

Adaptation of the Adult Neurophysiology of Pain Questionnaire for Use in Paediatrics

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Abstract

Background: Pain knowledge is often measured using the Neurophysiology of Pain Questionnaire (NPQ). The original NPQ was designed for adult populations and to-date, not adapted for kids. The aim of this study was to determine if the NPQ could be adapted for people aged 10-14 years old.

Methods: Using a Delphi framework, the adult NPQ questionnaire was evaluated by a convenience sample of experts for appropriate language and content for people aged 10-14.

Results: After three phases, consensus was reached on an adapted NPQ entitled NPQ-peds.

Discussion: Increased knowledge of pain has shown various benefits to people in pain, including reduction in self-reported pain, disability, fear-avoidance, pain catastrophizing, limited movement, and healthcare utilization. The NPQ has been used as the primary tool to measure increases in pain knowledge in a variety of diagnoses, clinical settings, and patient populations, including kids. To date, it's never been specifically scrutinized for use in kids with pain. Paediatric physical therapists can now begin to use the NPQ-peds to better understand patient's understanding to improve healthcare decision making.

Keywords: Pain Knowledge; Kids; Pain Neuroscience Education; Physical Therapy

Abbreviations

NPQ: Neurophysiology of Pain Questionnaire; NPQ-peds: Neurophysiology of Pain Questionnaire Paediatrics; PNE: Pain Neuroscience Education; US: United States.

Introduction

Epidemiological data indicates that approximately one in four people in the world experience some form of persistent

pain on a regular basis [1,2]. Preliminary data shows that the Coronavirus pandemic of 2019 (COVID19) added to the global pandemic of pain, as well as behavioural and mental health issues such as depression, anxiety, and social isolation [3-6]. In the United States (US) specifically, the COVID19 pandemic potentially increased the opioid epidemic [7]. More recently, pain data started highlighting a sub-group of people experiencing persistent pain – high-impact chronic pain, a subset of patients where pain significantly restrict daily living activities (work, social, and/or personal



care activities), experience more mental health problems, cognitive disorders, and personal care difficulties, and to use more healthcare services than patients with chronic pain not accompanied by activity restrictions [8,9].

This global, ever-increasing pain epidemic consumes significant resources globally and many of the current strategies aim to provide care for those impacted by persistent pain. This may include medical (pharmacological, surgical, etc.), behavioural (psychotherapy, cognitive behavioural therapy), rehabilitation (various forms of active physical treatment) and more [10,11]. As with most epidemics, tertiary care, although much needed to ease pain and disability, is only one part of the equation and unless significant upstream efforts are employed, this epidemic has little chance to decrease [12].

Regarding upstream efforts, historically, education, especially mass-education is needed - on a global scale. Campaigns such as smoking cessation, handwashing, early screening for cancer, and more, are significant public health examples that impacted major global healthcare issues [13-16] Within these campaigns, education allowed humans to learn more about disease states, and use this newfound knowledge to make healthier decisions. Even though education has been shown to have limited ability to change behaviours, smoking cessation campaigns show that 20% of smokers stop smoking after these campaigns and given the global prevalence of smoking, it could be argued such efforts have a place in smoke cessation [17]. In regards to pain, it has been proposed that a global pain literacy campaign be developed and delivered, with the intention to similarly increase knowledge about a disease state (persistent pain), and hopefully change behaviours [12,18-20]. To this effect, a series of recent studies set out to develop a pain literacy strategy for middle school students in the US, culminating in a multi-arm, public health trial that showed students who learned more about pain, increased their knowledge of pain, and more importantly changed behaviours, including a 30% reduction of the use of pain medication during the school year and increased participation in sports, recess, physical education and less absenteeism from school [12,18-21]. Ideally, for any upstream program to work, it should target the key participants. Today's children will be tomorrow's adults, and it's well established that pain experiences early in life not only predict pain experiences later in life, but also more powerfully their choices in treatment [22-25].

One major shortcoming in the series of studies related to pain neuroscience education (PNE) for middle school students was one of the instruments used [19,20]. The neurophysiology of pain (NPQ) questionnaire was designed and tested as an instrument in adults and used in the middle school programs [26-28]. The authors repeatedly highlighted the fact that the NPQ was used in their studies, and even though they showed significant improvements in pain knowledge after pain education, was never validated for children [18-20] The aim of this study was to review and develop an NPQ specifically for kids experiencing pain – NPQ Paediatrics [NPQ-peds]. Future studies then can test if the newly designed NPQ-peds is a better tool for measuring pain knowledge in kids than the original (adult) NPQ.

