trial investigated the efficacy of PNE in children with chronic pain. Therefore, we developed PNE4Kids, as explained above. The pilot testing supports its feasibility. In an ongoing pilot study (Clinical Trials Identifier NCT02880332), the developed PNE4Kids program as presented here, is examined in children with chronic abdominal pain. Further studies should also investigate the benefits of PNE4Kids as part of a

wider multimodal rehabilitation program, as it is clinically intended. Although this PNE4Kids is primarily developed for children with chronic pain, its content may also be adapted and subsequently used to educate children experiencing acute or procedural pain or even to prevent pain chronicity in children who will have to undergo multiple acute pain episodes.[34]

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## Conflicts of interest

The authors declare no conflicts of interest.

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