Measuring person-centred pain management: Development of a questionnaire using the fundamentals of care framework

Therese Avallin¹ | Eva Jangland¹ | Alison Kitson²,³ | Åsa Muntlin²,⁴,⁵

Abstract

Aim: To develop and test a questionnaire using the Fundamentals of Care framework to measure person-centred pain management.

Design: Cross-sectional exploratory descriptive design.

Methods: Development in three phases: (a) literature search for questionnaires measuring person-centred pain management, (b) seven-step process developing items using thematic analysis, (c) initial feasibility and validity testing. Theoretical and empirical evidence was used, including the ‘Strategic and Clinical Quality Indicators in Postoperative Pain management’ questionnaire, the Fundamentals of Care framework and person-centredness principles. Theoretical experts (n=2) reviewed the questionnaire, further evaluated by providers (n=5) and patients (n=5) using a think-aloud process, and by additional questions in the questionnaire answered by n=100 patients. The questionnaire was tested February to March 2021, at four surgical wards in a university hospital.

Results: The evaluation showed initial support for feasibility and validity, and the questionnaire was found to represent and be sensitive to capture the patients’ experiences of person-centred pain management and being easy to answer. The 100 patients with acute abdominal pain who answered the questionnaire (aged 18–89 years, 46 women and 54 men), identified missing elements of fundamental care in their pain management, indicating that the questionnaire is sensitive to capture specific areas for improvement.

Conclusion: This first attempt at transforming the essential components of person-centred pain management into measurable items in a questionnaire was found promising. The questionnaire is suggested to be further tested for psychometric properties and patient benefit to provide clinical guidance in acute surgical care to meet the patient care need of pain management.

Implications for the profession and/or patient care: The developed questionnaire addresses the need of nurses and nursing leaders to evaluate the delivery of person-centred pain management in acute surgical care, to relieve the patient from pain.
1 | INTRODUCTION

Well-managed pain, tailored to the physical, sensory and emotional experience of the person experiencing the pain, has been linked to reduced suffering, complications, time in care and chronic pain (Schug et al., 2020). Despite the known benefits, unresolved pain challenges patients and providers in acute surgical care across the world, and more research is needed to improve the pain management (Schug et al., 2020). The international movement towards person-centred fundamental care is a response to noted areas of missed nursing care such as pain management (Kalisch & Xie, 2014; Kitson, 2018a). The practice of meeting patients’ fundamental care needs is described in the Fundamentals of Care (FoC) framework, initiated by nurses and nursing leaders in the International Learning Collaborative (https://ilccare.org/). The framework describes (a) the trusting patient–provider relationship as a prerequisite for (b) the integration of care meeting the patient physical, psychosocial and relational care needs, and the benefit of (c) a supportive context to enable this process (Kitson et al., 2013). Fundamental care is the concern of every patient, and the framework is focused on the routine, everyday patient needs that form the bedrock of the caring encounter. The objective of the framework is to guide practice around person-centred fundamental care, the goal towards which both the nurse and patient work. Within the FoC framework, the established relationship is described as a core to care, also emphasizing the value of person-centredness (Kitson, 2018b). The country of the present study legally requires healthcare to be person-centred (SFS, 2014), but despite the legal obligation an evaluation shows that it not always the case (The Swedish Agency for Health and Care Services Analysis, 2017). Person-centredness is enabled by established relationships between the care providers, patient and persons significant to them. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding, and enabled by cultures of empowerment that foster continuous approaches to practice development (McCormack & McCance, 2017). Evaluation of clinical practice is essential to achieve care that meets patient care needs. However, measures for person-centred fundamental care are currently lacking and their development greatly needed (Conroy et al., 2021; Jeffs et al., 2018). In response to this need, the present study focuses on the fundamental care need of pain management and was designed to develop a questionnaire measuring person-centred pain management (PCPM) in acute surgical care.

