Achieving person-centred pain management for the patient with acute abdominal pain

Guided by the Fundamentals of Care framework

THERESE AVALLIN
Dissertation presented at Uppsala University to be publicly examined in H-son Holmdahl salen, Uppsala university hospital, entrance 100, Uppsala, Friday, 2 September 2022 at 13:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish. Faculty examiner: Professor Helle Wijk (Institute of Health and Care Sciences, University of Gothenburg).

Abstract

The overall aim of this thesis is to explore how to achieve and measure person-centred pain management (PCPM) for the patient with acute abdominal pain (AAP) in acute surgical care. The Fundamentals of Care (FoC) framework guides all studies.

The methods: In Study I, focused ethnography is used with 92h of participant observations (n=34) at the emergency department (n=1) and surgical wards (n=2), including 261 patient-provider interactions. In Study II, case study is used for secondary analysis of 20 observations from Study I. In Study III, a questionnaire is developed in a systematic process to measure PCPM, performed by combining; a validated questionnaire, theoretical and empirical evidence. The questionnaire is tested by question appraisal, theoretical experts (n=2), patients (n=5) and providers (n=5), and thereafter by patients (n=100) at surgical wards (n=4). In Study IV, a qualitative systematic review is performed with a synthesis by thematic analysis, to test and refine a model for PCPM from Study I. The synthesis includes 15 qualitative studies representing patients (n=495) and/or nurses (n=259) from n=3 emergency departments and n=17 hospital wards in n=9 countries. The patients are ≥ 18 years old, with AAP (Studies I-IV), or acute pain from surgery (Study IV). The results confirms that the patient still suffer from unmanaged pain in acute surgical care, and presents actions on behalf of the patient and provider, and contextual factors including the organizational culture, to achieve and measure PCPM. The studies presents a model for PCPM from the patient perspective (Study I), patient-provider communications contributing to meeting fundamental care needs (Study II), an initially feasible and valid questionnaire to measure PCPM (Study III), and a tested and refined model for PCPM from the patient and nurse perspective (Study IV).

Conclusion: This thesis presents scientific evidence providing an in-depth understanding of what is important for successful pain management from the patient’s and nurses’ perspectives, how these parts are interconnected, and how they can be achieved and measured. The results also show the feasible role of communication in meeting the patient’s fundamental care needs. This evidence is suggested to be tested and evaluated in clinical practice to perform PCPM, relieving the patient from pain.

Keywords: Acute abdominal pain, Case study, Communication, Culture, Ethnography, Fundamentals of Care framework, Nursing, Pain management, Person-centred care, Person-centred fundamental care, Surgical care, Systematic review, Pain Questionnaire, Qualitative synthesis

Therese Avallin, Department of Surgical Sciences, Nursing Research, Akademiska sjukhuset, ingång 70, 1 tr., Uppsala University, SE-751 85 Uppsala, Sweden.

© Therese Avallin 2022

ISSN 1651-6206
ISBN 978-91-513-1532-4
URN urn:nbn:se:uu:diva-474280 (http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-474280)
“There is no hope about it, it is just very hard work.”
Alison Kitson, 2022
To the patient who suffers needlessly from pain.
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


IV. Avallin, T., Muntlin, Å., Kitson, A., & Jangland, E. Testing a model for person-centred pain management: A systematic review and synthesis guided by the Fundamentals of Care framework. *(Manuscript).*

Reprints were made with the kind permission from the publishers.
Contents

Preface ......................................................................................................................... 11
Outline of the thesis ................................................................................................. 13
Introduction ............................................................................................................... 15

Background ............................................................................................................. 16
  Person-centred fundamental care ....................................................................... 16
  The Fundamentals of Care framework ................................................................ 17
  Pain ...................................................................................................................... 20
  Pain management .............................................................................................. 20
  Measuring person-centred pain management ..................................................... 21
  Communication ................................................................................................. 22
  Organizational culture ....................................................................................... 22
  The patient with acute abdominal pain ............................................................ 23

Rationale for the studies ......................................................................................... 24

The aims ................................................................................................................... 25
  Overall aim ......................................................................................................... 25
  Specific aims ....................................................................................................... 25
    Study I .............................................................................................................. 25
    Study II .......................................................................................................... 25
    Study III ......................................................................................................... 25
    Study IV .......................................................................................................... 25

Methods .................................................................................................................... 26
  Settings and participants .................................................................................... 27
  Study I ................................................................................................................ 28
    Design ............................................................................................................. 28
    Procedure ...................................................................................................... 28
    Analysis ......................................................................................................... 28
  Study II .............................................................................................................. 30
    Design ............................................................................................................. 30
    Procedure ...................................................................................................... 30
    Analysis ......................................................................................................... 31
  Study III ............................................................................................................ 33
    Design ............................................................................................................. 33
    Procedure ...................................................................................................... 33
Analysis ........................................................................................................ 34
Study IV ........................................................................................................ 35
   Design ...................................................................................................... 35
   Procedure .............................................................................................. 35
   Quality appraisal .................................................................................. 36
   Analysis .................................................................................................. 38

Ethical considerations .................................................................................. 39

Results ......................................................................................................... 40
   Study I .................................................................................................... 42
   Study II .................................................................................................. 42
   Study III ................................................................................................ 45
   Study IV ................................................................................................ 47

Discussion .................................................................................................... 51
   Person-centred fundamental care .......................................................... 51
   Task-focused care ................................................................................ 52
   The model for person-centred pain management .................................. 52
      Trustful patient-provider relationship including the patient in the care team .................................................. 52
      Patient–provider communication to share knowledge in the care team ......................................................... 53
      Timely pharmacological and non-pharmacological pain management ............................................................ 53
      Organizational support ...................................................................... 54
   Measuring person-centred pain management ......................................... 56

Methodological considerations ................................................................. 58
   Trustworthiness ...................................................................................... 58
   Confirmability ......................................................................................... 58
   Credibility ............................................................................................... 59
   Dependability ........................................................................................ 59
   Transferability ........................................................................................ 59
   The Fundamentals of Care framework .................................................... 60

Conclusions .................................................................................................. 62

Clinical implications ..................................................................................... 64

Future research ............................................................................................. 66

Svensk sammanfattning (Swedish summary) .............................................. 68

Acknowledgments ....................................................................................... 70

References ................................................................................................... 70
Abbreviations and concepts

AAP | Acute abdominal pain
Care team | Used for the providers (registered nurse, nurse assistant, surgeon), patient and relative in collaboration
DRS | Developmental Research Sequence
ED | Emergency department
ENTREQ | The Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement
FoC | The Fundamentals of Care framework
ILC | International Learning Collaborative
Nurse | Used for the registered nurse
Patient | Used for the person being cared for
PCFC | Person-centred fundamental care
PCC | Person-centred care
PCPM | Person-centred pain management
PRISMA | The Preferred Reporting Items for Systematic reviews and Meta-Analyses statement
Provider | Used for the registered nurse, nurse assistant and surgeon
Relative | Used for the person accompanying the patient
SCQIPP | The Strategic and Clinical Quality Indicators in Postoperative Pain management questionnaire
Preface

This preface provides a glimpse of one of the real-time data collections using observation and informal interview for Studies I and II of this thesis.

Whose agenda?
It is early morning in the surgical ward. I am sitting on a chair at the foot of Anna’s hospital bed. She has just told me that she experienced dying while being transported to the hospital, but that she has not talked to anyone about it. I am thinking that it is inexcusable that she has been in the ward for more than a week without help for this strong existential trauma.

As the observation continues, an assistant nurse, three other nurses, and a nurse student assists Anna with various tasks such as opening the curtains, taking blood samples, doing checkups, and adjusting the infusion pump.

Most likely, my reflections and the providers’ actions are adequate to Anna’s care, however, to Anna, nothing of what I am thinking or what the providers are doing is important. The only thing that matters to her is managing her pain, as it is the only thing she can think of: “The most important thing is to get rid of the pain! Then I can look at something else, but right now the highest priority is the pain!”

After a few hours I end my observation and leave. Anna is still suffering from pain.

…

I am a specialist nurse in surgical care, determined to help transform health care so that it holds each patient’s fundamental care needs essential to effective and high quality care. I began my health care experiences as a patient at young age, due to having a chronic disease. As I grew up my experiences were not only those of a patient, but also, and not the least, those of a relative. These experiences made me feel both grateful and vulnerable towards the providers I met. I could feel both genuine interest from and thus trust in the provider, as well as fright when not being heard or doubting that the best care was being delivered. An event that greatly impacted my interest in nurs-
ing, and that I in the end became a nurse, was an experience I had when I was visiting a friend in hospital. I observed a nurse who had this wonderful relationship with my friend. The nurse passionately shared her agenda while performing various task, unknown to me at the time, and synced them to my friend. At the same time she also made me feel welcome and part of the plan. We were all smiling when she left the room despite the troublesome reason for care. At this moment, I realized how much more there is to health care, especially nursing, than is articulated or understood outside the hospital. I wanted to understand this and to share these stories, so at the time I decided to become a journalist.

But reality beats that initial thought. I became a nurse. I am currently working as a specialist nurse at a university hospital in the surgical clinic where I have been employed for the last 16 years. Despite the sometimes overwhelming pressure of nursing, I am constantly reminded that this is the kind of place where I want to be. However not under the prevailing circumstances. Therefore, it is my determination to contribute to change. This thesis is for me a step towards manifesting fundamental nursing care as non-negotiable in clinical practice, and the collaboration with the patient as a prerequisite for high quality care. In combining my clinical work and research studies I found a way to fulfill my initial wish to explore and communicate the dimensions of nursing care. This is only the beginning.
Outline of the thesis

To approach the well-known challenge of missed fundamental care in pain management, this thesis combines qualitative and quantitative evidence from patients and providers. Data derived from real-time observations, a questionnaire, and scientific literature, were combined with the FoC framework to advance our knowledge about successful pain management for the patient with acute abdominal pain (AAP).

Study I presents a model for person-centred pain management (PCPM) based on data from the patient’s perspective, collected through observations and informal interviews in the emergency department and surgical wards. Study II presents guidance for communication to meet patients’ fundamental care needs, using data from Study I in a secondary analysis. The results from Study I and II were included in Study III, in the development of a questionnaire to measure PCPM. Study IV tests and refines the model for PCPM in a systematic review from patient and nurse perspectives from across the world.

All studies were theoretically grounded in the Fundamentals of Care (FoC) framework. This to maintain the holistic perspective on meeting the patient’s fundamental care needs, including the established patient-provider relationship enabling the integration of care, in a supportive context. The results presents found missed nursing care to enable understanding of the patients’ situations and needed improvements. The results also outlines guidance for performing person-centred fundamental care (PCFC) in general (Study II), and PCPM in particular (Studies I, III, IV). Anna, who we met in the preface, will follow us throughout the thesis as a representative of the patients in the results. The thesis concludes with implications of the results for clinical practice, education, and future research.
Introduction

This thesis focuses on PCPM for the patient with AAP in acute surgical care. Pain management is a fundamental care need that must be met to relieve the patient from suffering. Well-managed pain can also prevent serious consequences, for both patients and healthcare organizations, such as care-related injuries, other missed fundamental care needs, and prolonged care (1). Although pain and pain management are prioritized in research and practice, patients in acute surgical care around the world continue to suffer unmanaged pain (2-4). This puzzles providers and researchers globally, and is arguably not the result of a lack of interest or effort, but the lack of a personalized approach to pain management and the multiple dimensions involved. Such an approach has yet to be fully researched and explored (5). The international movement toward PCFC answers to this personalized, holistic approach to meet the patient’s fundamental care needs (6). However, there is a lack of guidance specifically for pain management. The practice process of PCFC is guided by the FoC framework (7-9). FoC is used throughout this thesis to explore patient and provider perspectives on how to manage the pain and relieve the suffering for the patient with AAP in acute surgical care.
Background

Person-centred fundamental care

The fundamental care needs, like food and water, comfort and pain management, are in common to all human beings and must be met to maintain or regain health. PCFC focuses nursing actions on meeting these care needs in a trusting collaboration with the patient in a supportive context (7). The collaboration with the patient is a core value of nursing that contributes to high-quality care, and is enshrined in Swedish law (10). Fundamental care needs and their vital impact on care outcome is long known, researched and described. Nurse Nightingale, documented the life-saving effects of nursing interventions on care outcome in the 1800’s (11). Nursing theorists have worked ever since to define and describe the science of nursing and guide its practice. Although a consistent focus on fundamental care needs, the nurse–patient relationship, and the contextual prerequisites, the combination of these dimensions of care were not described until recently (12, 13).

