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**TITLE PAGE****Development of Culturally Sensitive Pain Neuroscience Education for First-  
Generation Turkish Patients with Chronic Pain: A modified Delphi Study**

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**Conflicts of Interest**

Authors declared no conflict of interest.

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**Ethical committee information**

The protocol of this study was approved by the Ethics Committee of University of Ghent.

## Development of Culturally Sensitive Pain Neuroscience Education for First-Generation Turkish Patients with Chronic Pain: A Modified Delphi Study

### **ABSTRACT**

**Background:** Pain Neuroscience Education (PNE) has been recognized as an efficacious approach for chronic pain, but evidence for these findings have mainly been gathered in Caucasian patient populations. In recent years, it has been proposed that the treatment of pain and patient information materials should be culturally sensitive for different ethnic populations and cultures since cultural variations in pain beliefs and cognitions.

**Objectives:** To culturally adapt PNE material for first-generation Turkish patients with chronic pain.

**Design:** A modified Delphi study with three consecutive rounds.

**Method:** A total of 10 participants (8 experts and 2 first-generation Turkish patients with chronic pain) were recruited for this study. Three online questionnaire rounds were conducted to synthesize the perspectives and to reach agreement on the suggested PNE materials.

**Results:** Results on multiple-choice questions from the first round revealed that the compatibility of the visual information and the clarity of the message obtained lower scores. Examples, visual information (illustrations, pictures), and metaphors in the teaching materials and the home education leaflet were revised based on suggestions in Rounds 1 and 2. In Round 3, respondents reached an acceptable agreement level for the clinical usefulness of the PNE teaching materials and the home education material.

**Conclusions:** Culturally sensitive PNE materials were produced for first-generation Turkish patients. Since the results of the present study only reveal perspectives of the experts, further validation of education materials may be required before they are recommended for Turkish patients in clinical practices.

**Keywords:** Chronic pain; education; migrants; consensus.

**Word count for abstract:** 241

## **Development of Culturally Sensitive Pain Neuroscience Education for First-Generation Turkish Patients with Chronic Pain: A Modified Delphi Study**

### **1. INTRODUCTION**

Chronic pain is considered as a complex problem in which cognitive and emotional factors as well as biological factors affect pain perception significantly (Manchikanti et al., 2002; Crofford, 2015). In the last decade, an educational model of teaching people about pain biology and physiology has been recognized as a compelling approach for the management of chronic pain (Nijs et al., 2014; Louw et al., 2016a; Nijs et al., 2017). This model refers to a range of educational interventions (Moseley and Butler, 2015) and has been defined using several terms such as different terms as follows: Explain Pain (Moseley and Butler, 2015), Therapeutic Neuroscience Education (Louw et al., 2015), and Pain Neuroscience Education (PNE) (Nijs et al., 2011). PNE frequently uses illustrations, examples, and metaphors to allow patients to reconceptualize their pain (Nijs et al., 2014). The understanding that pain and tissue damage are not synonymous terms enables patients to change maladaptive pain beliefs and cognitions (Nijs et al., 2014; Nijs et al., 2017). The key target of PNE is to transfer pain-related beliefs and thoughts from a marker of tissue damage to a marker of a perceived need that protects the body (Moseley and Butler, 2015).

In the literature, an updated systematic review (Louw et al., 2016b) revealed supporting evidence regarding the use of PNE to reduce pain and disability and to improve pain knowledge, function, movement, and psychosocial factors including pain catastrophization, fear-avoidance, pain attitudes and behaviours in patients with chronic musculoskeletal disorders. However, the results of this systematic review should be

interpreted by taking into account different study methodologies in which comprising not only PNE-alone approach but also PNE with active-movement based therapy interventions and different mobilization techniques (Louw et al., 2016b). Although, nowadays, many physiotherapists integrate PNE into the treatment of chronic pain, the evidence for PNE and the application of PNE in clinical practice are still mainly restricted to Caucasian patient populations, and, specifically mainly to populations in North America (Louw et al., 2014), Australia (Moseley, 2002; Moseley, 2004), Europe (Meeus et al., 2010; Van Oosterwijck et al., 2013; Pires et al., 2015; Tellez-Garcia et al., 2015), and Canada (Sawhney et al., 2017).

The Turkish population is one of the largest migrant groups in Europe (Nielsen and Krasnik, 2010). It has been reported that first-generation Turkish migrants, especially, struggle to integrate fully into new societies because of significant language restrictions, different cultural backgrounds, and a lower socioeconomic status (Kavuk et al., 2006; Kanas and van Tubergen, 2014), all of which making it hard for them to access healthcare facilities. Unlike native populations, migrants have reported more severe pain, physical and depressive symptoms, and fearful thinking (Sleptsova et al., 2013). In the literature, there is some evidence of differences in pain beliefs, cognitions, perceptions, and behaviours between patients of Turkish origin and native patients (Kavuk et al., 2006; Sloots et al., 2009). It has been reported that Turkish migrants focus on symptoms of pain more explicitly than native Dutch patients (Sloots et al., 2009). Additionally, the differences in the external locus of control and external illness attribution between patients of Turkish origin and native patients have been indicated in previous research as another cultural difference (Baarnhielm and Ekblad, 2000; Sloots et al., 2009; Reich et al., 2015). When compared to native patients, Turkish migrants

take less responsibility for the treatment of their diseases (Sloots et al., 2009), believe they have a lower capacity for healing (Baarnhielm and Ekblad, 2000), and display greater external locus of control (Reich et al., 2015). Furthermore, it has been reported that Turkish patients more likely prefer to use passive coping strategies such as thermal agents, massage, and herbal remedies (Ozturk Birge and Mollaoglu, 2018). Similar to these findings, a study (Kavuk et al., 2006) revealed that first-generation Turkish migrants with chronic headache in Germany used passive pain coping methods including taking medications more frequently than German natives due to a lack of headache care in the studied population who had poor knowledge of the German language, were less educated, and had a lower socioeconomic status.