Methods

Study Design

This study utilized a 3-phase expert consensus method for adaptation of the NPQ for use by people aged 10-14 years old. This study design was based on the theoretical framework for the Delphi technique [29]. A feasibility study was chosen for this study since a tool exists for adults that has had rigorous psychometric testing completed. Adapting this tool for the age group was deemed the best way to have consistency across all age groups. In phase 1, the experts were asked whether each statement was appropriate for a person age 10-14 years old. They were also invited to provide suggestions on better phrasing. Any statement that had lower than a mean of 7 were then edited for the next round (Appendix 1).

In phase 2,3 suggestions for each statement were sent to the experts for consensus on best choice. The focus on phase 2 was readability, and the experts were the middle school teachers since they are most aware of reading levels. For phase three, the focus was on whether the content aligned with the original intent of the NPQ statements, so the pain experts evaluated this.

Participants

Four different groups of experts were recruited to evaluate the adaptation of the questionnaire, including a convenience sample of middle school teachers, pain experts, physical therapists who were part of the various previous PNE middle school studies for kids, and paediatric physical therapists. Participants were recruited via the professional network of the authors of the previous PNE studies, as well as a physical therapy pain fellowship in the US.

Middle school teachers were chosen given the current PNE research being conducted in middle schools and the convenience sample was from the authors and paediatric physical therapy contacts and professional network and connections of previous PNE study therapists [12,18-21]. Additionally, middle school teachers were selected due to their knowledge of reading and writing levels and patterns understood by the targeted age group. A convenience sample of pain experts were chosen due to their expert knowledge and experience with the NPQ. This included physical therapy pain science authors in the realm of PNE and the NPQ within the last 5 years based on a review of the current PNE literature.

Physical therapists who were part of the various previous PNE middle school studies delivering the classes to students were identified and invited to participate [12,18-21]. Finally, a convenience sample of paediatric physical therapists who routinely assess and treat patients within the targeted demographic of students was included.

Survey Methods

In phase 1 of the study, the identified participants were sent an electronic mail (E-mail) describing the study including the aims, invitation to participate in the study, current NPQ and an NPQ feedback form (Figure 1). A reminder email was sent 7 days later to participants who did not reply to the initial invitation. Participants were asked to complete phase one of the Delphi study in 30 days.



Following feedback from the expert panel in phase one, changes to the NPQ were made and sent back to experts for further review and feedback, again in 30 days. Following feedback from the expert panel in phase two, changes to the NPQ were made and sent back to experts for further review and feedback, again in 30 days. Per accepted Delphi study techniques, this process is repeated until a 70% consensus is reached for the new questions for the NPQ-peds [29,30].

Instruments

For this study two instruments were used: Neurophysiology of pain questionnaire (NPQ): The NPQ is based on a current pain science text and has been used in a previous study measuring the neurophysiology knowledge of patients and healthcare personnel [26]. The original NPQ is a 19-item questionnaire requesting 'true'; 'false'; or 'not sure' answers to statements, with higher scores indicating more correct answers. Since the development of the NPQ, a statistical analysis of the NPQ has led to the development of an abbreviated NPQ with 12 questions, which removed ambiguous questions [27].

The revised 12-question NPQ was used in this study. No data is available in patients or healthy controls as to what constitutes a meaningful shift. Adult studies (ages 18 and above) have shown NPQ mean improvements after a PNE session to typically range between 25-30% [26,31-33].

NPQ feedback form: In order to capture recommended changes to the NPQ, participants were given the NPQ and asked to rate, on a Likert scale anchored between 0 (strongly disagree) and 10 (strongly agree) if they felt children or adolescents aged 10-14 years old would be able to read, interpret, and understand the statement about pain. Additionally, an extra column was provided to allow experts to provide suggested changes to NPQ statements for further evaluation during the Delphi study phases. Demographic data from the expert panel was additionally obtained including highest degree, country and/or state of residence, and years of experience.

Results

Expert panel

Invitation to the study was sent to 49 individuals, including 13 middle school teachers, 15 pain experts, 8

physical therapists who participated in the recent PNE middle school initiative and 13 paediatric physical therapists (Table 1). Overall, 30 experts participated (61% response rate), with a mean experience of 17.75 years, representing 1 non-US expert, and 29 US experts representing 12 states.

Expert	Invited	Participated	Response rate (%)	Mean experience (years)	Highest degrees
Middle school teachers	13	11	84.6	19.29	Master's 8 Bachelor's 3
Pain experts	15	7	46.60%	10.33	PhD 2 DPT 3 Master's 2
PNE physical therapists	8	4	50%	25	DPT 3 Master's 1
Pediatric physical therapist	13	8	61.50%	23.3	DPT 8

Table 1: Expert panel.