Considering and treating patients as stakeholders and facilitators of their own care is increasingly seen as beneficial for both care outcomes and work environments (14, 15). In medicine, the need to personalize treatments to patients’ individual physiologies and genetics is well recognized. The patient-centered approach expands this acknowledgment of each patient’s individuality, to include their experiences and their relational and contextual prerequisites. Person-centred care (PCC) further includes planning and performing care in collaboration with, rather than for, the patient (16). The person-centred approach includes but does not isolate care; it establishes relationships between the care provider, the patient, and the patient’s relatives, and is underpinned by values of mutual respect and understanding (17). There is also a strong emphasis on the need for the person-centred culture to apply to everyone in the organization (18). This approach requires a transformation of care, and despite many initiatives, PCC remains available only for some patients. Although Swedish healthcare is legally required to be person-centred (10), it still not always is (19). Suggested explanations are missed use of empirically developed theoretical frameworks, incomplete understanding of what constitutes person-centredness, and unsupportive contexts and workplace cultures (18, 20). To approach this challenge, the empirically developed,
Theoretical FoC framework aims to bring PCFC into practice by integrating the trusting patient-provider relationship with the integration of multiple fundamental care needs in a supportive context (7).

The Fundamentals of Care framework

Focusing on the desired outcome of PCC, the FoC framework recognizes the core values of person-centredness and guides the practice of PCFC. It emphasizes the importance of a supportive care context, including the organizational culture, resources, and evaluation of delivered care. The framework guides the provider to develop a trusting relationship with the patient, to perform timely and responsive care that meets the patient’s physical, psychosocial, and relational care needs, supported by the context (7, 9). The FoC framework was established in response to the missed nursing care around the world (21) and the Francis report revealing systematically missed fundamental care with devastating consequences for the patients (9, 22). An international group of nurse clinicians, leaders, educators, and researchers united with the ambition to transform healthcare and improve the global delivery of fundamental care. This International Learning Collaborative (ILC) was founded on the conviction that PCFC would improve the outcomes, safety, and experiences of patients, the well-being of providers, and the economy of healthcare organizations. The convictions were and are also that this has to be based on empirical evidence (researched), put into action by health systems (practiced), and embedded in nursing curricula (taught), which is beginning to happen around the world (6, 23).

The ILC presents the FoC framework that emphasizes the holistic approach to care and outlines what is involved in the delivery of safe, effective, high-quality fundamental care. The framework aims to guide practice, research, education and politics around PCFC (6). Fundamental care is concerned with every patient, and the framework focuses on the routine everyday patient needs that form the bedrock of the nurse’s caring encounter with the patient. In emphasizing the trusting relationship and the supportive context, the framework embrace the core values of person-centredness, while the integration of care needs directs the focus to fundamental care (8, 18). The framework connects the importance of (1) a trusting patient–provider relationship, (2) the recognition and meeting of patients’ physical and psychosocial care needs, and (3) the contextual support as shown in Figure 1 (8). Stakeholders in nursing care are guided by the framework to meet the patient’s fundamental care needs, and voices from around the world have united in calling for PCFC to be on every healthcare agenda to end the global pandemic of missed nursing care (6). The framework is used in the international research
program Seamless Management of Patients Seeking Care for Acute Abdominal Pain—a Person-Centred Approach (SMAAPP), of which this thesis research is part.
Pain

Pain is an universal but individual experience described as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Box 2 in Raja et al., 2020) (24). The present studies are focused on acute pain, which is described to promote healing by engaging the sensory and autonomic nervous systems to signal tissue trauma and inhibit movement. The physical and subjective responses to acute pain 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 unique to each person (5). The function of pain as an alarm system to alert the mind to the potential injury or disease is beneficial at the initial stage, but the pain has negative consequences for the patient if not relieved. Moreover the suffering and an increased risk of developing chronic pain, the pain blocks out vital functions like proper breathing and bowel function, and hinder the meeting of other fundamental care needs like mobilization and sleep. This hampers the patient’s recovery, urging pain management as a fundamental care need to manage without delay (25-27).

Pain management

Pain management has garnered much interest for many years because of its vital impact on patient suffering and on the quality and effectiveness of care (5). It is one of the oldest recognized care needs, and access to pain management is argued to be a fundamental human right (28). Pain management is historically described as having evolved from the focus on medicines, with analgesics such as opium (1600’s), ether and chloroform (1800’s), and later morphine and heroin (1900’s) commonly given to the patient with acute pain. In the mid-1900s, awareness began to develop of the relationship between pain and psychological and emotional reactions such as anxiety. About the same time, the adverse effects of opioids were found to cause care-related injuries, and the benefit of multimodal treatment including non-pharmacological management was acknowledged (5, 29). Pain management, included within the fundamental care need of comfort, have been recognized within nursing for the last century (13). The holistic approach to meet patient fundamental care needs that is the core of nursing, are also recognized in medicine as a successful approach to pain management (30). A practiced example of this is found in the initiatives with multi-professional care teams with specific focus on pain management. These teams are argued to benefit from the multiple competencies to meet the interconnected dimensions in the patient’s care need for pain management (31, 32). The imperative to manage acute pain is part of the professional ethical obligation of the providers to
relieve the patient from suffering, prevent or reduce adverse advents such as pressure ulcers and pneumonia, and enable the meeting of other fundamental care needs (5, 33).

Despite the providers’ obligation and the multi-professional initiatives, pain management continues to be dominated by medical treatment, primarily opioids, and unmanaged pain prevails leaving the patient suffering from acute pain (5). The recent update on the definition of pain includes factors listed as essential to manage pain; the biological, psychological, and social characteristics of the patient; the difference between pain and other sensory experiences; the concept of pain as a person’s individual experience; the obligation of healthcare to respect a person’s report of their experience of pain; the possible adverse effects of pain on function and social and psychological well-being; and the multiple behaviors used to express pain (24). The complexity of the pain experience is suggested to be met by a multidimensional pain management adapted to the individual patient (30). This is possible through the approach of PCFC, and promising results are found for involving the patient as an active partner to manage their acute pain (34). This thesis follows up on those results with further research aimed to improve pain management and reduce suffering through focusing on PCPM.

Measuring person-centred pain management

Measuring the multiple dimensions of PCPM practice is key to evaluate the delivered care, and know what to improve in order to successfully manage the patient’s pain (35). To evaluate such fundamental care, it is argued that the measurement must be clear about what is evaluated and address all dimensions included, while at the same time reflect the most current science and empirical evidence (18, 36). Emphasis is placed on the holistic consideration of the care need, including a trusting relationship with the providers (37). Initiatives to evaluate the performance of PCFC, such as the unit-level quality measurement and improvement program being developed in New Zealand (38), have not yet established a standardized data set or fixed set of items to evaluate PCFC such as pain management (39).

There are one-dimensional and multi-dimensional measurements available to evaluate pain management. The one-dimensional measurements are useful for rapid evaluation of changes in pain intensity, while the multi-dimensional measurements are required to evaluate performed care as a knowledge base for improvement (40, 41). There are well-used and validated multidimensional instruments available, such as the short-form McGill Pain Questionnaire and the revised version of the American Pain Society Patient Outcome Questionnaire, but they are not designed to measure PCPM (41).
The greater involvement of patients and necessary changes in organizational structures and processes needed to improve clinical outcomes, are argued to benefit from being measured (42). The lack of instruments to evaluate PCPM challenges the holistic understanding of the quality of delivered care and needs to be acted upon to enable evaluation of PCPM to guide clinical improvement.

Communication

Communication is a cornerstone in nursing and the person-centred approach to care, enabling the co-creation of care between patients, relatives, and providers. Positive effects include reduced uncertainty, fewer readmissions, and more satisfaction for patients and providers (43). Communication in this thesis refers to verbal or other transmissions of information or emotion between a sender and a receiver. All communication is characterized by the receiver’s interpretation. Meaningful communication requires an interest in the other’s perspective and a wish to create mutual understanding, both of which are also cornerstones of PCFC (44). Communication is a central component of the FoC framework, where the five elements of establishing the essential trusting patient–provider relationship; [1] developing and maintaining trust, [2] focusing on the person being cared for, [3] anticipating the person’s needs, [4] getting to know the person and how best to care for them, and [5] evaluating the quality, progress, and outcomes of the relationship, all include communication as a vital component (45). As well as in establishing the trusting relationship, communication plays an important role to integrate care by keeping the care team informed about the patient’s experience, the care plan, and the response to treatment. While effective communication is arguably a nursing skill that contributes to positive care outcomes (46, 47), it is not specifically articulated how in the FoC framework.

Organizational culture

The organizational culture is acknowledged to be essential to PCFC, since shared professional knowledge and workplace norms guide the behaviors of the care team (18, 45). The organizational culture affects how care is performed, leading or misleading providers in their efforts to meet patients’ fundamental care needs (19, 48). In this thesis organizational culture is defined as the set of beliefs that are shared among providers and so widely accepted that they are unseen and preserved over time and generations of providers. This culture includes visible manifestations in behaviors, espoused values and priorities in written and verbal statements, and tacit assumptions that guide daily behavior (49). The organizational culture is de-
scribed as induced by leadership, and manifested in provider actions and behavior, affecting the patient outcome (50, 51). The FoC framework includes the organizational culture in the contextual dimension (45).

The patient with acute abdominal pain

This thesis focuses on the patient with AAP, one of the most common reasons around the world for seeking care at the ED, and highly prevalent in post-operative care on surgical wards (3, 52). AAP occurs regardless of age, origin, or lifestyle and can be caused by inflamed organs or injuries from trauma or surgery, and the care needed varies from discharge to life-saving interventions (53). The studies in this thesis included patients of different ages, genders, origins, language skills, cognitive abilities, diagnoses, care experiences, and support from relatives. Being accompanied by a relative is not uncommon for the patient, which can be beneficial for meeting fundamental care needs, however presupposes that the relative is guided to know how to participate (54, 55). Meeting the fundamental care needs including pain management is of high priority for the patient with AAP. When pain is not managed well, it can inhibit communication and the meeting of other fundamental care needs (4, 56). The various demographics and diagnoses for the patient being cared for AAP, highlights the benefits of PCFC since considering the individual prerequisites when planning and performing care, possibly contributing to a successful care outcome.
Rationale for the studies

The evidence confirms my clinical experience from surgical care where pain is a prioritized, however challenging fundamental care need to manage. Despite providers’ ethical obligations and the high interest in research and practice, the patient with AAP still suffer from unmanaged pain.

Successful pain management, as suggested to require a holistic approach tailored to the individual patient, is addressed by PCFC. The person-centred practice-process emphasizes the trusting patient-provider relationship and a supportive context, and describes the patient-provider collaboration to meet fundamental care needs such as pain management. However, despite the theoretical knowledge provided, more research is needed to put PCPM into practice.

In this thesis, evidence for PCFC and for pain management is integrated by combining the FoC framework with the patient’s and providers’ perspectives. Through this integration of theoretical and empirical evidence, the aim of the thesis is to provide practice-relevant guidance to be used in acute surgical care to achieve and measure PCPM for the patient with AAP.
The aims

Overall aim
The overall aim was to explore how to achieve and measure person-centred pain management for the patient with acute abdominal pain in acute surgical care.

Specific aims
Study I
To explore and describe the impact of the organizational culture on and the patient-practitioner patterns of actions that contributes to or detract from successful pain management for the patient with AAP across the acute care pathway.

Study II
To explore, through the patient perspective, how patient–provider communication is linked to missed nursing care vs. meeting patients’ fundamental care needs.

Study III
To develop and test a questionnaire using the Fundamentals of Care framework to measure person-centred pain management

Study IV
To test the model for person-centred pain management using qualitative evidence in the literature, and refine it based on the results.
Methods

The methods were chosen to explore how to achieve and measure PCPM guided by the FoC framework through the perspectives of patients and providers. The methods are presented with an overview in Table 1.

Table 1: Overview of the methods for Studies I-IV

<table>
<thead>
<tr>
<th>Design</th>
<th>FoC framework</th>
<th>Data collection</th>
<th>Settings</th>
<th>Participants</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Focused ethnography</td>
<td>Guided the observations and the interpretation of the results</td>
<td>Participant observation and informal interviews using fieldnotes</td>
<td>University hospital n=1; ED n=1 Surgical wards n=2</td>
<td>Total n=229 Providers n=198 Patients with AAP n=31</td>
</tr>
<tr>
<td>II</td>
<td>Case study: secondary analysis</td>
<td>Guided the analysis</td>
<td>Same as Study I</td>
<td>Same as Study I</td>
<td>Total n=141 Providers n=121 Patients with AAP n=20</td>
</tr>
<tr>
<td>III</td>
<td>Cross-sectional: quantitative exploratory descriptive</td>
<td>Represented in the items</td>
<td>Questionnaire (development and testing)</td>
<td>University hospital n=1; Surgical wards n=4</td>
<td>Total n=112 Phase 2: Providers (think aloud) n=5 Patients with AAP (think aloud) n=5 Theoretical experts n=2 Phase 3: Patients with AAP n=100</td>
</tr>
<tr>
<td>IV</td>
<td>Systematic review with a synthesis of qualitative evidence</td>
<td>Guided the interpretation of the results</td>
<td>Literature search in scientific databases</td>
<td>Hospitals n=18; EDs n=3 Surgical/medical wards n=17 Countries n=9</td>
<td>Total n=754 Nurses n=259 Patients in acute pain including AAP n=495</td>
</tr>
</tbody>
</table>
Settings and participants
The setting for Studies I–III is a university hospital with around 800 patient beds and 6000 providers. The studies took place in the ED (n=1) and the surgical wards (n=4). At the time of the studies, the ED provides care for around 140 patients per day, divided into sections for general surgery, internal medicine, or orthopedic surgery. The surgical wards provides care for 12 to 24 patients with planned surgeries or acute care needs caused by trauma or abdominal, endocrine, or vascular diseases.