For these reasons, it has been suggested that merely translating materials may not be sufficiently effective for Turkish patients, who have different cultural backgrounds and must deal with significant cultural barriers regarding the understanding of pain (Holzel et al., 2014). According to the literature and our perspectives, cultural adaptation of existing PNE for Turkish patients may be essential, as this educational model aims to change maladaptive pain-related beliefs and cognitions that are influenced by Turkish culture (Ozturk Birge and Mollaoglu, 2018). Additionally, using standard illustrations, pictures, or metaphors may not be relevant for different ethnicities and cultures. Gender is also an important factor for Turkish patients, since it has a significant impact on pain-related coping behaviours (Ovayolu et al., 2013). The lower education and sociocultural levels of Turkish migrants when compared to the native population is another reason to apply culturally adapted PNE. A previous report also indicated that a patient's level of intellectual ability and health literacy should be taken into account (Nijs et al., 2014). Thus, the application of PNE by using more simple methods, patients' native language,

and examples related to Turkish culture may be necessary. To the best of our knowledge, evidence is still lacking in the field of culturally sensitive PNE for the Turkish population. Therefore, the aim of this study was to conduct a modified Delphi survey to collect and synthesize perspectives about culturally sensitive PNE materials in terms of the content, the appropriateness of the provided information, the clarity and understandability of the information, the visual characteristics of the presentations and home education leaflet, and the compatibility of the stories/characters/examples/metaphors for Turkish patients. Based on the perspectives of experts and researchers, we aimed to culturally adapt separate PNE teaching materials for Turkish women and men with chronic pain, along with a general home education leaflet.

## 2. METHODS

### 2.1. First Draft of the Culturally Sensitive PNE Material

Prior to the Delphi rounds, first drafts of the PNE teaching materials and the home education leaflet were developed based on a focus group meeting. Six experts participated in the focus group. All are experienced in PNE programs and familiar with Turkish patients (these experts are different from those in the “Delphi expert panel”). The focus group discussion primarily started from the content and characteristics of an existing PNE program and discussed possible adaptations for Turkish patients. The core material for the culturally sensitive PNE program was based on specific guidelines (Nijs et al., 2011; van Wilgen and Keizer, 2012) and books “*Explain Pain*” (Butler and Moseley, 2003) and “*Pijneducatie: Een Praktische Handleiding voor (Para) medici*” (van Wilgen and Nijs, 2010) about applying PNE programs in clinical practice. Similar to the current PNE, the culturally sensitive PNE program explains the differences between acute and chronic pain, the protective role of pain, neurophysiology of pain (including how pain originates in the nervous system), how pain becomes persistent, and factors related to the increased sensitivity of the nervous system.

Drawing from an adapted PNE program for Brazilian chronic pain patients (Reis et al., 2017), different female and male characters were developed, each with their own stories of acute and chronic pain, to make the educational program more interactive. These were then integrated into the teaching presentations and the home education leaflet. Examples, metaphors, and visual information were selected based on the cultural background of Turkish patients. Separate teaching materials were prepared for Turkish women and Turkish men suffering with chronic pain, and different examples and stories for Turkish women and Turkish men were used to explain the biology and physiology

of pain. The normal biology of pain, pain modulation, and central sensitization were explained using different metaphors related to gender. Additionally, the effects of pain-related beliefs and behaviours on pain modulation were explained in a gender-specific way.

The first drafts of the teaching materials and the home education leaflet were prepared in English, so they could be understood and comprehended by international experts. Following this, all materials were translated into Turkish by one researcher, and then checked by one independent researcher. Prior to each round, the same translation procedure was repeated for Turkish patients participating in Delphi rounds. After the final versions of the PNE materials were developed, the Turkish language was checked independently by two researchers and one professional translator.

## **2.2. Study Design**

Based on previous recommendations (Hasson et al., 2000; Hasson and Keeney, 2011), a modified Delphi study consisting of three online survey rounds was designed and conducted to adapt the teaching materials and a home education leaflet for Turkish patients with chronic pain. The protocol of this study was approved by the Ethics Committee of X University. The experts' consent was implied by their voluntary participation. The data collection was conducted between December 2017 and March 2018.

## **2.3. Experts**

Experts were recruited through purposive sampling (Wells et al., 2014b, a; Goodwin et al., 2015). The selection of experts was based on the international networks and personal contacts of senior researchers and peer-reviewed publications on culturally