1.1 | Background

Acute pain is an individual multifactorial experience that engages the sensory and autonomic nervous systems to signal tissue trauma and inhibit movement to promote healing. The physical and subjective responses include the sensation of pain, immunological deficits and anxiety. Biological, psychological and social factors such as genetics, previous pain experience, and ability to cope affect the experience and are unique to each person (Raja et al., 2020). This study is part of the research programme ‘Seamless Management for the patient with Acute Abdominal Pain—SMAAPP’, focusing on the patient with acute abdominal pain (AAP). AAP occurs regardless of a persons’ age, gender or origin and is one of the most common reasons for care in acute surgical care (Gregory & McGowan, 2016). The pain varies in intensity and character and has various causes. Associated care needs vary from discharge to life-saving interventions (Schug et al., 2020). Unfortunately, pain management is repeatedly reported to be insufficient, exposing the patient to unnecessary suffering and the risk of developing chronic pain (Gerbershagen et al., 2013; Pavedahl et al., 2021). Failed pain management can also hinder recovery and expose the patient to the risk of developing complications such as delayed wound healing, pressure ulcers and pneumonia (Schug et al., 2020).

Successful pain management requires valid and pragmatic assessment, and the development of appropriate measures to evaluate the multidimensions of pain management to improve clinical practice is an ongoing international challenge (Breivik et al., 2008; St Clair & Papadopoulos, 2020). The continuing development of instruments to evaluate pain and pain management has yielded a variety of validated and reliable instruments. One-dimensional instruments such as numeric rating and visual analogue scales, on which patients grade the intensity of their pain on a scale of 0 to 10, facilitate rapid evaluations of pain severity to guide immediate treatment. Additional dimensions are required to individualize and evaluate ongoing pain management and guide clinical improvement. This is approached in the multidimensional instruments, measuring parts of the pain management process such as the short-form McGill Pain Questionnaire and the revised version of the American Pain Society Patient Outcome Questionnaire (Moore, 2006). There is, however, a lack of instruments to evaluate and guide practice around person-centred pain management. Such instruments addressing person-centredness and the fundamental care need pain management would holistically combine the patient experience for the multiple dimensions involved. These dimensions comprise: the

Patient or public contribution: Patients and providers were involved in testing the questionnaire.

KEYWORDS
acute abdominal pain, fundamentals of care, instrument development, measurement, nursing, pain management, person-centred care, person-centredness, questionnaire, surgical care
patient-provider relationship; the pain and pain management addressing the physical, psychosocial and relational care needs; as well as the contextual prerequisites (Jeffs et al., 2018; Kitson et al., 2013, 2019; McCormack & McCance, 2017). Moving beyond simple pain ratings towards more comprehensive measures has been proposed as the first step in achieving the ultimate goal of effective acute pain management (Radovich et al., 2014).

To take on the challenge with missed care, there is an international movement towards person-centred fundamental care to successfully meet the patient’s care needs, including pain management (Kitson et al., 2019; Schug et al., 2020). To utilize and add to the knowledge around person-centred fundamental care and pain management, the care should be evaluated. An instrument capturing the multiple dimensions of the care process could be used for systematic evaluation and guide everyday practice. Developing such an instrument requires a systematic process including theoretical and empirical evidence to capture the phenomenon of interest: Person-centred pain management and be clinically relevant (Lor et al., 2017). Hence this study.

2 | THE STUDY

2.1 | Aim

The study aim was to develop and test a questionnaire using the Fundamentals of Care framework to measure person-centred pain management.

2.2 | Methods

2.2.1 | Design

We used a cross-sectional quantitative exploratory descriptive design. The systematic developmental process was designed in three phases: (a) searching the literature for questionnaires measuring PCPM, (b) developing the items in a seven-step process using theoretical and empirical evidence and (c) testing the questionnaire for initial feasibility and validity (Rattray & Jones, 2007). The study was reported with support from Streiner and Kottner (2014) concerning the development of the questionnaire and the STrengthening the Reporting of OBServational studies in Epidemiology (STROBE) Statement (Data S1) (von Elm et al., 2007).

2.2.2 | Developmental process in three phases

Phase 1

A literature search was conducted assisted by a librarian specialized in literature search to identify existing questionnaires for PCPM in acute care. The search identified no such questionnaire. The search did find the ‘Strategic and Clinical Quality Indicators in Postoperative Pain management (SCQIPP)’ questionnaire, which was included in this study to inform the item design and content in the developmental process (Idvall & Berg, 2008). SCQIPP is a multidimensional measure for pain management validated in the country and language of this study. It was developed from strategic and clinical quality indicators (QI) representing surgical nurses’ perspectives on nursing elements essential to achieve high quality postoperative pain management for adult patients in surgical wards. The 14 items of SCQIPP are presented in the four categories: ‘Communication’, ‘Action’, ‘Trust’ and ‘Environment’ (Idvall et al., 1999, 2001, 2002; Idvall & Berg, 2008).