In both settings, the patient is cared for by a responsible nurse and a nurse assistant who works day, evening, and night shifts. The care team also include a surgeon, who examines the patient at the ED, and visits the patient at the ward 1-2 times a day during rounds or when medical attention is needed. On one of the wards a nurse practitioner performs rounds on weekdays. The nurse and nurse assistant at the ED are responsible for 1-20 patients depending on the time of day and amount of patients seeking care. These patients are assigned a stretcher and are cared for either in a separate room or in the corridor. On the surgical wards the nurse and nurse assistant are responsible for 4–12 patients depending on the time of day. Patients are assigned a bed in a one-, two-, or four-bed room in Studies I and II, and in a single or double room in Study III.

In Study IV, six scientific databases relevant to nursing, PCFC, PCC, AAP, acute pain, and pain management are searched. The results includes studies performed at three EDs and 17 surgical or medical wards at 18 hospitals in 9 countries, more details are provided in Table 1.

The participants in Studies I, II, and III are 18 years or older seeking care for AAP at the ED (Study I, II) or being cared for AAP, including post-operative pain, on a surgical ward (Study I, II, III). Studies I and II are observational and patients were included regardless of their ability to communicate. Study III includes patients who were able to understand and fill out the questionnaire. All participants read and signed the informed consent either in person or with the assistance of a relative.

The participants represented in Study IV are nurses and patients ≥18 years old with AAP including post-operative pain, and with other acute pain. Due to the lack of studies found for patients with AAP (only one found), the inclusion criteria were broadened to include other acute pain for samples that includes the patient with abdominal pain.
Study I

Design

Focused ethnography was used according to the systematic Developmental Research Sequence (DRS) (57) to enable the exploration of patient–provider behaviors and experiences regarding pain management. The method is well suited to provide a deeper understanding of clinical practice from the patient perspective, by allowing observation of what actually happened concerning pain management, with immediate feedback from the patient. It also made it possible to connect the individual behaviors in patterns of actions to identify the organizational culture (58, 59). The FoC framework (9) was used to design the observations and to interpret the results.

Procedure

Data were collected using participant observation and informal interviews, n=34, each lasting 20 min–10 hr, representing all 24 hours of the day and 7 days of the week for a total of n=92 hrs before saturation was attained. The participants (n=31, age 20-90 years, 17 women and 14 male) were identified by the observer assisted by the responsible nurse on duty at the ED or surgical ward, and invited to participate by the observer (TA). Vulnerable patients with reduced ability to communicate (n=9, whereof n=4 were unable to speak Swedish, n=4 had cognitive dysfunction, and n=1 lacked strength), were able to participate as the observer could take part of the situation in relation to the patient’s reactions and expressions. To blend in but not be mistaken for a nurse, the observer wore scrubs with a tag labeled “observer,” did not participate in the care, and was positioned behind the participant to have the same view of the room. Fieldnotes and sketches were used during the observations and covered actions, interactions, interviews, and descriptions of the room (e.g., persons, furnishings, lighting, sounds, and smells). To reduce interpretation, the fieldnotes were intended to be concrete descriptions and included reflexive notes of the observer’s thoughts. After each observation, expanded notes were written up directly, and used in the analysis.

Analysis

Applying the DRS (57), the analysis was integrated with the data collection using preliminary findings from each performed observation to guide following observations toward greater depth and nuance. The analysis was intended to explore which patient–provider behaviors facilitated or impeded successful pain management, the relationships between these specific behaviors, and the impact of the organizational culture on how these behaviors were manifested.
The analysis was performed in the five steps described in the DRS, as presented in Table 2 with an example of the analysis.

Table 2: The analysis for Study I performed accordingly to the Developmental Research Sequence (Spradley, 1987), including an example from the fieldnotes.

<table>
<thead>
<tr>
<th>Step in the analysis</th>
<th>Description of the step</th>
<th>Example from the fieldnotes</th>
</tr>
</thead>
</table>
| 1. Domain analysis   | 1.1 Empirical data      | Nurse: "If you would assess your pain..?"  
Patient: "Yes, eight*"  
Nurse: "Is it that troublesome?"  
Patient: "Yes it is".  
Nurse: "Let me know if it gets too much trouble for you". The nurse leaves.  
*NRS 0-10 where 10 is the worst possible pain. |
|                      | Extracts from the fieldnotes related to pain management were identified | Nurse: "How are you feeling at the moment, if assessing the pain..?"  
Patient: "Four."  
Nurse: "Do you want analgesics now?"  
Patient: "Yes, if it gets higher it is so hard to get it back down".  
Nurse: "Good, I will be back". In a few minutes she is back with analgesics. |
|                      |                         | Nurse (to the relative assisting with interpretation): "We will evaluate if the pain goes away, or else she can have another medicine, stronger". |
|                      | 1.2 Sub-categories      | The provider assessing or evaluating the pain but do not act upon the patient's experience.  
(This subcategory is not used further in this example) |
<p>|                      | Patients’ and providers’ behaviour related to pain management were identified and organized in subcategories | |
|                      | 1.3 Categories          | Administering analgesics based on assessment |
|                      | Subcategories were organized into larger categories | |
| 2. Taxonomic analysis| 2.1 Groups              | Actions supporting individualized analgesics |</p>
<table>
<thead>
<tr>
<th>Componential analysis</th>
<th>3. Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>The groups were compared for similarities and differences to refine the groups and identify patterns of behaviour affecting the patient’s experience of pain management</td>
<td></td>
</tr>
<tr>
<td>Pattern of behaviour: Assessment of pain and acting timely upon the assessment</td>
<td></td>
</tr>
<tr>
<td>4. Theme analysis</td>
<td>4.1 Subthemes</td>
</tr>
<tr>
<td>Recurrent patterns of behaviour contributing to the patient’s positive experience of pain management, representing the organizational culture were identified</td>
<td></td>
</tr>
<tr>
<td>Individualized analgesics</td>
<td></td>
</tr>
<tr>
<td>Cultural inventory</td>
<td>5.1 Main theme</td>
</tr>
<tr>
<td>Identification of what mattered the most to the patient concerning pain management</td>
<td></td>
</tr>
<tr>
<td>Well-managed pain</td>
<td></td>
</tr>
</tbody>
</table>

### Study II

#### Design

A case study design was used to address questions about clashes noted in patient–provider communications in the observations in Study I, but that were not examined due to the narrow focus on pain management. Through secondary analysis of data collected in Study I, the design enabled the exploration of patient–provider communication as it affects the meeting of fundamental care needs (60, 61). The FoC framework was used in the study design and guided the identification of the fundamental care needs in the analysis (8).

#### Procedure

A purposeful sample of 20 observations (57 hr) from Study I was chosen to include a variation in the participants’ (n=20); ages (21-90 years), gender (n=9 women, n=11 male), communicative abilities (n=4 not speaking Swedish, n=2 having cognitive dysfunction), and the company of relatives (n=6). The variation also included; day of the week (representing Monday-Sunday), time of the day (representing 24h), and locations in the ED (n=10) or surgical ward (n=10).
Analysis

The case analysis was intended to explore from the patient’s perspective, whether and how communication facilitated or impeded the successful meeting of fundamental care needs and what could be done to improve communicative practice. The analysis was performed in six steps to identify ‘how’, ‘why’ and ‘what’ could be done to improve the communication to meet patient fundamental care needs in clinical practice (60, 61), explained with an example from the fieldnotes in Table 3.

Table 3: The case study analysis in Study II performed to identify ‘how’, ‘why’ and ‘what’ can be done to improve the communication to meet patient fundamental care needs in clinical practice, including an example from the fieldnotes.

<table>
<thead>
<tr>
<th>Step in the analysis</th>
<th>Description of the step</th>
<th>Example from the fieldnotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Identification of a fundamental care need</td>
<td>A fundamental care need was identified using the FoC framework</td>
<td>Psychosocial: Emotional well-being</td>
</tr>
<tr>
<td>2. Identification of communication affecting the meeting of that care need</td>
<td>The fieldnote was re-read in entirety to identify all communication that affected meeting that care need. Excerpts referring to the same fundamental care need were placed together.</td>
<td>Summary of the excerpts: The patient and relative arrives at the ED, the providers asks him to leave a urine-sample, tells him to lay down on a stretcher, and then takes a blood-pressure and asks him to grade his pain. After a few minutes, a provider takes blood samples, followed by an EKG. After a few more minutes, a provider takes some more blood samples. No information is given about the reasons for the assessments or about their results. One hour after the first meeting with the providers, the patient sits at the stretcher moving around due to the pain: “It hurts all the time, all all the time, I think about the pain (…) it must be in here somewhere”. Holds his hand at the right side of the stomach. Three hours after meeting the first provider, a provider sits down by the stretcher and asks him to tell about his pain. The patient tells him about his worry about the pain. The provider palpates the abdomen and listens to the lungs, while telling the patient what is found and what he thinks about that. The provider leaves and the patient takes a deep breath relaxing on the stretcher. The answer to the observers question of what he thought about the meeting with</td>
</tr>
</tbody>
</table>
the provider he just met was: “He seemed to know what he was doing, but that is not just about education, you need something else too, a feeling for the patient, that it is not machines that you are working with”.

<table>
<thead>
<tr>
<th>3.</th>
<th>Case: The 'How'</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>To determine how it was for the patient, a summarizing statement for each communication affecting the care need was made in the form: ‘The communication leads to ... for the patient’.</td>
</tr>
<tr>
<td>3.2</td>
<td>Summary of the parts of the fieldnotes including the units of analysis (fundamental care need and communication affecting the meeting of that need)</td>
</tr>
</tbody>
</table>

The patient and relative have been at the ED for three hours meeting different providers performing various assessments without telling them the results or what they mean. The patient is uncomfortable, in pain, and is worrying about the cause of the pain.

<table>
<thead>
<tr>
<th>4.</th>
<th>Code: The &quot;Why&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>To determine why it happened like that for the patient, codes were assigned to each communication that affected the patient care needs, defined as facilitating or counteractive to the meeting of fundamental care needs.</td>
</tr>
</tbody>
</table>

When being examined and informed about what the providers think about the cause of the pain and what to do, the patient takes a deep breath and relaxes. The provider performing assessments and telling the patient about the results from the assessments and what was to be done made him feel comfortable.

<table>
<thead>
<tr>
<th>5.</th>
<th>Identification of all fundamental care needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>The procedure was repeated until no more fundamental care needs were identified.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.</th>
<th>Subcategory: The &quot;What&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>To determine what can be done to improve the communication to meet patient fundamental care needs in clinical practice, the codes were grouped into subcategories, followed by categories representing successful communication for meeting that care need.</td>
</tr>
<tr>
<td>6.2</td>
<td>Guiding the patient and relative through the care process, interpreting the results of assessments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7.</th>
<th>Category: The &quot;What&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1</td>
<td>The aim of communication to facilitate meeting fundamental care needs.</td>
</tr>
<tr>
<td>7.2</td>
<td>Mutual holistic understanding of care needs and the care plan (grouped from the subcategories)</td>
</tr>
</tbody>
</table>

(Several codes were made from each case)
Study III

Design

A cross-sectional quantitative exploratory descriptive design was used to systematically develop and test a questionnaire to measure PCPM in three phases: (1) searching the literature for questionnaires measuring PCPM, (2) developing the items for a new questionnaire in a seven-step process, and (3) testing the questionnaire for initial feasibility and initial validity (62).

Procedure

Phase 1

The literature search, assisted by a specialized librarian, found no validated questionnaires for PCPM in acute or surgical care. The Strategic and Clinical Quality Indicators in Postoperative Pain Management questionnaire (SCQIPP) was found and chosen to inform the development of the items concerning design, content and scale in Phase 2 (63). Although not explicitly person-centred, SCQIPP has the strength of being a multidimensional measure, validated in Sweden, the country of the study. SCQIPP was developed from the nurse’s perspective, and hence complementary to the patient perspective in the model for PCPM, Study I, also used to develop the questionnaire.

Phase 2

The wording of the items from SCQIPP was adjusted and additional items were developed from theoretical and empirical evidence to achieve the questionnaire to measure PCPM (9, 17, 64, 65). Items including patient demographics, pain intensity, and overall satisfaction were added, as was a patient evaluation of the feasibility and validity of the questionnaire. 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 (66). To evaluate its initial feasibility and initial validity, cognitive testing was performed including a review by two experts and think-aloud interviews with five patients and five providers (n=3 nurses and n=2 nurse assistants) (67, 68). This phase resulted in changing eight items and removing one item, presented in Table 4.
Table 4: Items modified or removed in the evaluation of the questionnaire

<table>
<thead>
<tr>
<th>Method</th>
<th>Items modified</th>
<th>Items removed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expert review</td>
<td>Items modified n = 2</td>
<td>Items removed n = 1</td>
</tr>
<tr>
<td><em>(Theoretical experts n = 2)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question appraisal</td>
<td>Items modified n = 3</td>
<td>Items removed n = 0</td>
</tr>
<tr>
<td><em>(Tools used n = 2)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Think-aloud interviews</td>
<td>Items modified n = 3</td>
<td>Items removed n = 0</td>
</tr>
<tr>
<td><em>(Providers n = 5, patients n = 5)</em></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The questionnaire was tested by n=100 patients (n=46 women, n=54 male, aged 18-89). The sample size was decided in consultation with a statistician and intended to find variations in the answers to provide descriptive data and to initially test for feasibility and validity (69). The patients were identified by the responsible nurse on duty at each surgical ward and invited to participate by a member of the research team (TA). The questionnaire was tested between 9:00 a.m. and 9:00 p.m. on all days of the week, filled in by the patients, and collected after 30–60 minutes. Assistance was offered to those who needed help with reading and/or writing (n = 31).