sensitive PNE. This selection process was defined in a previous study (Luedtke et al., 2016). It has been reported that no guideline exists to define who is an expert and how many experts are required (Hsu and Sandford, 2007; Luedtke et al., 2016). Duo's of experts with different backgrounds and insights were selected in the present study in order to examine the appropriateness of PNE material from varying perspectives and with differing fields of expertise. Five groups of expertise were predefined and two potential experts screened for eligibility per group were contacted: 1) those having at least two years of expertise in applying PNE, 2) those with at least two years expertise in assessing and treating first-generation Turkish patients with chronic pain, 3) those with at least two years' expertise in adapting PNE for specific groups and with at least one publication in a peer-reviewed journal regarding the adaptation process of PNE, 4) therapists who speak both Turkish and Dutch and having Turkish relatives, 5) first-generation Turkish patients living with chronic musculoskeletal pain, who were born in Turkey, indicate Turkish as their first language, and live in Belgium. Patients with chronic pain who were not actively seeking treatment or not undergoing treatment at the time were included in order to eliminate the influence of active symptoms or any treatment approach on the results of the Delphi rounds. Thus, the materials were evaluated on their suitability for Turkish patients and culture and their compliance with the original PNE model. All groups of participants were considered to be experts based on their experiences. Eligible experts were determined by senior researchers (MM, BC, and DL) and a clinician (AF). Prior to the first round, experts were informed of the purpose of the study and were invited by a senior researcher (MM) to become a member of the Delphi panel. All contacted experts agreed to participate. Experts remained anonymous in order to express their opinions independently and to avoid group bias.

Additionally, experts were not provided the Round 1 and Round 2 results to avoid their being influenced by group results.

#### **2.4. Procedure**

Experts were sent the teaching materials and the home education leaflet and then they were asked to complete questionnaires about the material in each round of the Delphi study. The culturally adapted PNE materials were evaluated primarily on the basis of the content, the appropriateness of the provided information, the clarity and understandability of the information, the visual characteristics of the presentations and leaflet, the appropriateness of the materials for Turkish patients and culture, and the compatibility of the stories/characters/examples/metaphors for Turkish patients. The core information of the PNE teaching materials and the home education leaflet remained unchanged. Questionnaires developed by CO and MM were sent electronically to the experts, whereas hard copies of the questionnaires were given to the Turkish patients since they were not familiar with the use of online sources. The experts were asked to complete each questionnaire within two weeks. To increase the adherence rate, a reminder e-mail was sent during the second week (Dewitte et al., 2016). If experts were unable to complete the questionnaires within the allotted time, one extra week was provided to submit their responses.

**In the first round**, experts evaluated two teaching presentations (one for female and one for male patients). After completing this assessment, they reviewed a general home education leaflet (Figure 1). In this round, the teaching presentations and the home education leaflet were evaluated separately because the questionnaires were very detailed, including a total of 50 questions for the teaching materials and 42 questions for the home education leaflet. Both quantitative and qualitative data were gathered for the

teaching presentations and the home education leaflet using multiple-choice and open-ended questions.

The questionnaire was structured by grouping the content of the teaching materials or the home education leaflet under several headings: acute pain, normal biology of pain, the pain modulation mechanisms of the central nervous system, adaptations in chronic pain, central sensitization, and implications. Additional headings, such as pain neuromatrix and negative pain beliefs and thoughts, were only included in the questionnaire for the teaching materials. In the questionnaire for the home education leaflet, introduction was added as an extra heading. These headings introduced pre-determined topics that were then evaluated critically via multiple-choice questions (yes, no, uncertain) related to five issues: the content, relevant information regarding the specific headings, the clarity and understandability of the information, the visual appropriateness for Turkish patients; and the compatibility of the stories/characters for Turkish patients (Table 1). Experts indicated additional suggestions by answering open-ended questions under each heading. A section was available in which general remarks on the presentations and the home education leaflet could be made by answering three open-ended questions.

**In the second round**, experts used different questionnaires to evaluate two teaching presentations (one for male and one for female patients) and the home education leaflet. In Round 2, questionnaires comprised 11 questions for the teaching materials and 10 questions for the home education leaflet. Qualitative data, obtained separately for the teaching materials and the home education leaflet, were derived from the open-ended questions that invited the experts to provide further suggestions. As in Round 1,

questionnaires included the same headings together with the general remarks of the materials. Unlike in Round 1, the experts evaluated all materials (two teaching presentations and the home education leaflet) at the same time (Figure 1).

Questionnaires were simpler than in Round 1. In addition, experts were familiar with the teaching materials and the home education leaflet, and thus they assessed both simultaneously in Round 2.

**In the last round**, the experts were asked to rate the *clinical usefulness* of the teaching presentations and the home education leaflet (**Q1-2**: How do you rate the clinical usefulness of the teaching materials (presentations)/the home education leaflet?), the *satisfaction level* with the material (**Q3-4**: How satisfied do you feel with the teaching materials (presentations)/the home education leaflet?), and the *compatibility with their expectations* (**Q5-6**: How compatible are the teaching materials (presentations)/the home education leaflet with your expectations?). These questions were answered on a 5-point Likert-type scale (0 = Definitely not useful/satisfied/comply; 1 = Probably not useful/satisfied/comply; 2 = Don't know; 3 = Useful/satisfied/comply; 4 = Extremely useful/satisfied/comply). Based on previous research (Goodwin et al., 2015; Dewitte et al., 2016; Dewitte et al., 2018), researchers determined an acceptable agreement level so that more than 80% of the experts allocated a score of 3 or 4 to six questions.

## **2.5. Data Analysis**

Following Round 1 and Round 2, the data from the experts' responses to open-ended questions regarding their suggestions about the teaching materials and the home education leaflet were qualitatively analyzed using the content analysis (Patton, 1999; Dewitte et al., 2018) by CO and MM. First, main topics regarding the experts'

suggestions were identified. Then, the experts' suggestions were grouped according to the related topics. The PNE program was then edited and adapted based on the experts' suggestions. However, there were conflicting suggestions especially regarding the detailed explanation of pain neurophysiology and the examples of pain modulation and the poor relationship between tissue damage and pain. In this case, decisions about the revision of the PNE teaching materials and the home education leaflet were made after critical evaluation by CO and MM. Descriptive statistics were analyzed by using the Statistical Package for Social Sciences software, version 21 (IBM SPSS Statistics; IBM Corporation, Armonk, NY). After Rounds 1 and 3, descriptive statistics were presented as median (25% and 75%) for ordinal data or as frequencies (percentages) for categorical variables.