Phase 2

For the new questionnaire to represent PCPM for the patient with AAP, the wording of the items from SCQIPP was adjusted, for example from ‘Before my operation I was told about the type of pain management I would be offered after surgery’, to ‘I was told about the type of pain management I was offered’. After the adjustment in wording, all 14 items from SCQIPP (Idvall & Berg, 2008) were included as preliminary items in the new questionnaire.

Complementing items (n = 18) were developed from theoretical and empirical evidence. The theoretical evidence included the Fundamentals of Care framework and the definition of person-centredness (Kitson et al., 2013; McCormack & McCance, 2017). The empirical evidence included studies based on observations from the patient perspective and interviews with patients. The study results guide the patient-provider communications facilitating fundamental care and person-centred pain management (Avallin et al., 2018, 2020). The results for communications facilitating person-centred fundamental care concern: Interpersonal respect, a humanized care context, open channels of communication and a mutual holistic understanding of care needs and the care plan (Avallin et al., 2020). The results guiding person-centred pain management are presented in a model describing that the organizational culture needs to support the patient-provider collaboration in identifying and meeting the care need. The patients are to disclose the intensity and other details of their pain and to ask for analgesics, information, or other methods to help manage the pain. The model describes that the providers are to continuously and consistently: (1) Establish a trusting relationship with the patient, (b) Communicate to reach a mutual understanding of the pain and pain management, (3) Administer individualized analgesics based on the assessment, reassess the pain and repeat steps 1–3 (Avallin et al., 2018). The items are presented in Appendix S1.

Thematic analysis was used to develop the complementing items, by (a) line-by-line coding of text representing the theoretical and empirical evidence, (b) grouping codes into descriptive themes and (c) grouping descriptive themes into analytical themes phrased as preliminary items (Thomas & Harden, 2008). The data representing the theoretical and empirical evidence and an example of the thematic analysis are presented in Table 1.

All items (n = 14 from SCQIPP + n = 18 complementary = 32 items) were then compared with each other, condensed and phrased into the items constituting the new questionnaire (n = 24). Items to
### Developing complementary items: Examples of the thematic analysis of the theoretical and empirical data.

<table>
<thead>
<tr>
<th>The Steps of the Thematic Analysis (1-3)</th>
<th>(1) Line-by-line coding</th>
<th>(2) Descriptive themes</th>
<th>(3) Analytical themes</th>
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<td>Text lines from the data marked in bold italics were missing in the items from SCQIPP and forwarded to descriptive themes.</td>
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<td>The analytical themes were compared to each other and grouped into the final preliminary items.</td>
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#### The Theoretical Evidence

**Theoretical data from: The Fundamentals of Care framework (Kitson et al., 2013)**

- The established relationship:
  - ‘Be nice to me’: Treat me as a person and respect and involve me in my care.
  - ‘Keep me safe’: I trust you to have the right knowledge, skill and expertise to know how to keep me from any harm.
  - ‘Help me to heal’: Base your care on my individual physical and emotional needs and help me to set goals that maintain my hope and spirit to get better and feel better.

**Integration of care:**

- Represented in the model for person-centred pain management (Avallin et al., 2018).

**Contextual support:**

- ‘Resources’: Do you have the right environment, equipment and staff numbers here to keep me safe and help me get better?
- ‘Culture’: Do you value caring for people like me?

**Example of the thematic analysis (1), (2), (3)**

(1) ‘Be nice to me’

- Treat me as a person and respect and involve me in my care

(2) To be personally respected and involved in the care

(3) I have felt respected as a person

(3) I have been told how to participate in my pain management

#### The Empirical Evidence

**Empirical data from: The Model for Person-centred pain management (Avallin et al., 2018)**

- Providers should:
  1. Establish/maintain a trustful relationship with the patient by showing competence and willingness to care, being mindful in interactions, making eye contact, sharing knowledge with the patient and acting upon the shared knowledge.
  2. Communicate to reach a mutual understanding of the pain and pain management by asking about the pain, pain experience and need for pain management and listening to the patient and need for information. Confirm the mutual understanding.
  3. Administer individualized analgesics based in the assessment, reassess the pain and repeat steps 1–3.