Analysis

Thematic analysis was applied to construct the items on the questionnaire, since it allowed a representative summary of the multiple sources of evidence included in the study. The analysis was performed by (1) line-by-line coding of text, (2) grouping codes into descriptive themes, and (3) grouping descriptive themes into analytical themes phrased as preliminary items (70). An example of the thematic analysis is presented in Table 5. Descriptive statistics presenting the results of the test of the questionnaire were produced with IBM SPSS Statistics 27 and summarized as median (min/max) or percent (71).
Table 5: Example of the three steps in the thematic analysis in Study III to derive the items from theoretical and empirical data.

<table>
<thead>
<tr>
<th>The step in the analysis</th>
<th>Example from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Line-by-line coding</strong></td>
<td>‘Help me to heal’</td>
</tr>
<tr>
<td><em>Theoretical evidence: The Fundamentals of Care framework</em></td>
<td>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 to feel better</td>
</tr>
<tr>
<td>Underlined parts are chosen as missing in the questionnaire and forwarded to descriptive themes</td>
<td></td>
</tr>
<tr>
<td><strong>2. Descriptive theme</strong></td>
<td>To understand the goal of the pain management and maintain hopeful to feel better</td>
</tr>
<tr>
<td><strong>3. Analytical themes: Preliminary items</strong></td>
<td>I knew what the goal was with the pain management</td>
</tr>
<tr>
<td></td>
<td>I felt hopeful that the pain would feel better with the management I received</td>
</tr>
</tbody>
</table>

Study IV

Design

A systematic review of qualitative studies was used with deductive thematic synthesis to test and refine the model for PCPM from Study I. The review was guided by the Swedish Agency for Health Technology Assessment and Assessment of Social Services (72), and reported accordingly to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (73) and Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statements (74). The FoC framework was used to refine the model to outline pain management–specific elements of the three dimensions of PCFC (7).

Procedure

A systematic literature search was performed in six scientific data bases: CINAHL, PsycInfo, PubMed, Scopus, Social Science Premium Collection, and Web of Science. The search was assisted by a librarian specialized in systematic search to increase the quality, in accordance with the PRISMA statement (74). A bibliographic check of the reference lists of the included studies was performed at the full-text screening. The studies found were evaluated for inclusion at three screenings: (1) title, (2) abstract, and (3) full-text. The review team performed a consistency check at levels 1 and 2 using a subset of articles; independent appraisal of quality at level 3; and consensus discussions at all levels.
Quality appraisal

The studies included in the synthesis were appraised for methodological deficiencies and study quality using the tool “Appraising studies with qualitative methodology” based on GRADE (72). The studies were assessed at two levels. Level 1 included categorization of any methodological deficiencies as ‘Minor’, ‘Moderate’, or ‘Major’ after assessment for consistency between study methodology and theory/philosophical grounding, selection of participants, methods for data collection and analysis, including researcher reflexivity and validation of the results, researcher qualifications and pre-understanding, and relevance, coherence and adequacy of the results. Level 2 categorized study quality as ‘Low’, ‘Medium’, or ‘High’ after assessment for presentation of setting, research question, sampling process, data collection method, transcribing process and method of analysis, awareness of methodology, systematic stringent presentation of data, the interpretation being based on the data, discussion of the trustworthiness and dependability of the interpretations, previous research on the topic, and clinical implications. Studies assessed as low quality (n=7) were excluded at this level (72). Reasons for exclusion were methodological deficiencies (n=4), or unclear presentation of methodology or data (n=3). The remaining 15 studies, assessed as medium (n=13) or high (n=2) quality, were included in the synthesis and presented in the results.

The synthesis was appraised for overall confidence in the evidence using GRADE-CERQual, assessing the likelihood that the findings are a reasonable representation of the phenomenon of interest. The appraisal includes; methodological limitations (concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding), coherence (how clear and well-supported the fit is between the data from the primary studies and a review finding that synthesizes that data), adequacy of data (overall determination of the degree of richness and quantity of data supporting a review finding), and relevance (the extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context specified in the review question) (75). The inclusion process is presented in Figure 2.
Studies identified from:

*Databases N = 13,591*

- APA PsycInfo n = 1,204
- CINAHL n = 2,616
- PubMed n = 5,020
- Social Science Premium Collection n = 1,686
- Web of Science n = 3,065

*Bibliographic checking n = 11*

Studies removed before screening:

- Duplicate studies removed n = 5,440

Studies screened (title, abstract) n = 8,162

Studies excluded n = 8,103

Studies not retrieved in full text n = 1

Studies assessed for eligibility (full text):

n = 58

Studies excluded: n = 36

Reason 1-5:

1. Not empirical research n = 20
2. No impact factor n = 5
3. Not acute pain management n = 5

Studies assessed for quality (full text)

n = 22

Studies excluded: n = 7

Reason:

1. Methodological deficiencies n = 5
2. Unclear presentation of methodology or data n = 2

Studies included in the synthesis n = 15

Figure 2: Inclusion process of studies for the synthesis.
Analysis

Thematic analysis was used to synthesize the results concerning pain and pain management in the included studies, according to the four themes in the model for PCPM and one additional theme for evidence not represented in the model. The data extraction and synthesis were performed using the three stages of thematic synthesis described by Tomas & Harden in 2008 (70). The analytical themes in Stage 3 were used to refine the model for PCPM from Study I. Table 6 presents an example of the analysis.

Table 6: Example from the thematic analysis for the synthesis in Study IV.

<table>
<thead>
<tr>
<th>The step in the analysis</th>
<th>Example from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predefined theme</strong></td>
<td>Theme 2: Communication to share knowledge</td>
</tr>
<tr>
<td>Allocation of the identified line in one of the predefined themes (1–5)</td>
<td>Guiding description from the model for person-centred pain management (Study I): Communicate to reach a mutual understanding of the pain and pain management by asking about the pain, pain experience, and need for pain management; listening to the patient and meet the need for information. Confirm the mutual understanding.</td>
</tr>
<tr>
<td><strong>Stage 1: Line-by-line coding (original study)</strong></td>
<td>A direct question seemed to make it easy for patients to talk about pain and pain medication. (Dihle et al., 2006).</td>
</tr>
<tr>
<td>Quote from the original study representing the line</td>
<td>‘For example, a patient replied with worries of addiction, making it possible for the nurse to act on these worries: But I’ve taken so many tablets. I have been so afraid to take painkillers, but now I’ve turned into a real addict. Nurse: I absolutely don’t think you have taken too much medication. Patient: I tried not taking painkillers, but then I didn’t sleep for two nights. Nurse: Yes, you need medication for your pain in that kind of situation.’</td>
</tr>
<tr>
<td><strong>Stage 2: Descriptive theme</strong></td>
<td>The patient being informed and invited as an active partner in the pain management</td>
</tr>
<tr>
<td><strong>Stage 3: Analytical theme</strong></td>
<td>Patient-provider collaboration</td>
</tr>
</tbody>
</table>
Ethical considerations

The patients participating in the studies were considered vulnerable due to their acute illness, the hierarchical care culture, and their knowledge disadvantage relative to the providers, all of which put them in a dependent role (76). Patients eligible for inclusion (Studies I–III) were identified by the responsible nurse on duty and a member of the research team, who considered the physical and psychosocial well-being of each suggested patient. The voluntary nature of participation was emphasized in the oral and written information given before written consent was collected. Patients unable to sign the consent were assisted by a relative. The signed written consents were separated from the coded fieldnotes (Studies I and II) or questionnaires (Study III) and stored in locked desks. The patients were assured that their choice to participate, to decline, or to withdraw from participation would not affect their care.

Ethics were considered throughout the studies to safeguard the patients’ well-being during data collection, and respect their efforts by planning rigorous studies to make scientific use of their contributions (77). For example, Study II was performed to make use of the data collected but not used in Study I. Before conducting the observations the research team discussed how to act in situations of missed nursing care, such as patients suffering from unmanaged pain during the observations, and decided not to interrupt or participate in the care unless there was an immediate threat to the patient’s safety. If needed, the observer would inform the responsible nurse about unmet care needs after the observation ended.

The providers in Studies I and II were informed about the observations and told that they could ask me, as the observer, to leave the room if they wished. This happened on one occasion. For Study III, considerations were taken not to interrupt care. The leaders at the ED/surgical wards approved the studies (I-III), the Regional Ethics Review Board approved Studies I and II (Dnr: 2015/002), and the Swedish Ethical Review Authority approved Study III (ID: 2020-05587). Study IV did not impose any burden on the patients participating in the original studies, so no ethical approval was needed. Ethical principles were followed throughout the studies (78, 79).
Results

The results answer to the overall aim of how to achieve and measure PCPM for the patient with AAP in acute surgical care. Study I presents a model for PCPM including the components of well-managed pain from the patient perspective, emphasizing the impact of the organizational culture on the performance of pain management. Study II presents patient–provider communications that can be used to meet patients’ fundamental care needs such as pain management. Study III includes the results of Studies I and II and presents a questionnaire to evaluate PCPM. Study IV tests the model from Study I and presents a refined model for PCPM from patient and nurse perspectives. An overview of the results is presented in Table 7.
Table 7: Overview of the results from the four studies in the thesis, outcome, main themes and components constituting those themes

<table>
<thead>
<tr>
<th>Study</th>
<th>I: Results</th>
<th>II: Main theme</th>
<th>III: Components</th>
<th>IV: A tested and refined model for PCPM from the patient and nurse perspectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>A model for PCPM from the patient perspective</td>
<td>Well-managed pain</td>
<td>(1) Trustful relationship</td>
<td>1) Nurses should establish and maintain a trustful relationship that includes the patient in the care team</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interpersonal respect</td>
<td>2) Nurses should enable communication to share knowledge in the care team</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(2) Communication to share knowledge</td>
<td>3) Nurses should deliver timely pharmacological and non-pharmacological pain management</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mutual holistic understanding of care needs and the care plan</td>
<td>4) The nurse leader should enable the nurse to meet each patient’s need for pain management through organizational support</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(3) Individualized analgesics</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Available and accessible communication channels</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(4) Support from the organizational culture</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Humanized care context</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>A communication guide to meet the patient’s fundamental care needs</td>
<td>Include the patient as an equal member of the care team</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The questionnaire</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>A questionnaire to measure PCPM</td>
<td>The questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The items: Demographics n = 7 Pain intensity n = 3 Overall satisfaction with pain management n = 1 Overall experience of person-centredness n = 1 Experiences of pain management n = 23 Evaluation of the questionnaire n = 4</td>
<td>Initial feasibility and validity were found.</td>
</tr>
</tbody>
</table>
Study I

Well-managed pain was found to be crucial for the patient and the observations revealed an organizational culture with considerable impact on how well pain was managed, leading or misleading providers to behave according to certain patterns. The results show that successful pain management benefits from an organizational culture supporting the combination of the three components: (1) a trustful relationship between the patient and provider, (2) communication in that relationship to share knowledge and understanding so providers understand the patients’ pain and need for pain management, and (3) individualized analgesics delivered when and as needed according to the information shared between patient and provider. This combination was not always attained, and providers were observed to be inconsistent in their pain management, paying attention to specific tasks rather than focusing holistically on the patient. This could leave the patient suffering, as observed by the relative of a patient waiting to see the surgeon at the ED, crumpled in bed and panting: “Is there nothing for her to get against the pain? She has been in pain all day now!”

Well-managed pain was found to presuppose a patient–provider collaboration in which the patient is an active partner who contributes by disclosing the intensity and other details of the pain and by asking for analgesics, information, or other experienced need for help to manage the pain. While the providers are to act in a continuous process including the following steps:

1. establishing a trustful relationship with the patient by showing competence and willingness to care, being mindful in interactions, making eye contact, sharing knowledge, and acting upon that shared knowledge;
2. communicating to reach a mutual understanding of the pain and pain management by asking about the patient’s pain, pain experiences, and need for pain management, listening to the patient, meeting their needs for information, and confirming the mutual understanding;
3. administering individualized analgesics based on the pain assessment, reassessing the pain, and repeating steps 1–3.