### **3. RESULTS**

A total of 10 experts, eight international health professionals and two first-generation Turkish people living with persistent pain, were recruited in the present study. In Round 1, the response rates for the teaching materials and the home education leaflet were 9/10 and 7/10, respectively. The characteristics of the experts who evaluated the teaching materials in Round 1 are presented in Table 2. All health professionals were physiotherapists. Most of the experts described their roles in PNE as clinical (6/9). Additionally, most of the experts were familiar with PNE. In Rounds 1 and 3, four experts had between one and five years' experience with PNE and one expert had between 6 and 10 years' experience. In the Round 2, four experts who evaluated the home education leaflet indicated that they had between one and five years' experience with PNE. In Round 2, the response rates for the teaching materials and the home education leaflet were 6/10 and 5/10, respectively. Nine of the 10 experts responded to Round 3.

#### **3.1. Results from Rounds 1 and 2**

The quantitative data from Round 1 for both the teaching materials and the home education leaflet are presented in Table 3. **For the teaching presentations**, more than 50% of the experts reported they did not agree (with a score of 'no' or 'uncertain') with the **appropriateness of visual information** in the *pain modulation* and *central sensitization* headings and the **clarity of message** in the *normal biology of pain*, *pain modulation*, and *pain neuromatrix* headings. **For the home education leaflet**, more than 50% of the experts (with a score of 'no' or 'uncertain') did not agree with the **appropriateness of visual information** in the *normal biology of pain* and *implications*

headings and the **appropriateness of stories** in the *central sensitization and implications* headings.

Qualitative data from Round 1 and 2 for both the teaching materials and the home education leaflet are presented in Table 4 and Table 5. Experts' suggestions of for the teaching presentations and the home education leaflet were grouped as follows: additional information, simplification of the teaching materials, changes in examples, and changes in visual information. Conflicting suggestions were identified and then discussed depending on the sociocultural background, intellectual ability, and health literacy of Turkish migrants. For PNE teaching materials, the primary suggestion was to provide additional information on the neurophysiology of the pain mechanism including "normal biology of pain", "pain modulation", and "pain neuromatrix". On the other hand, expert committee had concerns about clarity and proposed simplification of the teaching materials. Based on the conflicting suggestions, we aimed to limit detailed information on the neurophysiology of pain and to avoid difficult neurophysiology mechanisms and terms, as the target population has a low level of education. However, we provided additional information on the specialized nature of the sensors, the role of the central regions of the pain matrix, and the importance of gradually increased physical activities in accordance with the experts' suggestions.

For the home education leaflet, there was no agreement regarding the additional information on topics such as the normal biology of pain, pain modulation, and central sensitization. Therefore, due to the concerns related to the education level of the target population, we could not provide detailed information on the neurophysiology of the pain mechanism. Additional information was provided on the role of sensitivity after injury in acute pain, the importance of gradually increased physical activities, and the

importance of the exercise-induced analgesia.

Based on the suggestions of respondents from Rounds 1 and 2, changes in examples, changes in information regarding interactive characters, changes in visual information (illustrations and pictures), and changes in metaphors were performed in the PNE teaching materials and the home education leaflet, an agreement was reached with the authors. After Rounds 1 and 2, culture- and gender-specific changes were made, including examples of the protective role of pain, the jobs of patients in the stories of acute and chronic pain, examples for explaining pain modulation and poor relation between tissue damage and pain, and physical activities. Additionally, in the teaching materials for women, two different kinds of illustrations were added including a younger woman and an elderly woman.

### **3.2. Results from Round 3**

Agreement levels for the teaching materials and the home education leaflet are presented in Table 6. Respondents reached an acceptable agreement level for the clinical usefulness of the PNE teaching materials and the home education material. In addition, the compatibility with expectations and the level of satisfaction were higher for the teaching materials than the home education leaflet.

#### **4. DISCUSSION**

This study aimed to achieve an evidence-based culturally sensitive PNE program for first-generation Turkish migrants with chronic pain. A three-round modified Delphi study was employed to reach a consensus on the content and compatibility of the teaching materials and the home education leaflet for Turkish patients. After editing the teaching materials and the home education leaflet based on the experts' suggestions and opinions from Round 1 and Round 2, an acceptable agreement level was achieved in Round 3 on the culturally sensitive PNE for Turkish patients. This modified Delphi survey may provide a direction for future research to determine the effectiveness of culturally sensitive PNE in Turkish patients when compared to standard translated materials.

To our knowledge, this is the first Delphi study to include a modified protocol for gathering the opinions of the experts on a culturally sensitive PNE program for the treatment of chronic pain in Turkish patients. In previous studies, different approaches were used to develop culturally sensitive patient material (Holzel et al., 2016) and treatment programs for chronic pain (Sleptsova et al., 2013; Reis et al., 2017). A focus group approach was used to develop culturally sensitive patient information materials for Turkish migrants with chronic low back pain (Holzel et al., 2016). In this focus group, experts with migration backgrounds who lived in Germany and were able to speak German and Turkish discussed the cultural adaptations related to the structure of the presentations, rather than to the core information (Holzel et al., 2016). In another recent study, the expert committee discussed the main steps for developing online pain intervention for Brazilian patients (Reis et al., 2017).