- Patients should be actively encouraged to:
  1. Disclose the intensity and other details of their pain.
  2. Ask for analgesics, information, or other needed help to manage their pain.
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Example of the thematic analysis (1), (2), (3)
(1) Communicate to reach a mutual understanding of the pain and pain management by asking about the pain, pain experience and need for pain management and *listening to the patient and need for information*
(2) Providers being aware of the patient experience
(3) I have been asked to share my pain experience

Empirical data from: Communication facilitating person-centred fundamental care (Avallin et al., 2020)

*Showing interpersonal respect by:*
- Using professional language
- Including the patient and relative at all times when within hearing distance
- Speaking personally but not privately
- Using a respectful tone of voice
- Choosing an appropriate setting when speaking with the patient,
- Respecting the patient’s confidentiality
- Referring to the patient by name as a person, not as a diagnosis or object.

*Supporting a mutual holistic understanding of care needs and the care plan by:*
- Guiding patients and relatives in how and why to participate in the care plan and share their care needs
- Combining the patients’ subjective parameters with objective assessments when planning care
- Guiding patients and relatives through the care process, including interpreting the results of assessments
- Ensuring all parties understand both care needs and the care plan

*Showing available and accessible communication channels by:*
- Being visible, accessible and responsive by noticing, listening and responding to patients and their relatives
- Guiding patients and relatives in how and when to contact which provider
- Involving relatives as channels of communication
- Using the right tools to ensure that patients, relatives and providers understand the language and what is being said at all times

*Humanizing the care context by:*
- Greeting and acknowledging all patients and relatives within speaking distance
- Customizing visible communications to the patient and relative
- Providing guidance on negotiating the physical environment and care process
- Providing a designated space where the patient can rest

Example of the thematic analysis (1), (2), (3)
(1) *Guiding patients and relatives in how and when to contact which provider*
(2) Providers being available to the patient
(3) I have known how to reach the healthcare providers when I needed pain management
include patient demographics (n=7), pain intensity (n=3), and overall satisfaction (n=2) were also added, as well as a patient evaluation of the feasibility and validity of the questionnaire (n=4). The final items are presented in the results. The questionnaire was developed and tested in Swedish.

Phase 3
A systematic appraisal of the questionnaire’s construction and wording was performed according to the Question Appraisal System (QAS-99; Willis & Lessler, 1999). To evaluate initial feasibility and validity, cognitive testing included an expert review performed by the two experts in the research team (EJ, AM). The review concerned the questionnaire’s relevance and comprehensiveness for person-centred fundamental care for patients with AAP. The cognitive testing also included think-aloud interviews with patients (n=5) and providers (n=5) who answered the questionnaire by reading the questions and saying their thoughts out loud, while a member of the research team (TA) listened and took notes (Boateng et al., 2018; Streiner et al., 2015). The four items in the questionnaire addressing its initial feasibility and validity asked about the following factors: (1) the overall experience of completing the questionnaire (Likert scale: very difficult/difficult/easy/very easy), including multiple choice suggestions for improvements to the (a) instructions, (b) design, (c) formulations, (d) answer options, (e) sequence of questions, (f) number of questions, (g) time required to answer the questionnaire, and/or (h) text size; (2) the relevance of the questions to pain management (numeric scale from 0—not relevant to 10—very relevant); (3) the difficulty of answering any questions (yes/no and ‘If yes, please describe’) and (4) whether anything affecting pain management was missing from the questionnaire (yes/no and ‘If yes, please describe’). The developmental process including results are summarized in the results, Figure 1.