Study II

Patient-provider communications that included the patient as an equal member of the care team were found to make a difference between adequate and missed nursing care. The patient’s psychosocial and relational care needs could be met directly using only communication, while physical care needs
were met secondarily, for example by enabling providers to know about the pain experience and need for analgesics. Overcoming communication challenges was found essential to meeting patients’ fundamental care needs, and the results show the value of interpreters or relatives to bridge the gap to the providers for patients with communicative challenges. This was exemplified in the observations of a patient visiting from a foreign country for treatment, who had assistance from an interpreter for a limited few minutes of information from the surgeon, but was also accompanied at all times by her sister, who assisted with the daily communication. The accompanying relatives in the observations were found to facilitate patient–provider communication by translating or clarifying communications and by speaking for the weary patient. Although there were good examples of successful communications, many patients suffered from missed care due to its lack. As exemplified by a woman at the ED expecting to receive pain management without asking for it, “I had to wait four hours for pain relief, quite a bit actually! In a way, I have myself to blame. I don’t like to whine... but no one asked.” The providers’ task-focused attitude was observed to impede successful communication by limiting their response to the patient’s questions while focusing on something else. That the patients were found to respond differently to the same communication also challenged the providers to act accordingly to the individual patient’s response.

The communications that helped providers meet the patient’s care needs involved the patient as an equal partner in the care team through; (1) showing interpersonal respect, (2) supporting a mutual holistic understanding of care needs and the care plan, (3) showing available and accessible communication channels, and (4) humanizing the care context, as guided in Figure 3.
Figure 3: Communications to be used by the provider to meet the patient’s fundamental care needs.
Study III

The developed questionnaire was found initially valid and feasible to measure PCPM in the tests by the theoretical experts (n=2), providers (n=5), and patients (n=105) who evaluated it for relevance, comprehensiveness, and effort to use. One area not included in the questionnaire was identified as possibly relevant to include: sleep as related to pain. The analysis indicated that the questionnaire is sensitive to capture specific areas for improvement from the patients’ reported experience of pain management. The n=100 patients who answered the questionnaire in the last test in phase 3 (response rate 100%) agreed that they felt safe and respected, listened to, and trusted their providers’ availability and knowledge of how to manage the pain. At the same time they identified vital missing elements of PCFC in their pain management such as pain relief, pain assessment, information about their pain and its management, and knowledge of how to participate. The answers varied between patients for the same item and between items for the same patient. The items in the questionnaire and patient answers are presented with the median and min/max values in Table 8. The questionnaire as developed in Swedish is attached this thesis as Appendix 1.

Table 8: Description of the items in the developed questionnaire and answers from the patients

<table>
<thead>
<tr>
<th>Demographics and pain experience Items 1–10 (answer options)</th>
<th>Median (min/max) or percent</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Age (years) (Open answer)</td>
<td>68 (18/89)</td>
<td>n = 100</td>
</tr>
<tr>
<td>2: Gender identification (Open answer)</td>
<td>Female 46 Male 54</td>
<td>n = 100</td>
</tr>
<tr>
<td>3: Education in pain or pain management (Yes/No)</td>
<td>24/76</td>
<td>n = 100</td>
</tr>
<tr>
<td>4: Experience of pain management (Yes/No)</td>
<td>70/30</td>
<td>n = 100</td>
</tr>
<tr>
<td>5: Length of stay (days) (Open answer)</td>
<td>3 (0.5/28)</td>
<td>n = 100</td>
</tr>
<tr>
<td>6: Diagnosis known (Yes/No)</td>
<td>47/53</td>
<td>n = 100</td>
</tr>
<tr>
<td>7: Had surgery (Yes/No)</td>
<td>35/65</td>
<td>n = 100</td>
</tr>
<tr>
<td>8: Worst pain experienced 0–10 (No pain–Worst pain imaginable)</td>
<td>9 (2/10)</td>
<td>n = 100</td>
</tr>
<tr>
<td>9: Least pain experienced 0–10 (No pain–Worst pain imaginable)</td>
<td>2 (0/8)</td>
<td>n = 100</td>
</tr>
<tr>
<td>10: Pain right now 0–10 (No pain–Worst pain imaginable)</td>
<td>2 (0/8)</td>
<td>n = 100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experience of the pain management Item 11–36</th>
<th>Median (min/max) or percent</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 11-12, Likert scale 0-10: Strongly disagree–Strongly agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Overall satisfaction with the pain management</td>
<td>9 (2/10)</td>
<td>n = 100</td>
</tr>
<tr>
<td>12. Care being person-centred</td>
<td>9 (0/10)</td>
<td>n = 100</td>
</tr>
</tbody>
</table>

| Items 13–36, Likert scale 1–5: Strongly disagree–Strongly agree |
|---------------------------------------------------------------|-----------------------------|----------|

45
<table>
<thead>
<tr>
<th>Question</th>
<th>Score (1/5)</th>
<th>N = 100</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Felt safe at the ward</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>14. Was asked several times about pain when breathing/moving around</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>15. Received pain management until satisfied with pain relief</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>16. Received information about how to manage the pain</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>17. Providers were able to manage the pain</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>18. Received information about the cause of the pain</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>19. Received analgesics without having to ask</td>
<td>4</td>
<td>*99</td>
</tr>
<tr>
<td>20. Received information about the goal of the pain management</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>21. Good cooperation between the providers</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>22. Understood the information received</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>23. Having access to providers</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>24. Being respected as a partner</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>25. Providers involved relatives (Extra answer option: Not applicable N/a)</td>
<td>1</td>
<td>53%</td>
</tr>
<tr>
<td>26. Being asked to grade the pain between 0–10 several times a day</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>27. Pain experience being taken seriously</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>28. Receiving help to a comfortable position</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>29. Providers respected integrity</td>
<td>5</td>
<td>*98</td>
</tr>
<tr>
<td>30. Received help quickly</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>31. Able to ask questions</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>32. Able to influence the pain management</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>33. Providers being knowledgeable about whole care episode</td>
<td>3</td>
<td>*99</td>
</tr>
<tr>
<td>34. Providers being knowledgeable about pain management</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>35. Able to share pain experience</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>36. Received information about how to participate</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

*Total of missing items: n = 4

**Evaluation of the questionnaire (EQ) Patients n=100**

<table>
<thead>
<tr>
<th>EQ1a. Experience of answering the questionnaire</th>
<th>Median (Min/Max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likert scale 4 levels: Very difficult, Difficult, Easy, Very easy</td>
<td>4 (2/4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EQ1b. Suggested improvements</th>
<th>Not applicable: 87%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of questions: 4%</td>
<td></td>
</tr>
<tr>
<td>Wording: 3%</td>
<td></td>
</tr>
<tr>
<td>Answer options: 3%</td>
<td></td>
</tr>
<tr>
<td>Time needed to complete the questionnaire: 2%</td>
<td></td>
</tr>
<tr>
<td>Order of the questions: 1%</td>
<td></td>
</tr>
</tbody>
</table>
EQ2. Relevance of the questions (items)
Likert scale 11 levels: 0 (Not at all relevant) – 10 (Very relevant)  
Median (Min/Max)
10 (1/10)

EQ3. Descriptions of what was difficult
1. Question 4: Difficult to remember.
2. Question 7: Do not know if it was about this or all occasions.
4. Question 33 (n=7 patients): I do not know, Hard to know, Hard to know what
the staff knows, Hard for me to know, Not relevant (as answer option) was missing
when it came to what the staff knew, The staff may, for example, have read without
me telling them - i.e. then I am unaware.
5. Question 27 (N=2): Difficult to know what the staff knows.
6. Too many questions.
7. Missing "Do not know!"
8. Difficult to respond to the nuances of pain, difficult to know if you are getting
the right help or medicine.
9. Experiences that there are some differences depending on which staff is on
duty.

EQ4a. Missing questions
EQ4b. Description of what was missed
1. That I did not get help when I should get up, they just watch, it hurts more
then! They say 'just do it yourself'! You cannot do that!
2. They don't listen to me. It is difficult when you cannot talk to each other, when
they cannot speak Swedish!
3. I needed to be motivated to take painkillers.
4. When it was changed from liquid to pill form. I thought that the pain relief
worked faster and was more effective via the iv, than pills, I do not think/feel
that it helps as much - even if it is the same drug.
5. The staff does not have time to listen, they would need to be many more.
6. Disappointed that one person at night was so careful to give, when during the
day they gave much more so it worked better.
7. The difficulty of talking to a doctor more regularly, in order to get more in-
depth information about the current situation, treatment, etc.
8. It is important to be able to sleep, to get help with it.
9. It is important with the personal contact, that they see the person in the bed.
The staff does not have time, and that everyone says different things.

Study IV
The 15 studies meeting the inclusion criteria after screening and quality
appraisal included nurse and patient perspectives across countries and
cultures. The methods used in the included studies were; ethnography (n=3),
hermeneutics (n=1), phenomenography (n=1), grounded theory (n=1),
thematic analysis (n=7), or content analysis (n=2). Data were collected by
observations (n=6), interviews (n=11), and focus group sessions (n=3), five
studies used a combination of observations and interviews. The studies were
performed in Australia (n=3), Ghana (n=1), Iran (n=1), Jordan (n=4), Norway (n=1), South Africa (n=1), Sweden (n=1), United Kingdom (n=1), and the United States of America (n=2), at surgical or mixed surgical/medical wards (n=17) and EDs (n=3) at 18 hospitals. Four studies did not report the number of wards included. The participants were adult (≥18 years) patients (n=779) or nurses (n=262). The patients’ pain was described as related to surgery (n=741) or not related to surgery (n=38). The providers were described as registered nurses (n=186), nursing staff (n=39), or surgical nurses (n=37), working at EDs (n=12) or surgical or medical wards (n=250). The included studies were assessed as having medium or high quality.

The scientific literature supported the model for PCPM from the patient perspective (Study I) and presented refinements to be made by expanding the four themes. The refined model encompasses the four components to be applied together in a patient-nurse collaboration supported by the organization:

1. Establish and maintain a trustful relationship including the patient in the care team. Similar to the tested model, the relationship was described in the studies as being established through nurses acting in a professional and caring manner and listening to and believing the patient’s experience. To maintain the trust, nurses were found to need to inform the patient about the cause of the pain and the care plan, confirm the mutual understanding, and act upon the care plan. The refinements made to the model included clarification of the importance of listening to and believing the patient experience, and achieving mutual understanding of the experience, cause, and management of pain.

2. Enable communication to share knowledge in the care team. Communication enabling the nurse and patient to share their knowledge was described as necessary to manage the patient’s pain. For this to happen, nurses were found to need to invite the patient to be an active partner by asking questions and encourage them to share their experiences. Obstacles like reluctance or inability to communicate could thereby be overcome. Refinements to the model included clarification of the need for nurses to enable communication by inviting and guiding patients to be active partners.

3. Deliver timely pharmacological and non-pharmacological pain management. In the same way as the tested model, delivering analgesics based upon assessment and reassessment was described as essential in the studies. Refinements made to the model included clarification of the importance of timing when delivering the
management, expanding the theme to include non-pharmacological management, and informing patients about, and managing, side effects of analgesics, including addiction.

(4) Provide organizational support enabling the nurse to meet the patient’s need for pain management. Similar to the tested model, the organizational culture guiding nurses behavior was confirmed as essential to pain management. The well-functioning and competent care team was emphasized as crucial and found to be enabled by clear roles, and responsibilities, established routines, and guidance on the when, who, and how of pain management. Nurses were found to need to have the time, knowledge, and skills to manage pain, and to be attentive, caring, and able to prioritize pain management. Refinements to the model included clarification of the organizational support and nurse behaviors to prioritize pain management, and expansion of the theme to include routines, nurse qualifications, and a well-functioning care team.

The refined model was assessed with moderate to high confidence in the evidence and aims to guide the nurse–patient collaboration to provide the patient with PCPM relieving the pain. This collaboration and contextual support is outlined in Figure 4.
Figure 4: Person-centred pain management contributing to well-managed pain for the patient, as achieved by the nursing leaders providing contextual support for the nurses to develop a trusting relationship with the patient, to enable communication for shared knowledge in order to provide timely pharmacological and non-pharmacological pain management.
Discussion

This thesis set out to explore how to achieve and measure PCPM for the patient with AAP in acute surgical care. In the results of the individual studies, the patients and providers from around the world showed high awareness of pain as a crucial need to manage. It was also evident that too many patients suffer from unmanaged pain. The observations and systematic review revealed multiple components affecting pain management. These were combined in a holistic model to guide the patient–provider collaboration toward PCPM, including organizational support as a necessary prerequisite. The results also present a multimodal questionnaire to be used to evaluate the practice of PCPM. FoC framework helped to maintain the holistic focus throughout the thesis including the presentations of the results, to guide the providers to effective PCPM relieving the patient from needless suffering.