Before the Delphi rounds were started, separate teaching materials were developed for female and male patients based on previous research (Ovayolu et al., 2013). It has been reported that gender can influence the way patients in the Turkish population demonstrate their pain (Ovayolu et al., 2013). Men tend to avoid expressing pain-related symptoms because male gender is considered as a symbol of power, whereas women are more willing to seek treatment to manage their chronic pain as soon as possible (Ovayolu et al., 2013). Similarly, another study reported that the separation of female and male Turkish patients was performed as a structural adaptation for culturally sensitive intervention in Sweden (Sleptsova et al., 2013). Moreover, drawing from previous study that developed an online pain intervention program for Brazilian patients (Reis et al., 2017), interactive male and female characters resembling the patients' situations and backgrounds were integrated into the PNE materials to increase cultural relevance.

Based on the suggestions from Rounds 1 and 2, cultural adaptations to the PNE teaching materials and the home education leaflet included several components. The structural adaptations included changes in the examples of the mechanism of pain neurophysiology, interactive stories, metaphors, and visual information (pictures). Didactic changes comprised the removal of difficult neurophysiology terms. A previous study also reported that the use of written materials was limited due to the education level of Turkish patients (Sleptsova et al., 2013). Thus, didactic and visual adaptations such as the addition of graphical displays in written materials were performed for the culturally sensitive interventions (Sleptsova et al., 2013).

Based on the results from Rounds 1 and 2, a major concern about the present PNE materials was whether they matched the educational and intellectual levels of Turkish

migrants. To increase the understandability of the PNE materials, detailed information on the mechanism of pain neurophysiology was limited. Although there were some suggestions in Round 1 and 2 regarding additional information on the neurophysiology of pain, especially for the home education leaflet, simplification of the PNE materials was preferred. Although PNE materials were simplified, all necessary information was retained. In the last round, respondents reached an acceptable level of agreement for the clinical usefulness of the PNE teaching materials and the home education leaflet. However, the compatibility with expectations and the level of satisfaction were higher for the teaching materials than for the home education leaflet. These results may be related to the reduced content regarding pain neurophysiology.

#### **4.1. Limitations and Suggestions for Further Research**

The findings of the present study should be interpreted in light of some limitations. The first limitation was that Round 1 began with the open-ended and multiple-choice questions regarding the draft versions of the teaching materials and the home education leaflet. In previous studies (Goodwin et al., 2015; Wiangkham et al., 2016), the content of a post-surgical leaflet or treatment program was determined by means of Delphi rounds before these materials were developed. In the present study, the modified Delphi protocol conducted for the cultural adaptation of PNE materials started with multiple-choice and open-ended questions because the content of the PNE program had already been identified (Butler and Moseley, 2003; Nijs et al., 2011; van Wilgen and Keizer, 2012), and draft versions of the materials were developed based on the original versions of the PNE teaching materials. Nevertheless, this study provided open-ended questions in Rounds 1 and 2, with the aim of obtaining the experts' comments and suggestions to

achieve more evidence-based results.

A second limitation was that the number of experts was low in the present study. Since the research domain of the study was very specific and narrow, a limited number of experts with expertise in first-generation Turkish patients and culturally sensitive PNE materials were identified. In the literature, there is no consensus or guideline regarding the definition and selection of an expert committee (Dewitte et al., 2016; Dewitte et al., 2018). Information regarding the appropriate sample sizes for Delphi studies is also lacking (Wells et al., 2014a). It has been reported that the quality of the expert panel is more important than the number of experts in order to determine the representativeness of the sample (Wells et al., 2014a). Although the number of experts is limited in the present study, all are experts in the field and have guiding suggestions to contribute to the cultural adaptation process of PNE materials. Moreover, since the selection and invitation of experts were based on the personal contacts and international networks of senior researchers, a selection bias could have played a role. The selection of experts and a lack of information regarding non-respondents may affect generalizability. To increase generalizability, further studies can recruit experts from the fields of sociology and anthropology, in addition to those in different settings including pain clinics and the domains of social medicine.

Finally, previous research (Wells et al., 2014b, a) revealed that the recurrent process of the Delphi protocol might encourage experts to agree, although the experts did not interact with each other. It has been indicated that the results of Delphi surveys should be considered as expert opinions (Wells et al., 2014a). Therefore, the perspectives of experts in Delphi surveys should be evaluated and validated by further research. Based on the results of future studies to assess the validation and efficacy of culturally

sensitive PNE materials for Turkish patients, further adaptations may eventually be performed for the present program.

## **5. CONCLUSION**

In conclusion, this is the first study to recruit experts for the purpose of culturally adapting PNE materials used for the treatment of chronic pain in first-generation Turkish patients. Based on the guiding input of experts who are experienced in PNE and familiar with Turkish culture and Turkish patients, culturally sensitive PNE teaching materials and a home education leaflet were produced for first-generation Turkish patients with chronic pain. In the final round, respondents reached an acceptable agreement level for the clinical usefulness of the PNE teaching materials and the home education leaflet. However, the level of satisfaction and the compatibility with expectations leaflet was lower for the home education leaflet than for the teaching materials. Since the results of the present study can only reveal the perspectives of the experts, further validation of the education materials may be required before they are recommended for Turkish patients in clinical practices.