NPQ-peds: Phase 1

Thirty experts representing the four expert domains completed phase 1 (Table 1). Six of the twelve NPQ questions

reached the 70% consensus threshold for the Delphi study (Table 2). The remaining six statements on the NPQ failed to reach 70% consensus (Table 2), requiring the remaining six statements to undergo further consensus feedback.

NPQ Number	NPQ Statement				
NPQ Statements not in need of change for the NPQ-peds					
10	Pain occurs whenever you are injured.				
8	Worse injuries always result in worse pain.				
12	The brain decides when you will experience pain.	8.97			
3	Pain only occurs when you are injured or at risk of being injured.	8.03			
7	Chronic pain means that an injury hasn't healed properly.	7.6			
1	It is possible to have pain and not know about it.	7.33			
NPQ Statements in need of phase 2 expert review					
5	Special nerves in your spinal cord convey 'danger' message to your brain.	6.6			
11	When you injure yourself, the environment that you are in will not affect the amount of pain you experience, as long as the injury is exactly the same.				
2	When part of your body is injured, special pain receptors convey the pain message to your brain.	5.83			
4	When you are injured, special receptors convey the danger message to your spinal cord.	5.8			
6	Nerves adapt by increasing their resting level of excitement.	4.73			
9	Descending neurons are always inhibitory.	1.87			

Table 2: NPQ Consensus phase 1 – ranked from highest to lowest.

NPQ-peds: Phase 2

During phase 1, experts were asked to provide alternative wording for the NPQ statements they deemed troublesome for kids to comprehend. In phase 2, paediatric physical therapy experts selected three alternative options for each of the remaining six NPQ statements below the 70% threshold to be scrutinized to best fit kids in the middle-school age.

The six remaining NPQ questions with three alternatives were sent back to the eleven middle school teachers to choose the best alternative statements (Table 3), with 100% response rate.

NPQ Number	Original statement	Options for phase 2 with consensus choice (bold)		
5	Special nerves in your spinal cord convey 'danger' message to your brain.	 Special nerves in your spinal cord send the danger message to your brain. Special nerves in your spinal cord tell the brain you are in danger. Special nerves in your spinal cord communicate the danger message to your brain. 		
11	When you injure yourself, the environment that you are in will not affect the amount of pain you experience, as long as the injury is exactly the same.	 When you hurt yourself, what is happening around you will not cause you to feel less or more pain, as long as the injury is exactly the same. If the injury is exactly the same, the environment you are in will not affect the amount of pain you experience. When you injure yourself, the environment that you are in will affect the amount of pain you have. 		
2	When part of your body is injured, special pain receptors convey the pain message to your brain.	 When part of your body is injured, it activates nerves that tell the brain the body is in pain. When part of your body is injured, specific pain receptors communicate the pain message to your brain. When part of your body is injured, special nerves that sense pain send a message to your brain. 		
4	When you are injured, special receptors convey the danger message to your spinal cord.	 When you are injured, it activates nerves that tell your spinal cord something is wrong. When you are injured, special messengers bring the danger message to your spinal cord to communicate that something is wrong. When you are injured, special pain receptors that sense pain send a danger message to your spinal cord. 		
6	Nerves adapt by increasing their resting level of excitement.	 Nerves can change by becoming more or less sensitive. Nerves adapt by becoming easier to turn on. Nerves adapt by increasing their normal level of sensitivity. 		
9	Descending neurons are always inhibitory.	 Nerve messages that come down from the brain always stop pain Nerves sending messages from the brain are always to calm things down. Messages from the brain always calm nerves in the body. 		

Table 3: Best alternative statements.

NPQ-peds: Phase 3

Phase 2 specifically focused on comprehension and readability for middle school kids. With choices made, the new proposed statements needed to be vetted by pain experts to ensure the original intent and scientific accuracy remained intact. In phase 3, the new options were circulated to eleven pain experts.

All eleven completed phase 3 (100% response rate), with 100% agreement with the new statements, resulting in the final NPQ-peds (Table 4).

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Number	Original NPQ	NPQ-peds	
1	It is possible to have pain and not know about it.	It is possible to have pain and not know about it.	
2	When part of your body is injured, special pain receptors convey the pain message to your brain.	When part of your body is injured, special nerves that sense pain send a message to your brain.	
3	Pain only occurs when you are injured or at risk of being injured.	Pain only occurs when you are injured or at risk of being injured.	
4	When you are injured, special receptors convey the danger message to your spinal cord.	When you are injured, special messengers bring the danger message to your spinal cord to communicate that something is wrong.	
5	Special nerves in your spinal cord convey 'danger' message to your brain.	Special nerves in your spinal cord tell the brain you are in danger.	
6	Nerves adapt by increasing their resting level of excitement.	Nerves can change by becoming more or less sensitive.	
7	Chronic pain means that an injury hasn't healed properly.	Chronic pain means that an injury hasn't healed properly.	
8	Worse injuries always result in worse pain.	Worse injuries always result in worse pain.	
9	Descending neurons are always inhibitory.	Messages from the brain always calm nerves in the body.	
10	Pain occurs whenever you are injured.	Pain occurs whenever you are injured.	
11	When you injure yourself, the environment that you are in will not affect the amount of pain you experience, as long as the injury is exactly the same.	When you hurt yourself, what is happening around you will not cause you to feel less or more pain, as long as the injury is exactly the same.	
12	The brain decides when you will experience pain.	The brain decides when you will experience pain.	

Table 4: Original NPQ and newly designed NPQ-peds.

Discussion

This Delphi study is the first attempt at adapting an adult NPQ to a survey tool specifically for kids aged [10-14], to assess their knowledge of pain. Half of the original twelve NPQ statements were deemed appropriate for kids aged [10-14], while six statements needed to be adjusted.

The result from this study aligns with previous work done on the original NPQ to edit and abbreviate it to allow for more clarity yet assure its ability to assess pain knowledge. The original NPQ was developed by using examination papers given to postgraduate pain medicine students, consisting of 30 items, but was paired down since some phrases were "difficult to phrase" them for patients and healthcare professionals [27]. The final NPQ (19 points) were then also checked for accuracy, similarly to the current study. Following the development of the 19-point NPQ, similar criticism of the tool ensued, leading to a more comprehensive Rasch analysis which eliminated seven items with patients struggling to conceptualize the questions and deemed psychometrically redundant [34]. The newly designed 12-point NPQ was deemed a useful tool to assess a patient's conceptualization of modern pain science, and ready for clinical and research use.

This process is exactly what was followed in this Delphi study. In this study, half the questions were deemed appropriate for the target audience, leaving the other half to be scrutinized for readability and understanding, as well as ensuring the content is in line with the current pain science literature, and still convey the intent of the original NPQ, as per the expert panel. A strength of this study is its use of a diverse, yet very applicable, series of experts. Phases one and two specifically address comprehension of the target audience (adolescents), and middle school teachers, paediatric physical therapists and physical therapists who have conducted previous PNE studies for middle school, could speak to the ability of kids aged [10-14] to understand the phrases of the NPQ. In phase one and three, pain experts and physical therapists trained in pain science ensured the statements proposed for the new NPQ-peds, still represent modern pain science and align with the intent of the NPQ.

The end-result of this study is important, since it now proposes a pain questionnaire, aligned with modern pain science, that can be used for people aged [10-14]. It's during this phase of life into early adolescence that many health behaviors are adopted, including dietary habits, exercise habits, exposure to risky substances, etc [35,36]. In regard to

pain, beliefs, attitudes, experiences, and knowledge of pain are key factors in the lived pain experience of a human being, including a kid. With epidemiological data showing that approximately one in five kids in the demographic of the newly designed NPQ-peds experience some type of persistent pain on a regular basis, it is important to have a tool that assesses pain knowledge associated with kids, versus adults, to better target strategies to help kids who experience pain [37]. This tool can be useful to healthcare workers who work in paediatrics to help assess pain knowledge for determination of appropriate care. Instead of previous studies using the (adult) NPQ, researchers, educators and clinicians will now more reliably be able to assess true pain knowledge, which impacts the decisions surrounding interventions, curriculums, understanding of the scope of paediatric pain, and more. Future studies will now need to use the NPQ-peds and test its test-retest reliability with the age-appropriate cohorts of kids aged [10-14].

A major limitation of the study is the high number of US-based experts for the review. It is well-established that cultural and regional difference influence pain experiences, including pain measurement tools, and the results from this study should be viewed from this potential regional biased point-of-view. Even though the intent of the study was to merely adapt the adult NPQ into a paediatric version for use, the generalized, new NPQ-peds may not accurately assess pain knowledge in all paediatric pain conditions due to the diverse presentation of pain. Future studies need to explore if additional NPQ-peds adaptations are needed to serve different paediatric populations, be it clinically, in schools or for public health initiatives.

Conclusion

The NPQ has been a valuable tool for clinical and research purposes. With this new iteration, the NPQ-peds can be used for similar purposes in a younger age group of individuals. Paediatric physical therapists will now have improved decision-making for patients in pain.

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