Person-centred fundamental care

The thesis was performed with the preunderstanding of PCFC as a desired outcome of care. The person-centred approach is not, however, universally accepted, and possible negative outcomes concerning costs and the exclusion of some patients have been discussed, and merits further exploration (80). No such negative results were found in the research for this thesis. To the contrary, the results suggest that the provider can and should include vulnerable patients in the pain management through existing prerequisites such as behavior and communication. A potential cost of PCFC may be that of funding professional interpreters to bridge communication gaps, but this needs to be evaluated in relation to the possible reduction of missed nursing care, which is linked to a decrease in adverse advents and length of stay which would lessen other costs (81, 82). The benefits of PCFC to manage patients’ pain were confirmed throughout the thesis. The trusting collaboration between the patient and provider was repeatedly confirmed as a prerequisite to meeting patients’ fundamental care needs (83), and essential for well-managed pain. The results from the observations showed that the holistic approach to care described in PCFC, including a trusting relationship and an organization-supported integration of care needs, was beneficial to
meeting patients’ needs for pain management (Studies I and II). This was confirmed in the literature review (Study IV). In Study III, patients and providers confirmed all three dimensions of PCFC as important in pain management. The FoC framework provided useful support in performing the studies in this thesis, however there were challenges as further discussed in the Methodological Considerations section.

Task-focused care

Despite the known benefits of PCFC and the healthcare system’s legal obligation, Studies I, II, and III confirm that PCFC is still not regular practice in Sweden (84) and Study IV confirms the same in the international context (85). One known hindrance to the person-centred approach to care, apparent in all four studies, is the provider’s focus on routine tasks rather than on patients’ care needs (86). The results of the observations (Studies I and II) and the systematic review (Study IV) confirm that nurses are subject to multiple interruptions (87) and habitually prioritize tasks such as taking phone calls or doing rounds over seeing to pain management. This behaviour was linked to a task-focused culture encouraging this behaviour, also previously acknowledged to challenge the person-centred approach in acute care (85). While the task-focused culture can be considered to be effective in the short term (88), evidence to the contrary is clear. It impedes the meeting of fundamental care needs and inhibit communication, as also observed in Studies I and II, causing missed nursing care (89, 90).

Let us go back to the preface where we left Anna still in pain after more than a week in the surgical ward. “Whose agenda?” was already ringing in my head as I listened to Anna’s experience of pain and saw how it conflicted with the providers’ performance of tasks related to other care needs. It was obvious that the agendas of the nurse and nurse assistant were filled with tasks to check off, not tailored to managing Anna’s pain or understanding her experience. Whether or not the tasks were relevant to Anna’s care, this task-focused neglect of PCFC led to her continuous suffering. PCFC means connecting tasks holistically to meet patients’ care needs, identified in the patient-provider collaboration (7, 12). This is acknowledged in the results of Studies I–IV, included in the questionnaire in Study III and addressed by the model for PCPM in Study IV.

The model for person-centred pain management

The model for PCPM (Study IV), based on the results of Studies I and II, seeks to overcome the task-focused care by combining the identified components in PCPM in a holistic care process. The model reaffirms the im-
portance of the three dimensions in the FoC framework, reflecting the relationship-based integration of physical, psychosocial, and relational fundamental care, supported by the contextual elements related to pain management (7). The four themes in the model are discussed as follows, using clinical examples from the observation of Anna, continuing to represent the patients in the results.

Trustful patient-provider relationship including the patient in the care team
In Studies I, II, and IV, patients and nurses in Sweden and around the world confirmed the trusting relationship as essential to care outcomes (4, 37). Patients in Studies I and IV who were assured by providers that their experiences were believed, and that analgesics would be available when necessary, said this assurance helped them to cope with pain even without medication. The contrary was also found, as exemplified by Anna, who neither felt listened to or able to trust the providers’ willingness to help: “You feel so lonely when you are in pain, and you tense your body from it too.” We can see how the lack of trust impedes Anna’s ability to manage the pain, and adds to her sensory (tensed body) and emotional (hopeless) response. Because pain management is multidimensional and involves both sensory and emotional responses, it is vital that the patient trust the providers’ ability and willingness to manage their pain (24). Developing an established relationships is a nursing skill essential in the person-centred approach to care; however, it is not always mastered (91). The FoC framework holds the patient–provider relationship as a core component of successful fundamental care. The five central elements presented shows the multidimensional, though not complicated, steps to be performed by the nurse to establish and maintain a trusting relationship with the patient (8), which is confirmed throughout the thesis as essential for pain management.

Patient–provider communication to share knowledge in the care team
The connection between communication and meeting fundamental care needs such as pain management was found in Studies I, II and IV, and was explored and outlined in Study II. The observations revealed how the sole means of communication could make a difference between successful or missed fundamental care. This supports the importance of providers’ communication skills that are described to have an impact on person-centredness and outcome of the care for the patient (43, 92). Other aspects found to affect the providers ability for effective communication with the patient is the organizational support such as guidelines and leadership (93, 94)
In PCFC, providers enable the patient to take responsibility for communicating their care needs and experiences, and to participate as best they can. Transferring responsibility to the patient transforms them from a passive recipient to an active partner in their own care, enabling the essential collaboration. This must however be clarified to avoid providers’ delegating care responsibilities to patients who neither recognize nor accept them, leaving the care left undone, as described by Britten and colleagues in 2020 (43). This was exemplified in Study II, where patients expected providers to invite them to communicate their pain experience and did not tell providers about their pain because “They didn’t ask.” Meanwhile providers made similar mistakes because “She hasn’t complained.” This clash of understanding was confirmed in Study IV. These uncommunicated needs or knowledge put patient safety at risk and hinder person-centredness (89, 95). This emphasizes the need for mutual understanding of care needs and the care plan found in Study II, where the results showed that the provider should invite the patient to communicate. Other results point to the need for senior providers with the benefit of experience, to help train less experienced colleagues how to communicate in the care team (95). The risk of different understandings were also exemplified in the observation of Anna when the providers do tell her about the pain management, but do not check that she understands, leaving her still not knowing how to manage her pain. The power of communication between the patient and provider to facilitate successful fundamental care has been confirmed, but the message is not only to be delivered, but also understood (44).

In the observations and literature review (Studies I, II, and IV), relatives were found to be important in facilitating provider–patient communications by interpretation of language, or when the patient was too weary to understand what was being said, or to make their wishes known. Empowering the patient and relative to participate has been shown to improve the quality of fundamental care (96), however, as confirmed in this thesis, the relative need guidance on how to contribute to be a resource (54, 55).

Timely pharmacological and non-pharmacological pain management

Pharmacological management was found essential in pain management, and as found in the results of Studies I and IV, it is commonly accepted as an intervention requiring individualization. The results also show its need to be complemented, or sometimes replaced, by non-pharmacological methods. Both patients and nurses emphasized the importance of considering pharmacological management as only one part of the care plan and the necessity of using other methods or strategies to help relieve the patient’s
pain (Studies I and IV). This multimodal management has recently been recognized as a key to solving the challenge of successful management of acute pain (5). The outcome of pain management was found to depend on the timing (Study IV), and it was essential that the patient did not have to wait for management. So was receiving information on time, to be prepared to manage the pain when occurring. This was exemplified by a woman who recalled providers telling her how to handle her just-installed patient controlled intravenous analgesic pump, but she was in such pain that it was impossible for her to think straight. The outcome was that she was unable to use it and continued to suffer while providers considered her well taken care of. It is essential to keep in mind that acute pain blocks out both physical and psychosocial functions, when planning care and patient participation (97) as shown in the results of Studies I, II, and IV.

The results confirm that the pharmacological management include more than just administering the analgesics to meet the patient’s care need, as emphasized by also Small and colleagues in 2020 (30). The analgesic treatments were found to help patients when combined with information about their effects and the plan for their evaluation. Assessment to evaluate given pain management is urged as a prerequisite to successful pain management (35), supported by our results where pain assessment was found to be essential to both patients and providers. What was crucial was however that the assessment led to action. For Anna, none of the five providers performing tasks for her during the three-hour observation assessed how her pain affected her or reacted to her rating on the numeric pain scale as 10, i.e., worst possible pain. A nurse student was observed to write the rating down on a pain protocol, observed by the nurse, but no further actions were taken, again displaying the damaging effect of the task-focus on patient outcome.

Organizational support

Patients’ relief from pain was found to be influenced by, or even depend on, whether or not the organization provided support, confirming the importance of the contextual dimension in the FoC framework (8). The individual actions of the providers were decisive in the actual moment, indicating the responsibility of each provider to do right. However, the pattern of different providers acting in similar ways under different circumstances suggests they were guided by a workplace culture (49). Their following “the way things are done around here,” rather than referring to professional knowledge, ethical obligation and evidence, shows the major impact of that culture, known to risk evidence based care if not aligning with the evidence (98).

Nursing care being invisible in many health care organizations is argued to contribute to the task-focus found to inhibit successful pain management
This urgent problem is apparent not only in healthcare systems that do not value fundamental care, but also—and more alarmingly—in nurses who themselves do not value fundamental care (37, 99). This emphasizes the importance of a strong nursing leadership to guide the individual actions and behaviors, however not always present (91, 100). Skillful nursing meeting patient fundamental care needs is known to improve patient care outcomes in general, and reduce adverse events and lengths of stay in particular (101). For the nurse competence to best benefit the patient though, organizational guidance is needed for example to enable the nurse with higher competence to care for the patient with complex care need and support the less experienced or educated nurses (102). For the providers caring for the patient with AAP, there is a lack of guidelines in general and for PCPM in particular, making it more challenging to create a beneficial culture aligning with the evidence (51, 103).

PCFC is at the core of nursing, for the clinical performance of PCPM however, the well-collaborating care team with clear roles and responsibilities was confirmed as essential in the international review in Study IV. The provider collaboration is also previously described as essential for patient outcome, but rendering challenges due to different perceptions of the nature of the collaboration (104, 105). PCFC is argued to require a supportive culture shared by everyone in the organization, however not so easily attained (106), urging the strong leadership promoting this culture in organization as well as in behaviour (7, 18, 83).

The results from the studies shows an organization with fragments of person-centredness, and, despite successful examples, it was evident that nurses tend not to prioritize fundamental care such as pain management. The impact of the task-focused culture was also exemplified in the observation of Anna, where the providers behaved mechanically as according to a culture or routines, rather than to meet Anna’s need for pain management. Again, the important question: whose agenda leads the care?

Measuring person-centred pain management

The initial tests of the questionnaire developed in Study III showed promising results of its representativeness of PCPM. As a multidimensional measurement, which is recommended to evaluate PCPM (35, 107), the questionnaire could evaluate the care provided, and also raise awareness of the dimensions to be considered when delivering care. Using a questionnaire enables nursing leaders to evaluate performed care in a systematic, repeatable, and (for the patients) confidential way (40). The outcome of the evaluation is to be used in practice to increase provider awareness of the care process and
for quality improvement concerning pain management. This answers to the internationally identified challenge that fundamental care is invisible in many healthcare systems, and thus contributing in the prevention of missed nursing care (108).

Evaluation of care is emphasized in order to succeed with providing PCPM. It is part of the contextual prerequisites described in the FoC framework and hence a responsibility for the leader, again emphasizing the essential nursing leadership (45, 109, 110). According to the results from the patients testing the questionnaire, providers failed to provide complete fundamental care related to pain management, providing some parts, but missing others. To succeed in pain management, there is a need to step away from the culture of performing separate, isolated tasks. It is time to move forward to managing patients’ physical, psychosocial, and relational care needs as an integrated whole within the defined context (6). The new questionnaire (Study III) aims to evaluate daily pain management and thus help providers visualize the elements as parts of a multidimensional care process. In this way the evaluation could identify specific areas in need of improvement to succeed in PCPM in acute surgical care, relieving the patient with AAP from pain.

The developed questionnaire is a first attempt to translate the essential components in PCPM into measurable items. The urge to develop valid measurements for PCFC has resulted in several initiatives, and it is important to continue this quest to enable evaluation of practiced PCFC (39, 111, 112). The delicacy of measuring the multidimensional performance of pain management however requires careful testing and evaluation of the psychometric properties of the instrument, so that it measures what is intended in a reliable way and is useful for the patient and practice (40, 113). The developed questionnaire (Study III) shows promising results in the initial test, and is suggested for further testing and evaluation.
Methodological considerations

The studies in this thesis used qualitative and quantitative designs supported by the FoC framework to answer the study aims. The combination has the advantage of combining the deeper understanding provided by qualitative design, with the broader understanding provided by quantitative design, relating the results to previous knowledge (40, 114). In this thesis, the combination allows a comprehensive understanding of the research area: how to achieve and measure PCPM for the patient with AAP in acute surgical care.

Trustworthiness

To be trustworthy and, as Lincoln & Guba stated already in 1985 “worth paying attention to”, confirmability, credibility, dependability, and transferability was considered throughout the thesis as required for qualitative studies. Study III was also considered for validity and feasibility since it included quantitative method (114, 115).

Confirmability

Confirmability concerns the objectivity of the research and protects the clean representation of the participants’ views, and the results from researcher bias (114). This was addressed in several ways in the studies. An expert in the ethnographic method was consulted to strengthen the design and performance of Study I. Before data collection for Studies I and II, the observer recorded pre-understandings which were later compared with the results. Reflexive notes were kept during the observations to highlight observations identified with a risk of observer interpretation. Interviews with the participants were used to confirm the observations and minimize researcher interpretation. Open questions were used to minimize influencing the participants. The fieldnotes aimed to include all persons, actions and interior including sound, light and smell. A control observation by a member of the research team, also participating in the analysis, was performed to test the observation protocol and compare the fieldnotes to the performed observations. Nothing missed was detected in the comparison (59).
The data used to construct the questionnaire in Study III were existing evidence confirmed by theoretical experts, patients, and providers. In Study IV, all found data concerning pain and pain management were extracted for the analysis and constituted the results. The analyses for all studies are presented step by step to provide a trail from the original data. The results in the studies are presented using representative quotations from the participants to show the connection between the data and the results (116). The FoC framework was used to guide interpretation of the results, allowing the researchers to maintain the wide perspective of the practice process of PCFC, including the contextual prerequisites.