## **FIGURE LEGENDS**

**Figure 1.** Flow-chart for the cultural adaptation process of the PNE material.

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**TABLES****Table 1.** Multiple-choice questions for the teaching materials and the home education leaflet in Round 1.\*

<p><b>Q1. Content of the program</b> Do you think that the information about the “acute pain” or “normal biology of pain” or “pain modulation” or “pain matrix” or “chronic pain” or “pain beliefs and thoughts” or “central sensitization” or “implications” is related to the content of the original pain education program?</p>
<p><b>Q2. Relevant information</b> Do you think that these slides provide relevant information on the “acute pain” or “normal biology of pain” or “pain modulation” or “pain matrix” or “chronic pain” or “pain beliefs and thoughts” or “central sensitization” or “implications”?</p>
<p><b>Q3. Stories</b> Do you think that the stories used to describe the “acute pain” or “normal biology of pain” or “pain modulation” or “pain matrix” or “chronic pain” or “pain beliefs and thoughts” or “central sensitization” or “implications” are appropriate for the Turkish population?</p>
<p><b>Q4. Visual information</b> Do you think that visual information (pictures) for the “acute pain” or “normal biology of pain” or “pain modulation” or “pain matrix” or “chronic pain” or “pain beliefs and thoughts” or “central sensitization” or “implications” is appropriate for the Turkish patients?</p>
<p><b>Q5. Clarity of message</b> Do you think the message is clear and understandable?</p>

\*For teaching materials, there is no question about stories (Questions 3). For home education leaflet, the “pain matrix” and the “pain beliefs and thoughts” domains are not included.

**Table 2.** Characteristics of the experts included in the first round.

<b>Characteristics of experts</b>	<b>(n=9)</b>
Age	42.22 ± 11.13
Role in pain education	
Clinical purposes	6 (66.7)
Research purposes	3 (33.3)
Experience in pain education	
Non existing	3 (33.3)
Heard of it	1 (11.1)
Familiar with it, <1 year	- (0)
Familiar with it, 1-5 years	4 (44.4)
Familiar with it, 6-10 years	1 (11.1)
Familiar with it, 11+ years	- (0)
Application/received pain education	
Yes	8 (88.9)
No	1 (11.1)
Country of residence	
Belgium	7 (77.8)
Netherlands	1 (11.1)
Brazil	1 (11.1)

Data were presented as mean ± standard deviation or absolute figures (and percentages).

**Table 3.** Results from Round 1 for the teaching materials (n=9) and the home education leaflet (n=7).

Questions	Acute pain	Normal biology of pain	Pain Modulation	Pain neuromatrix	Chronic pain	Pain beliefs and thoughts	Central sensitization	Implications
<b>Results of the teaching materials</b>								
Content of program								
<i>Yes</i>	9 (100)	8 (88.9)	7 (77.8)	8 (88.9)	9 (100)	9 (100)	8 (88.9)	9 (100)
<i>No</i>	- (0)	- (0)	1 (11.1)	- (0)	- (0)	- (0)	- (0)	- (0)
<i>Uncertain</i>	- (0)	1 (11.1)	1 (11.1)	1 (11.1)	- (0)	- (0)	1 (11.1)	- (0)
Relevant information								
<i>Yes</i>	9 (100)	8 (88.9)	8 (88.9)	9 (100)	9 (100)	9 (100)	8 (88.9)	9 (100)
<i>No</i>	- (0)	- (0)	- (0)	- (0)	- (0)	- (0)	- (0)	- (0)
<i>Uncertain</i>	- (0)	1 (11.1)	1 (11.1)	- (0)	- (0)	- (0)	1 (11.1)	- (0)
Stories								
<i>Yes</i>	6 (66.7)	-	6 (66.7)	7 (77.8)	7 (77.8)	7 (77.8)	5 (55.6)	7 (77.8)
<i>No</i>	- (0)		- (0)	- (0)	- (0)	- (0)	- (0)	- (0)
<i>Uncertain</i>	-3 (33.3)		3 (33.3)	2 (22.2)	2 (22.2)	2 (22.2)	4 (44.4)	2 (22.2)
Visual information								
<i>Yes</i>	8 (88.9)	8 (88.9)	4 (44.4)	6 (66.7)	7 (77.8)	7 (77.8)	4 (44.4)	7 (77.8)
<i>No</i>	- (0)	- (0)	1 (11.1)	- (0)	- (0)	1 (11.1)	- (0)	- (0)
<i>Uncertain</i>	1 (11.1)	1 (11.1)	4 (44.4)	3 (33.3)	2 (22.2)	1 (11.1)	5 (55.6)	2 (22.2)
Clarity of message								
<i>Yes</i>	7 (77.8)	4 (44.4)	3 (33.3)	3 (33.3)	6 (66.7)	7 (77.8)	5 (55.6)	7 (77.8)
<i>No</i>	- (0)	2 (22.2)	- (0)	- (0)	- (0)	1 (11.1)	- (0)	- (0)
<i>Uncertain</i>	2 (22.2)	3 (33.3)	6 (66.7)	6 (66.7)	3 (33.3)	1 (11.1)	4 (44.4)	2 (22.2)
<b>Results of the home education leaflet</b>								
Content of program								
<i>Yes</i>	7 (100)	6 (85.7)	6 (85.7)	-	6 (85.7)	-	7 (100)	7 (100)
<i>No</i>	- (0)	- (0)	- (0)		- (0)		- (0)	- (0)
<i>Uncertain</i>	- (0)	1 (14.3)	1 (14.3)		1 (14.3)		- (0)	- (0)