2.2.3 | Participants and setting
To test the questionnaire n=100 eligible patients according to the inclusion criteria in being aged ≥18 years, seeking care for AAP or having post-surgical abdominal pain, admitted for 12h or more at the surgical ward, understanding the language of the study and cognitively well-functioning (alert and oriented to person, place and time) were included to participate in the study. The sample size was decided in consultation with a statistician and intended to find variations in the answers to provide descriptive statistics of the questionnaire at this initial stage (Streiner & Kottner, 2014). The study took place at four surgical wards with 10, 11, 24 and 24 beds, respectively, (1 or 2 beds per room) at a university hospital. The patients were cared for by a team including a registered nurse and a nurse assistant present 24/7 and a surgeon visiting the ward at rounds once or twice a day. Due to an ongoing pandemic few relatives were allowed to visit the ward.

2.2.4 | Data collection
Data was collected during February and March, 2021, between 9:00am and 9:00pm covering all days of the week. The nurse in-charge during each data collection was asked to recommend eligible patients, who were then informed about the study and asked verbally and in writing to participate by a member of the research team (TA). After signing written informed consent, patients filled in the questionnaire, which was collected after 30–60 min. Assistance was offered to those who needed help with reading and/or writing (n=31).

2.2.5 | Data analysis
Thematic analysis was used to derive appropriate items from the evidence in a representative summary of data from multiple sources (Thomas & Harden, 2008). Descriptive statistics were produced with IBM SPSS Statistics 27 and since non-parametric summarized as median (min/max) or percent (Altman, 1991).

2.3 | Ethical considerations
The study was approved by the Swedish Ethical Review Authority ID: 2020–05587. Patients eligible for inclusion were identified by the in-charge nurse on duty and a member of the research team, who considered the physical and psychosocial well-being of each suggested patient. The researchers recognized that patients’ vulnerability due to their acute pain and dependence on the providers, and the voluntary nature of their participation was emphasized in the oral and written information given before written consent was collected. In addition to the written information, before administering the questionnaire the researcher assured patients that their answers would not be personally identified, nor would they affect their care in any way. The questionnaires were coded, and the written consents were separated from the questionnaires and stored separately behind lock.

2.4 | Reporting method
Relevant EQUATOR guidelines have been used: the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) Statement and Streiner and Kottner (2014).

3 | RESULTS
The results are presented according to the systematic developmental process, phase 1–3 of the questionnaire including the patients’ test and evaluation. In phase 1, the literature search resulted in
FIGURE 1 The developmental process of the questionnaire described in three phases. AAP, Acute abdominal pain; FoC, Fundamentals of Care framework; QAS-99, Question Appraisal System.

<table>
<thead>
<tr>
<th>The developmental process of the questionnaire, phases 1-3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Searching the literature for questionnaires measuring person-centred pain management in surgical or acute care</td>
</tr>
<tr>
<td>The validated questionnaire, ‘Strategic and Clinical Quality Indicators in Postoperative Pain Management (SCQIPP; Idvall, 2008) was chosen.</td>
</tr>
<tr>
<td>2. Designing the questionnaire in a seven-stages process to identify, construct and refine the items:</td>
</tr>
<tr>
<td>2.1 Preliminary items from a validated questionnaire</td>
</tr>
<tr>
<td>The items from SCQIPP were included as preliminary items in the new questionnaire (n = 14).</td>
</tr>
<tr>
<td>2.2 Preliminary items representing person-centred fundamental care and pain management</td>
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<tr>
<td>Components representing:</td>
</tr>
<tr>
<td>✓ Person-centred pain management (Avallin et al., 2018)</td>
</tr>
<tr>
<td>✓ Communications supporting the meeting of fundamental care needs (Avallin et al., 2020)</td>
</tr>
<tr>
<td>✓ The Fundamentals of Care framework (the three dimensions as described in Kitson et al., 2013)</td>
</tr>
<tr>
<td>✓ The definition of person-centredness (McCormack &amp; McCance, 2017)</td>
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<td>were identified and represented as preliminary items (n = 18) in the new questionnaire. The new items concerned: patient participation, mutual understanding of the pain, cause and treatment, availability to providers, respect, trust, and contextual prerequisites (total n=32 items).</td>
</tr>
<tr>
<td>2.3 Refinement of the items</td>
</tr>
<tr>
<td>All items were compared to each other and, after reduction, appraised and rephrased to fit the context and person-centred wording (total n = 24 items left).</td>
</tr>
<tr>
<td>2.4 Items for demographics, overall satisfaction, and evaluation of the questionnaire</td>
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<tr>
<td>Demographic items (n = 7) were added: Items concerning pain intensity (n = 3), overall satisfaction with pain management and person-centredness (n = 2), and evaluation of the questionnaire (n = 4) were added.</td>
</tr>
<tr>
<td>2.5 Expert review and appraisal, testing for initial feasibility and validity</td>
</tr>
<tr>
<td>1) The research team reviewed the items for relevance and comprehensiveness of the FoC framework and person-centred pain management including supportive communication.</td>
</tr>
<tr>
<td>2) The questionnaire was appraised and modified to align with QAS-99 (Willis &amp; Lessler, 1999) and the recommendations in ‘Questions and answers – question design in self-administered and interview questionnaires’ (Statistics Sweden, 2016). 3) Adjustments were then made to the 5 items that needed clarification (1: n = 2; 2: n = 3), and one (n = 1) was removed in the expert review.</td>
</tr>
<tr>
<td>2.6 Think-aloud interviews with providers and patients, testing for initial feasibility and validity</td>
</tr>
<tr>
<td>Three nurses, two nurse assistants, and five patients participated in think-aloud interviews (Boateng et al., 2018). They completed the questionnaire by reading the questions aloud and speaking their thoughts while a member of the research team listened and took notes. Adjustments were then made to the items that needed clarification (n = 3).</td>
</tr>
<tr>
<td>2.7 The final questionnaire to be tested</td>
</tr>
<tr>
<td>Demographics (n = 7 items)</td>
</tr>
<tr>
<td>Pain intensity (n = 3 items)</td>
</tr>
<tr>
<td>Numeric scale 0–10</td>
</tr>
<tr>
<td>Overall satisfaction with pain management (n = 1 item)</td>
</tr>
<tr>
<td>Likert scale 0–10</td>
</tr>
<tr>
<td>Overall experienced person-centredness (n = 1 item)</td>
</tr>
<tr>
<td>Likert scale 0–10</td>
</tr>
<tr>
<td>Experiences of pain management (n = 23 items)</td>
</tr>
<tr>
<td>Five-item Likert scale: disagree completely–agree completely</td>
</tr>
<tr>
<td>Evaluation of the questionnaire (n = 4 items)</td>
</tr>
<tr>
<td>3. Testing the questionnaire including initial feasibility and validity</td>
</tr>
<tr>
<td>The questionnaire was answered by n=100 patients with AAP at four surgical wards.</td>
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</tbody>
</table>

Identification of the validated questionnaire SCQIPP (Idvall & Berg, 2008), chosen to represent the nurse perspective on pain management, and guide the design in the new questionnaire.

In phase 2, the items representing the nurse perspective was complemented by items from empirical evidence representing the patient perspective, and theoretical evidence for person-centredness and meeting fundamental care needs including pain management.

The questionnaire underwent cognitive testing and item assessment before being tested by a larger sample of patients in phase 3. The cognitive testing of the questionnaire, where two theoretical experts...
on the FoC framework reviewed the items, and five patients and five providers filled out the questionnaire in a think-aloud interview, confirmed the questionnaire as relevant and easy to use. This test also resulted in the removal of one item and clarification of five items as presented in Figure 1: Phase 2.5 and 2.6. The assessment of the questionnaire applying the QAS-99 resulted in adjusting the wording of three items. Phase 1–3 are summarized in Figure 1. The adjusted items were tested in phase 3. The final items are presented in Table 3.

In phase 3, the questionnaire was tested and evaluated by n = 100 patients (response rate 100%), presented in Table 2. Four patients declined participation because they were not interested, two felt they did not have enough energy to complete the questionnaire, and seven agreed to participate but did not return the questionnaire before leaving the ward (total n = 13).

3.1 Testing the questionnaire: The patients’ answers for the pain management

The items representing PCPM (13–32) were answered with an overall median (min/max) of 4 (1/5). The answers varied between patients but also between items for the same patient. The items that the patients strongly agreed to happen (median 5) concerned: feeling safe and respected, being listened to, and trusting the providers’ availability and knowledge to manage the pain. In contrast, less than half of the patients were satisfied with the pain relief (n = 45 [45%]). Basics like information, evaluation and participation were found to be missing, and the item regarding assessing pain several times each day was not strongly agreed upon by more than 26 [26%] of the patients. Similar results were found for the items concerning: being informed about how the pain was to be managed (median 5 [25%]), knowing the goal of the pain management (n = 23 [23%]) and knowing how to participate (n = 15 [15%]). The item concerning participation of relatives was chosen as not applicable by n = 53 [53%] of the patients and not included in the statistics. The other 47 of the patients’ (n = 47 [47%]) answered that relatives were not included in the care, with a median (min/max) 1 (1/5). The tested items and findings are presented in further detail in Table 3. The variations between the patients’ answers are displayed in the min and max for each item.

3.2 The patients’ answers for the evaluation of the questionnaire

The patient evaluation (4 items) of the initial feasibility and validity of the questionnaire was completed by all participants (n = 100). The majority of patients answered that it was very easy to answer the questionnaire, median score 4 (2/4). Improvements were suggested concerning the number of questions (n = 4), the wording (n = 3), the answer options (n = 3), the time needed to answer (n = 2) and the order of the questions (n = 1). The patients reported that the items were relevant to their pain management, median 10 (1/10). Several patients (n = 19) reported that some items were difficult to answer because they could not remember what had happened, did not know the answer, did not know what the providers knew, and could not judge whether they were receiving the right care. Some patients (n = 9) also reported experiences related to their pain management that they found missing in the questionnaire, concerning: sleep, being listened to and respected, and receiving inconsistent care and information.

3.3 Initial feasibility and validity

Based on the tests performed in the developmental process as displayed in Figure 1, Phases 2.5, 2.6 and 3, support was found for the ability of the questionnaire to represent and be sufficiently sensitive to capture the patient’s experiences of PCPM, as well as for it being easy to answer. Hence, evidence was found for initial support for the questionnaire’s feasibility and validity.

<table>
<thead>
<tr>
<th>Items 1–10 (answer options)</th>
<th>Median/Percent</th>
<th>Min–max</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Age (years) (Open answer)</td>
<td>68</td>
<td>18–89</td>
</tr>
<tr>
<td>2: Gender identification (Open answer)</td>
<td>46% Female</td>
<td>54% Male</td>
</tr>
<tr>
<td>3: Education in pain or pain management (Yes)</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>4: Experience of pain management (Yes)</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>5: Length of stay (days) (Open answer)</td>
<td>3</td>
<td>0.5–28</td>
</tr>
<tr>
<td>6: Diagnosis known (Yes)</td>
<td>47%</td>
<td></td>
</tr>
<tr>
<td>7: Had surgery (Yes)</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>8: Worst pain experienced (0–10) (No pain–Worst pain imaginable)</td>
<td>9</td>
<td>2–10</td>
</tr>
<tr>
<td>9: Least pain experienced (0–10) (No pain–Worst pain imaginable)</td>
<td>2</td>
<td>0–8</td>
</tr>
<tr>
<td>10: Pain right now (0–10) (No pain–Worst pain imaginable)</td>
<td>2</td>
<td>0–8</td>
</tr>
</tbody>
</table>

TABLE 2 Demographics and pain experience of the patients answering the questionnaire. Number of patients answering n = 100.
**4 | DISCUSSION**

In this study we developed a questionnaire to evaluate person-centred pain management in clinical practice, guided by the FoC framework. To our knowledge, this is the first study to attempt to transfer the essential components of PCPM into measurable items. Based on theoretical and empirical evidence for PCPM, developed via a systematic three-phase process and tested by theoretical experts, providers and patients, the questionnaire shows promising results to be further tested for psychometric properties and use in clinical settings.

The results from the literature search in phase 1 aligned with the previously acknowledged lack of measures for fundamental care (Jeffs et al., 2018; Muntlin Athlin, 2018). Our study is a first attempt to transfer PCPM into measurable items, although the generalizability of these items to different fundamental care needs must be further explored.

To capture person-centred pain management we used the FoC framework to theoretically ground the questionnaire in a modern framework for person-centred fundamental care, complementing the empirical evidence of pain management (Kitson et al., 2013). Such multidimensional questionnaire has been argued as missing but essential to shifting healthcare to identify and overcome missed nursing care (Jeffs et al., 2018; Kitson et al., 2019; Muntlin Athlin, 2018). Hence capturing the multiple dimensions of the performed pain management was considered essential for the questionnaire to evaluate and guide clinical practice. Future research should develop...
a fixed set of items capturing person-centred fundamental care to enable its systematic evaluation when performed for the variety of care needs.

The theoretical and empirical grounding that was used in phase 2 are argued to be strong contributors to a robust questionnaire capturing the phenomenon of interest. This combined with expert review and cognitive testing by patients and providers likely contributed to the initially promising accuracy of the items (Lor et al., 2017; Streiner et al., 2015). The user evaluation by patients and providers were also successful in identifying potential improvements for upcoming refinements of the questionnaire. Developing with rather than for users, is a growing research area to be explored, recognized to enhance a questionnaire's feasibility, validity and reliability (McDowell, 2006). Our results confirm that user involvement is essential in the development of multidimensional questionnaires. Their unique perspective cannot be replaced, and hence should be part of future refinement of the questionnaire (Wideman et al., 2019).

The results from phase 3 showed that the questionnaire captures sensitive information about what works and what needs improvement in the care process to ensure that patients' care needs are met. According to the patients, providers failed to provide complete fundamental care related to pain management. For example, a patient could fully trust the providers while not at all agree with the pain assessment being performed. This finding is aligned with the global challenge of fundamental care being invisible in healthcare systems, resulting in dehumanizing behaviour and missed care (Kalisch & Xie, 2014).

Our results indicate that while some isolated parts of pain management are being performed, others are not. To succeed in pain management, there is a need to step away from the culture of performing isolated tasks and to move towards holistically managing the patient's physical, psychosocial and relational care needs (Feo et al., 2017). Using the new questionnaire to evaluate daily practice could help providers visualize the elements of pain management and identify what needs to improve to manage the patients' pain.

The results present another benefit of using a questionnaire capturing the multiple dimensions in PCPM, since displaying a discrepancy between patient overall satisfaction and pain assessment. The results confirm the well-known phenomenon of patients expressing satisfaction with care despite experiencing pain or missed care, making satisfaction an insufficient indicator for care quality (Wooldridge & Branney, 2020). Our findings from testing the questionnaire support the multidimensional assessment of pain and pain management to capture the detailed information needed to understand and improve care performance.

4.1 | Strengths and limitations

The systematic development of the questionnaire, including the use of a validated questionnaire from the same country and context as a guide, supports the study's strengths (McDowell, 2006). So does the combination of theoretical and empirical evidence, taking the theoretical evidence closer to practice and allowing the empirical evidence to represent a larger context, overcoming the limitations of using only one type of evidence. A further strength at this stage was the cognitive testing by theoretical experts and users, which allowed us to adjust items to improve the questionnaire's feasibility and validity before an upcoming evaluation of psychometric properties (Streiner et al., 2015).

A limitation of the study is the relatively small sample size of patients with AAP from one hospital, which was selected to provide an initial evaluation, in preparation for an evaluation of a refined version in a larger sample, and thus the generalizability of the results should be interpreted with caution (Polit-O’Hara & Beck, 2016). Another limitation particular to the use of questionnaires is the possible exclusion of patients who, for physical or linguistic reasons cannot complete the written material. In this study the personal distribution of the questionnaires to the participants allowed us to assist patients with reading and writing when necessary. Future research should explore the possibility for the instrument to target also more challenging patient populations, also including the patient with, for example cognitive impairment.

We acknowledge that this study represents the initial stage of developing a new instrument to measure PCPM. The questionnaire is to be evaluated for psychometric properties of validity, reliability and patient benefit, ensuring that it measures what is intended in a repeatable way and is clinically useful (McDowell, 2006; Streiner et al., 2015).

5 | CONCLUSION

This study contributes with new knowledge on transferring the essential components of PCPM into measurable items in a questionnaire, using the FoC framework in addition to empirical evidence from patient and provider perspective. The questionnaire is recommended to be further tested for psychometric properties and patient benefit in order to provide clinical guidance to meet the patient care need of pain management in acute surgical care.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*): substantial contributions to conception and design, acquisition of data or analysis and interpretation of data or drafting the article or revising it critically for important intellectual content.

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Strengths and limitations
CONFLICT OF INTEREST STATEMENT
The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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