Credibility

Credibility concerns confidence in the truth of the results, meaning how well the results represent the data (114). The analyses of the four studies were performed by more than one member of the research team to support a representative interpretation of the data. All available data were included in all steps of the analyses for the results to accurately represent the data (116). In Study III, the questionnaire underwent expert review for its representation of the FoC framework. It was also assessed by patients and nurses for its representation of pain management (67, 68). In Study IV, all themes from the results of Study I were confirmed, supporting the credibility in both studies. Expanding the context to include international hospitals and nurses’ perspectives also expanded the themes in Study IV. The absence of literature within our inclusion criteria specified for AAP led us to include a wider spectrum of acute pain. This could be considered a limitation due to the less specific target group, while also enabling to include data covering the patient with AAP but included in a broader group. Credibility was maintained by clearly presenting the participants and data upon which the results were based (114). Data for the studies were considered to be saturated, as is an essential criteria to enable delimited thematizing and abstraction of themes, and the results included all data to answer to the aim, as guided by Sandelowski & Leeman in 2012 (117). Care was also taken to include the context, in support of accurately representing the data (118).

Dependability

Dependability concerns the stability of the results should another researcher repeat the study. Dependability is incidental to confirmability, credibility, and the study presentation (114). Dependability was considered demonstrated by the systematic designs and the transparent reporting of participants, context, procedure, and results (Study I-IV). In testing the
questionnaire in Study III, dependability (reliability), was not assessed due to the aim to conduct a preliminary test of the questionnaire. Further testing of the questionnaire using a larger sample is needed (113).

Transferability

Transferability concerns the extent to which findings can be transferred to another context (114). The researcher can make suggestions about where and how the results may be transferred and used, however leaving it up to the reader to decide. The transferability was addressed throughout the studies by aiming to present structured, rich and detailed descriptions, in order to allow the reader to judge whether the results are transferrable to a particular context (116). The results of this thesis are intended for use in other contexts; however, further testing and evaluation is necessary.

The Fundamentals of Care framework

Using the FoC framework as a guide throughout the thesis provided support to remain the holistic focus of the practice process of PCFC and PCPM. The use of theory in research may allow the empirical evidence to represent a larger context and overcome the limitations of using only one type of evidence (40). This thesis benefitted from using the framework to outline the results and address stakeholders how to use them, which has been shown to facilitate the translation of theory and scientific evidence into practice (119). Using a theoretical framework under development has had both benefits and challenges, moreover the need to keep up with the developments (7-9, 12, 120). The benefits have included access to up-to-date evidence and comprehensive guidance of the practice process of PCFC. The challenges presented included the framework’s scant description of the context, making it challenging to study. The usability of the framework could possibly be enhanced by developing the descriptions of what is involved in the contextual dimension and how to address this in research and practice. Another challenge was the lack of measurements or guidance to evaluate performed PCFC, approached in Study III. In translating the components of the middle dimension; Integration of Care for Study II, there was a discrepancy in the address of the components, where some were fundamental care needs of the patient and some were actions required on behalf of the nurse, however not clearly articulated. This has since been clarified in the framework, however it could be of use to further explore the nurse’s competence and behavior required to meet the patient fundamental care need. Also, as suggested in Studies I and IV, to explore and clarify the roles of the patient and relative. This clarifying of the care team (stakeholders in performing the care) could possibly assist
the understanding and implementation of PCFC. Lastly, the relationship between fundamental care and PCC is somewhat articulated in the practice-process of PCFC, and elaborated in recent publications (12, 121). This has been helpful in the design and interpretations of the results from this thesis to address nursing practice, and a continuing clarification of the relationship is suggested to navigate the role of the framework in nursing science and practice.

The FoC framework is suggested to benefit from more detailed descriptions, but was found relevant and easy to use for supporting this thesis to explore and derive guidance for the practice process of PCPM.
Conclusions

The patients and nurses in the results confirms pain management as a crucial fundamental care need to meet. The evidence presented is clear that regardless of the examples of successful pain management, too many patients suffer from pain in acute surgical care, inexcusably caused by missed nursing care. The FoC framework is successfully used to address the research gap of PCPM and by combining empirical, scientific and theoretical knowledge, the results confirms the benefit of PCPM. The thesis presents tools to be tested in clinical practice and future research to achieve and measure PCPM for the patient with AAP in acute surgical care. The individual studies concludes;

✓ Successful pain management from the patient perspective is achieved by the patient and nurse collaborating in a trusting relationship, managing the pain using communication and individualized analgesics, in support from the organizational culture (Study I).

✓ The patient’s fundamental care needs, including pain management, can be met when the patient-provider communication is used to include the patient as an equal member of the care team (Study II).

✓ The questionnaire developed from a validated questionnaire, empirical and theoretical data, shows promising results to be used for the evaluation of practiced PCPM. Initial support for feasibility and validity encourages further testing (Study III).

✓ The practice process of PCPM is guided by the model presented in Study IV. The model describes contextual support, including leadership, required to guide the patient and nurse to collaborate establishing a trusting relationship, communicating to share knowledge, and tailoring pharmacological and non-pharmacological pain management to the individual patient.

✓ The FoC framework was found useful to guide the holistic perspective of the PCFC practice process, used throughout the thesis to connect the trusting nurse-patient relationship with the integration of care and contextual prerequisites. Suggestions for areas to be further explored in the continuous development of the framework concern the dimension of the context, and the integration of care. This is recommended to enhance the usability of the framework for research and practice (Studies I-IV).
The evidence found in this thesis (Studies I-IV) supports that PCPM can be achieved and measured using the guide for communication in Study II, the model in Study IV, and the questionnaire in Study III. Nurses and nursing leaders are to use this up-to-date evidence answering to the call for PCPM to relieve the patient with AAP in acute surgical care from pain.
Clinical implications

The results of this thesis aim to guide nurses and nursing leaders to bring PCPM into acute surgical care, meeting the pain management needs of the patient with AAP. To do so, the nurse is guided to act accordingly to the process of relationship-based integration of care, and the nursing leaders are guided to provide organizational support for this, including evaluation. PCPM as presented in the results should require little additional effort or cost to perform; even the single intervention of communication can help to relieve the patient from pain.

The absence of person-centredness in Anna’s care was obvious in the observation introduced in the preface of this thesis. This led to a mismatch between the needs she experienced and the care she received, and she reported suffering continuous pain for more than a week. Had the results from this thesis informed Anna’s care, the providers might have been better able to relieve her from pain. Had the questionnaire (Study III) been used to evaluate the pain management on continuous premises, the task-focus causing neglect of Anna’s experience could have been detected as counteractive to care quality, and replaced by a more person-centred behaviour. This could have been assisted by the model for PCPM (Study IV), guiding the nurses, supported by the organization, to understand Anna’s experience and prerequisites to cooperate in the pain management. With her pain well-managed, Anna could have had her other fundamental care needs met that were compromised by the pain, such as mobility, eating, and breathing.

The observations (Studies I and II), questionnaire (Study III), and systematic review (Study IV) revealed missed pain management for patients in surgical care, and evidence of how to manage their pain successfully. This evidence is to be used to benefit the patient. The model for PCPM (Study IV), the questionnaire to measure PCPM (Study III), and the guidance to communication meeting fundamental care needs (Study II) address nurses and nursing leaders as primary owners of the knowledge necessary to provide PCPM. The patient’s and providers’ evidence was, however, clear that a well-cooperating care team is required, and that organizational support is needed to guide the actions and interactions in the care team. The results of this thesis could be used to shift the organizational focus from tasks fulfillment to an
agenda that aligns with meeting the patient fundamental care needs of pain management

The well-known and studied gap between research evidence and practiced care is part of the global challenge of missed care. To transform the delivery of fundamental care, the ILC proposed five basic actions to unite upon (value, talk, do, own and research fundamental care), to engage clinicians, patients, leaders, students, educators, researchers and politicians in the quest, with the understanding that a coordinated, collaborative effort is needed to achieve real change (6). This intertwined agenda of multiple stakeholders is supported by the results (Studies I, II, IV) where individual actions of the patient and providers, organizational support, and more research was found crucial for the pain management to improve in acute surgical care. The results could also be tested for benefit of use in a wider perspective in teaching and planning care, for nurses, patients and students to understand PCPM, and by politicians and nurse leaders to demand and enable the performance.

In the end, a major contribution of this thesis would be if we – as nursing stakeholders, made use of the results to unite upon the mutual goal to meet the patient’s fundamental care need of pain management, guided by the experience of the person asking us for help – the patient. Which in fact is our ethical, professional and legal obligation.
Future research

This thesis adds to the scientific knowledge of practiced PCFC as related to communication, and the performance and evaluation of PCPM. The implications for future research concerns identified research gaps and bringing the results into practice. The results are to be tested empirically and further researched to enable successful implementation to achieve and measure PCPM in acute surgical care, relieving the patient with AAP from pain.

The guide for communication meeting fundamental care needs (Study II), and the model for PCPM (Study IV) needs to be tested empirically to evaluate feasibility and patient benefit. The two tools (Studies II and IV) could also be tested for benefit of use in educating providers and student in the PCPM process.

The questionnaire (Study III) needs to be empirically tested and assessed for psychometric properties to evaluate its validity, reliability, feasibility and patient benefit.

The guide for communication in Study II, the questionnaire in Study III and the model in Study IV could be tested for effects on patient outcome concerning care effectiveness (time and cost) to expand incentives for their implementation.

The FOC framework is under development and was tested as theoretical guidance and methodological support throughout the thesis. The practice process of PCFC is not widely tested empirically (23). Suggestions are presented for future research to test and keep evolving the framework as of clinical guidance, preferably involving the stakeholders that are to implement PCFC in practice.

Continuous researching and implementation of research evidence is essential in shifting the healthcare agenda to systematically meet and evaluate the patient fundamental care need of pain management. Shifting to PCFC not only involves a change of provider behaviour, it also requires the patient to become more active in planning, performing and evaluating care. The results provide a basis for exploring the more active role of the patient in PCPM.
The patients observed for Studies I and II who had relatives accompanying them was supported by their assistance to i.e. communicate with the providers. On the contrary, results from the studies included in the systematic review (Study IV) presented how relatives impeded care quality by being aggressive causing delay in treatments. The relative is part of the care team in the person-centred approach to care, and their role as a facilitator or guardian for meeting patients care needs shows promising results, but further research is warranted to integrate the relative to meet patient fundamental care needs.
Svensk sammanfattning (Swedish summary)


Det övergripande syftet med denna avhandling är att utforska hur man utför och mäter PCPM för patienten med AAP inom kirurgisk akutsjukvård. Alla studier vägledes av ramverket FoC.

individualiserad analgetika för att behandla patientens smärta, med stöd av organisationskulturen.


I Studie III utvecklades en enkät för att mäta PCPM. Enkäten togs fram i en systematisk process utifrån ett validerat frågeformulär samt teoretiska och empiriska evidens inklusive FoC. Initial testning av enkätns relevans, om den saknar någonting, och är lätt att använda, genomfördes med teoretiska expertgranskare (n=2), patienter (n=5) och personal (n=5), samt av patienter med akut buksmärta (n=100) på kirurgiska vårdavdelningar (n=4). Testningen gav initialt stöd för att enkäten är användbar och relevant för att mäta det den ska (validitet), PCPM.


Avhandlingen använder kvalitativ och kvantitativ metod för att med stöd av FoC öka kunskapen om vad som påverkar smärtbehandlingen vid akut buksmärta, och hur delarna hänger ihop. Resultatet presenterar en guide till kommunikation, en modell för att utföra-, och en enkät för att mäta PCPM i kirurgisk akutsjukvård. Resultaten rekommenderas att testas och utvärderas i klinik för att vägleda sjuksköterskan, teamet och omvårdnadsledaren i kirurgisk akutsjukvård att lindra patientens smärta.
Acknowledgments

It turned out that completing a thesis is not a one-woman job. The works of this thesis have been ongoing for the last eight years, and the support from colleagues, friends and family has been invaluable. I wish to express my sincere gratitude to all of you who have supported me.

I especially wish to show my gratitude to;

**The patients:** for unselfishly participating in the studies despite your acute illness, enabling the new knowledge and potential improvement of care.

**The providers and managers** at the emergency department and surgical wards, for your kind cooperation for the data collections for Studies I-III, for your interest and welcoming attitude.