Relevant information								
<i>Yes</i>	7 (100)	7 (100)	6 (85.7)	-	7 (100)	-	7 (100)	7 (100)
<i>No</i>	- (0)	- (0)	- (0)		- (0)		- (0)	- (0)
<i>Uncertain</i>	- (0)	- (0)	1 (14.3)		- (0)		- (0)	- (0)
Stories								
<i>Yes</i>	5 (71.4)	5 (71.4)	5 (71.4)	-	5 (71.4)	-	4 (57.1)	4 (57.1)
<i>No</i>	- (0)	- (0)	- (0)		- (0)		- (0)	- (0)
<i>Uncertain</i>	2 (28.6)	2 (28.6)	2 (28.6)		2 (28.6)		3 (42.9)	3 (42.9)
Visual information								
<i>Yes</i>	5 (71.4)	3 (42.9)	5 (71.4)	-	5 (71.4)	-	5 (71.4)	4 (57.1)
<i>No</i>	- (0)	- (0)	- (0)		- (0)		- (0)	- (0)
<i>Uncertain</i>	2 (28.6)	4 (57.1)	2 (28.6)		2 (28.6)		2 (28.6)	3 (42.9)
Clarity of message								
<i>Yes</i>	7 (100)	5 (71.4)	6 (85.7)	-	5 (71.4)	-	5 (71.4)	5 (71.4)
<i>No</i>	- (0)	1 (14.3)	- (0)		1 (14.3)		1 (14.3)	1 (14.3)
<i>Uncertain</i>	- (0)	1 (14.3)	1 (14.3)		1 (14.3)		1 (14.3)	1 (14.3)

Data were presented as absolute figures (and percentages).

**Table 4.** Results of open-ended questions of Round 1 for the teaching materials (n=9) and the home education leaflet (n=7).

<b>Results of teaching materials</b>	
<b>Domains</b>	<b>Changes based on the suggestions of experts</b>
Acute pain	Change examples [for women (cutting vegetables and sewing) and men (hammering a nail and playing football)]. Change visual information (pictures regarding the appearance of women for younger and elderly women with scarf; illustrations of alarm signal). Change examples of stories [jobs of patients: handicraft teacher (women) and musician (men)].
Normal biology of pain	Give additional information regarding the specialized nature of sensors. Give additional metaphors (specialized nature of sensors and filter mechanism in spinal cord). Change visual information (picture of spinal cord).
Pain modulation	Change examples of poor relation between tissue damage and pain intensity (culture-specific, different examples for women and men).
Pain neuromatrix	Give additional information regarding the role of central regions of brain in pain matrix.
Chronic pain	Change examples of stories [(jobs of patients: nurse (women) and office worker (men))]. Give additional information regarding metaphors (adaptations in chronic pain).
Pain beliefs and thoughts	Change visual information (representation of a worried person for women and men). Give additional information regarding thoughts of patients.
Central sensitization	Alterations in order of slides.
Implications	Give additional information regarding the influence of behavioral changes on pain. Give additional information regarding importance of gradually increased physical activities (a graph showing gradually increased physical activities). Change visual information (new picture of woman/man during walking).
General remarks	Simplification of slides (less text or removal of difficult neurophysiology terms such as neurons). Concerns about education level of Turkish patients.
<b>Results of home education leaflet</b>	
<b>Domains</b>	<b>Changes based on the suggestions of experts</b>
Introduction	Change content (sentences explaining the purpose of the brochure; information regarding danger messages; explanation of pain experience). Change visual information (new picture for introduction).
Acute pain	Change content (sentences explaining purpose of pain). Give additional information (role of sensitivity after an injury). Change examples [for women (using gloves for carrying hot pot) and men (hammering a nail)].
Normal biology of pain	Change visual information (sensors, spinal cord, and pain processing in brain).
Pain modulation	Change examples (culture-specific, different examples for women and men). Give additional visual information (additional picture regarding the descending inhibition and facilitation).
Chronic pain	Give additional information (additional information about metaphor in order to explain adaptations in chronic pain). Change visual information (pictures representing patients with persistent back pain).
Implications	Change content (culture-specific physical activities, explanation regarding the importance of gradually increased physical activities). Give additional information (explanation of the link between behaviors and pain reduction, information on exercise induced analgesia).
General remarks	Concerns about education level of Turkish patients.

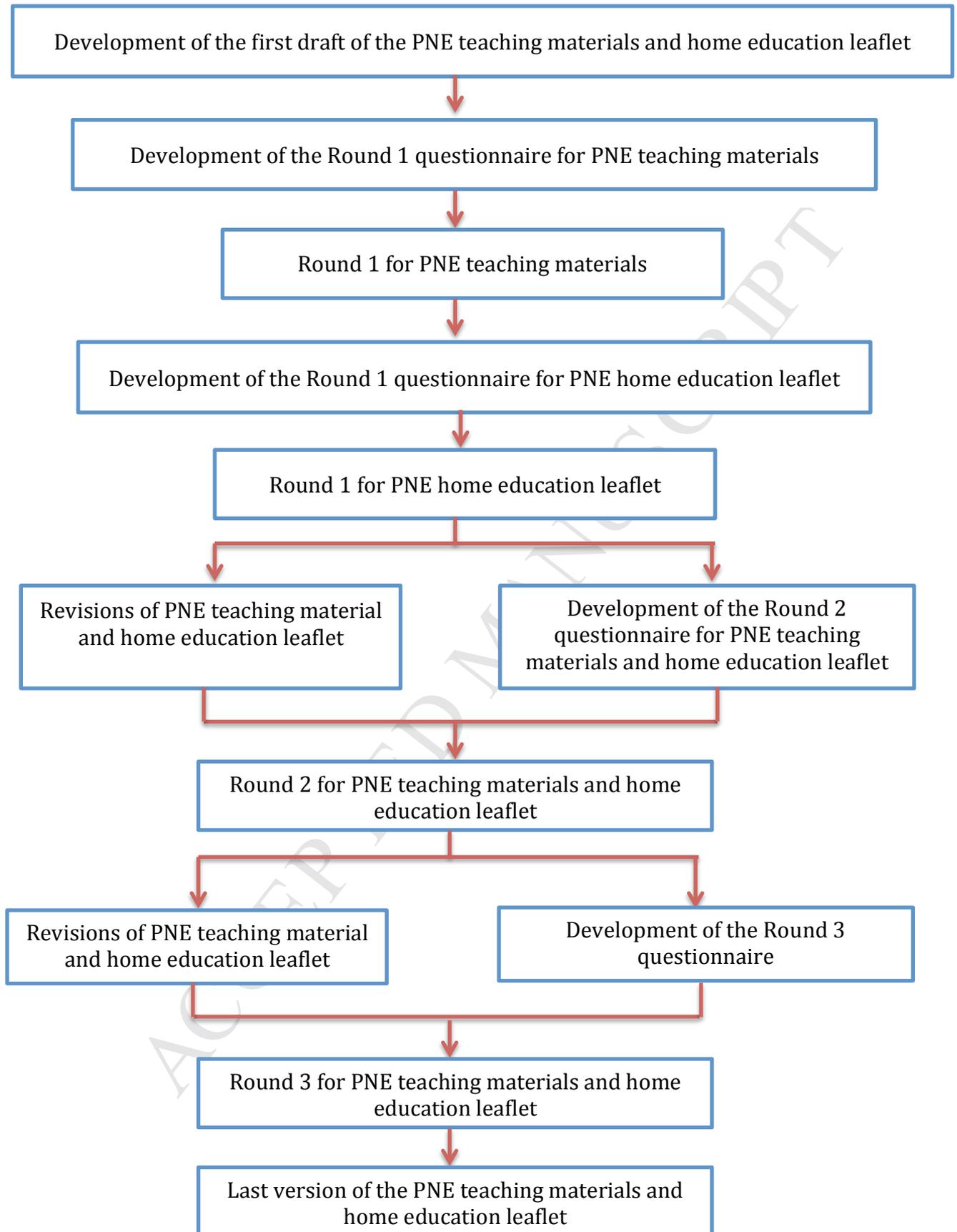
**Table 5.** Results of Round 2 for the teaching materials (n=6) and the home education leaflet (n=5).

<b>Results of teaching materials</b>	
<b>Domains</b>	<b>Changes based on the suggestions of experts</b>
Acute pain	Give additional information regarding the purpose of acute pain.
Normal biology of pain	Give additional information regarding the questions for interaction of patients regarding the nervous system (What is the nervous system? How do you describe the nervous system?) Change visual information (picture of sensors). Simplification of slides (removal of difficult neurophysiological words such as positive ions).
Pain modulation	Give additional information regarding the role of filter system and questions for interaction of patients regarding danger messages. Change examples (the poor relation between tissue damage and pain intensity).
Pain neuromatrix	Give additional information regarding the specific functions of brain areas involved in pain (Brain areas involved in pain include clusters of nodes used for sensation, movement, emotions and memory).
Pain beliefs and thoughts	Give additional information regarding underlying neurophysiology (vicious circle of pain due to negative pain beliefs and thoughts, overactive pain system by releasing more sad hormones).
<b>Results of home education leaflet</b>	
<b>Domains</b>	<b>Changes based on the suggestions of experts</b>
Introduction	Change information (minor changes in explanation of pain).
Pain modulation	Change in examples (poor relation between tissue damage and pain intensity).
Implications	Change in the information (impact of right therapy on oversensitive pain system).

**Table 6.** Results of Round 3 for the teaching materials and the home education leaflet (n= 9).

<b>PNE materials</b>	<b>Questions<sup>a</sup></b>	<b>Median (25 % - 75 %)</b>	<b>Agreement level<sup>b</sup> (%)</b>
Teaching materials	Clinical usefulness	3.0 (3.0 - 3.5)	<b>100</b>
	Level of satisfaction	3.0 (3.0 - 4.0)	<b>88.9</b>
	Compatibility with experts' expectations	3.0 (3.0 - 3.5)	<b>100</b>
Home education leaflet	Clinical usefulness	3.0 (3.0 - 3.0)	<b>88.9</b>
	Level of satisfaction	3.0 (2.5 - 4.0)	77.7
	Compatibility with experts' expectations	3.0 (3.0 - 3.5)	<b>88.9</b>

PNE= Pain neuroscience education. <sup>a</sup> Responses are categorized as follows: 0= Definitely not useful/satisfied/comply; 1= Probably not useful/satisfied/comply; 2= Don't know; 3= useful/satisfied/comply; 4= Extremely useful/satisfied/comply. <sup>b</sup> Agreement level is presented as the total percentage (%) of the experts, allocating a score of 3 or 4 to questions.



**Highlights**

- Culturally sensitive PNE materials were developed for Turkish patients.
- Culture and gender specific changes were performed in the PNE materials.
- Respondents reached an acceptable agreement level for clinical usefulness.
- Further validation of education materials may be required.