**My supervisors:** for sharing your scientific knowledge and experiences with me, for the thorough reading of my works, and for genuinely challenging and encouraging me with my best progress in interest. Thank you for enabling me to develop knowledge and confidence in becoming a researcher. *Eva Jangland;* my main supervisor, thank you for inspiring, challenging and encouraging me to become a better nurse ever since I set my feet in the surgical ward 16 years ago. For being a role model breaking ground as a nurse researcher at the Department of Surgery. For keeping your curiosity, empathy and strong engagement for involving the patient and nurse to improve fundamental care, and inviting me to come along. For your friendship and enriching discussions at the department, on park benches, in conferences, airports, at kitchen tables. I look forward to taking on future goals together.

And having coffee. *Åsa Muntlin;* thank you for your guidance and support in the progress of this thesis and me becoming a researcher. For constructively challenging me in learning about measurements and the FoC framework. For inspiring me to navigate towards increasing my scientific knowledge and becoming a clinical nurse researcher, as well as to navigate across countries and cultures on the road trip to- and the Oxford conference. I’lI keep that memory for upcoming challenges as: ‘there is always a way’. *Alison Kitson;* thank you for your support across time zones, for challenging and encouraging me to improve my knowledge, research and reporting skills. You impress
and humble me with your knowledge and experience, that you so generously share to support the improvement of fundamental care for the patient around the world. Also, I’ll never stop being impressed over your skill to explain to me what I am trying to say! Martin Björck; thank you for enabling my PhD-studies from the start, for supporting me to learn nursing science as a way forward to improve fundamental care. For the discussions advancing my knowledge, and encouragement in performing this thesis. I’ll bring with me your guidance on research and life. Thank you for the fika!

My co-author; Erik Elgaard Sørensen. Erik made a major impression on me and my way of viewing nursing care and research. As my co-author in Study I Erik upgraded my interest in nursing research as a way of making a clinical difference for the patients and nurse colleagues. He explained complicated research methods so that I as a rookie PhD-student understood, at least when he spoke English. Erik taught me, among other things, to park thoughts that are not relevant at the moment, and that the smallest step taken by a crowd makes a difference. I am grateful for having met you.

The heads of the Department of Surgical Sciences; Olle Nilsson and Per Hellman, former and present heads of the Department of Surgical Sciences; for supporting my research projects. Per Hellman, thank you for reminding me that performing a PhD is an education.

The heads of the Department of Surgery; former heads Claes Juhlin, Kristina Kask and Peter Stålberg, present head Bengt Isaksson, former assistant head Victoria Gozzi Svensson and present assistant head Anna Hedman, thank you for supporting me and my research projects, and providing me with the time to finish writing this thesis.

My nurse managers at the surgical ward; former managers Sofia Sundbom, Carina Vennström and Patrik Bodeby, and present manager Malin Hållinder, thank you for your support and interest in my PhD-studies, helpful assistance with my leaves of absence and work-study balance. Not the least, thank you for acknowledging that the competence earned is important to improve the care we deliver, and for your support to improve nursing care.

My colleagues:

in the nursing research group at the Department of Surgical Sciences, thank you for repeatedly confirming the worth of nursing research for clinical practice and education, and that though we can feel alone, we are in it together. Eva Wallin and Ing-Marie Larsson for valuable support late evenings at the office. Camilla Fröjd for empowering me when needed. Anna Hauffman, Anna-Karin Gunnarsson, Katarina Edfeldt, and Lena Nyholm,
thank you for the valuable feedback to improve and finish this thesis. Anna-Karin, a special thank you for the last-minute photo session for the cover! You all inspire me by having performed a PhD and found ways of bringing use of your competence to nursing research, education and practice. I hope for future groundbreaking collaborations together.

in the Jangland PhD-group, Anna Hult, Linda Lyttkens and Linda Haakseth, thank you for your constructive appraisal of my manuscripts and the use of the Fundamentals of Care framework. Linda Haakseth, thank you for the company at the department and last minute feedback before printing the thesis.

in the surgical wards at the Department of Surgery, thank you for keeping my feet grounded in clinical practice, always welcoming me back after leaves of absence, patiently listening and arguing wisely to my proposals of how to use the research evidence to improve fundamental care for the patients we care for. Together we make it happen.

in the national association for nurses in surgical care (NFSK), for proving to me that it is in the support and empowerment of each other that we are strong to make a difference. I am impressed over the many brilliant works happening across the country, and proud to be part of sharing the experiences and to contribute to needed prerequisites for successful nursing care in the surgical care context. A special thank you to my fellow board members supporting me with knowledge, strength and comfort to grow as a nursing leader. To Karolina Härle, for sharing the goals and having my back, making it possible.

The UU innovation mentor programme, led by Hillevi Englund and Nhils Forslund, thank you for giving me the opportunity to explore how to use my research results and knowledge to benefit the health care organization. Annika Remaeus, my mentor in the programme, thank you for generously sharing your knowledge and experiences, transforming my vision into actions. For the energizing meetings. Till alla som har sagt att jag är för mycket, hur kan de veta att det inte är de som är för lite. På med hatten, vi ses!

Maktrampolinen, the mentorship programme and network led by Linnéa Engström and Josephine Bladh, thank you, and the mentors and mentees, for creating enlightening and empowering interactions, discussions and insights to change leadership. I bring with me inner strength and friends for life. #all-tidtillsammans.
Kazuko Gustafsson, librarian at Uppsala University library, for kindly and professionally assisting with the literature search for Study IV, and always walking that extra mile to support with citation management.

Daphne Sams at Proper English, for proofreading my manuscripts and with encouraging and educating guidance supporting me in both language and communication of results.

Alexander Tegelberg, my fellow research student and friend in the SMAAPP research program, thank you for the collaboration, enriching discussions on research, education, clinical practice and life, navigating and learning together.

Elin Leander, thank you for sharing your experience with systematic reviews over that Italian pizza, and arguing so well for the method to answer my research questions, that it became Study IV. For generously providing constructive feedback on my work and encouraging me in finishing this thesis. But most of all - for being my friend! I look forward to going to the theater, mountains and to continue the talks on chaos theories!

Johanna Höglund, for being my friend and partner in crime coming to improve nursing care, at our ward and in the country. You help me link the theory to practice. Thank you for always seeing what is possible, for keeping my nursing spark burning in times of doubt, and for having my back. At work and in life. A special thank you for the last-minute photo-session for the cover. Looking forward to upcoming adventures together!

My friends and family, for providing me with all the support needed to finish my PhD, I am forever grateful. Learning to become a researcher has at times had a cost of time and energy. Thank you for letting me take that time and energy, for encouraging me but also reminding me of other joys in life! Most of all - thank you for being there, I would never want to be without you. Mom and dad, thank you for teaching me to believe in myself, and for your support also in finishing this thesis. For always being there for Anton and Irma. Johan, thank you for keeping my feet on the everyday life ground, for your support and love. I look forward to spending more time together with all of you. All my love.

Anton and Irma, let’s catch up the play.
References


49. Schein E. The corporate culture survival guide: John Wiley & Sons; 2009.
70. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology. 2008;8(1):45.
89. Tay L, Hegney D, Ang E. A systematic review on the factors affecting effective communication between registered nurses and oncology adult patients in an inpatient setting. JBI Libr Syst Rev. 2010;8(22):869-916.


Smärtbehandling

Utvärdering av vårdens kvalitet från patientens perspektiv

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ålder</td>
<td>Jag är:</td>
<td>år</td>
</tr>
<tr>
<td>2. Könsidentitet</td>
<td>Jag identifierar mig som:</td>
<td></td>
</tr>
<tr>
<td>3. Har du någon gång fått utbildning om smärta eller smärtbehandling?</td>
<td>Ja</td>
<td>Nej</td>
</tr>
<tr>
<td>4. Tidigare erfarenhet av att få behandling för akut smärta</td>
<td>Aldrig</td>
<td>En gång</td>
</tr>
<tr>
<td>5. Tid på vårdavdelningen</td>
<td>Jag har varit på vårdavdelningen i: .......... timmar/dagar</td>
<td></td>
</tr>
<tr>
<td>6. Orsak till vård</td>
<td>Jag vårdas på grund av:</td>
<td></td>
</tr>
<tr>
<td>7. Opererad under vårdtillfället</td>
<td>Jag har opererats</td>
<td>Jag har inte opererats</td>
</tr>
</tbody>
</table>

Nedan följer ett antal påståenden om din smärtbehandling. Markera svarsalternativet som bäst överensstämmer med din uppfattning om hur det har varit under din tid på vårdavdelningen.

<p>| | | | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Ringa in det alternativ som bäst beskriver din smärta när den varit som värst</td>
<td>Ingen smärta</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>9. Ringa in det alternativ som bäst beskriver din smärta när den varit som minst</td>
<td>Ingen smärta</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10. Ringa in det alternativ som bäst beskriver din smärta just nu</td>
<td>Ingen smärta</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>11. Ringa in det alternativ som bäst beskriver hur missnöjd/nöjd du är med smärtbehandlingen</td>
<td>Mycket missnöjd</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>12. Ringa in det alternativ som bäst beskriver hur personcentrerad du upplevt att vården har varit på avdelningen</td>
<td>Personcentrerad vård innebär att det finns goda relationer mellan dig och personalen (och om aktuellt dina anhöriga). Relationerna präglas av respekt och förståelse för varandra samt respekt för din personlighet och självbestämmande.</td>
<td>Inte alls personcentrerad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>
13. Jag har känt mig trygg på avdelningen
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

14. Personalen har frågat mig flera gånger varje dag om vilken smärta jag haft när jag andades djupt och rörde på mig
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

15. Jag har fått hjälp med att lindra min smärta tills dess att jag känt mig nöjd med den smärtstillande effekten
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

16. Personalen har berättat hur smärta skulle behandlas
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

17. Jag har känt mig trygg med att personalen har möjlighet att lindra min smärta
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

18. Personalen har berättat varför jag har ont (eller att de inte visste)
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

19. Jag har fått smärtstillande läkemedel när jag behövd det utan att jag själv sagt till om det
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

20. Personalen har berättat målet med smärtbehandlingen
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

21. Personalen har samarbetat bra med varandra för att min smärtbehandling skulle fungera
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

22. Personalen har berättat om smärtan och smärtbehandlingen på ett sätt som jag förstod
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

23. Jag har vetat hur jag skulle kontakta personalen när jag behövd hjälp med smärtbehandling
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra

24. Jag har känt mig respekterad som en viktig partner i min smärtbehandling
Detta stämmer: inte alls  lite  ganska bra  bra  mycket bra
<p>| | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>25.</strong> Personalen har tagit hjälp av mina anhöriga i smärtbehandlingen</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>26.</strong> Jag har fått gradera min smärta flera gånger varje dag genom att ange en siffra mellan 0 och 10</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>27.</strong> Personalen har tagit min smärtupplevelse på allvar</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>28.</strong> Jag har fått hjälp med en bekväm position för att undvika smärta</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>29.</strong> Personalen har respekterat min integritet* när de hjälpt mig med min smärta</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*Dina personliga gränser inom vilka du känner dig bekväm</td>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
</tr>
<tr>
<td><strong>30.</strong> När jag har behövt smärtlindring har jag fått snabb hjälp</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>31.</strong> Jag har fått ställa frågor om smärtan och smärtbehandlingen</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>32.</strong> Jag har haft möjlighet att påverka min smärtbehandling</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>33.</strong> Personalen har vetat hur min smärta och smärtbehandling varit tidigare under vårdtiden</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>34.</strong> Jag har känt mig trygg med att personalen har kunskap att lindra min smärta</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>35.</strong> Jag har fått berätta om min smärtupplevelse</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>36.</strong> Personalen har berättat hur jag kunde medverka i smärtbehandlingen</td>
<td><strong>Ej aktuellt</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detta stämmer:</td>
<td>inte alls</td>
<td>lite</td>
<td>ganska bra</td>
<td>bra</td>
<td>mycket bra</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Utvärdering av enkäten (4 frågor)

1. Hur var det att besvara enkäten?

a. Kryssa för det svar som bäst motsvarar din upplevelse av hur det var att fylla i enkäten:
   Svårt [ ]   Ganska svårt [ ]   Ganska lätt [ ]   Mycket lätt [ ]

b. Kryssa i de av nedanstående alternativ som du tycker kan förbättras i enkäten, du kan välja fler av alternativen:
   [ ] Ej aktuellt   [ ] Frågornas ordningsföljd
   [ ] Instruktionerna   [ ] Antalet frågor
   [ ] Utseendet   [ ] Tidsåtgång att besvara enkäten
   [ ] Formuleringar   [ ] Textstorlek
   [ ] Svarsalternativen   [ ] Annat:

2. Var frågorna i enkäten relevanta för din smärtbehandling?
   Inte relevanta 0 1 2 3 4 5 6 7 8 9 10 Mycket relevanta

3. Var någon av frågorna svår att besvara?
   Ja [ ]   Nej [ ]
   Om ja, beskriv vilken fråga och på vilket sätt:
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................

4. Är det någonting som påverkat din smärtbehandling som inte fanns med i enkäten?
   Ja [ ]   Nej [ ]
   Om ja, beskriv vad:
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................
   ..................................................................................................................................................................................

4
Acta Universitatis Upsaliensis

Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 1850

Editor: The Dean of the Faculty of Medicine

A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title "Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine").