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IMPLEMENTATION OF KNOWLEDGE- BASED PALLIATIVE CARE IN ACUTE CARE SETTINGS: OBSTACLES, OPPORTUNITIES AND EXPERIENCES

Susanne Lind



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IMPLEMENTATION OF KNOWLEDGE-BASED PALLIATIVE CARE IN ACUTE CARE SETTINGS: OBSTACLES, OPPORTUNITIES AND EXPERIENCES THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

Susanne Lind

Principal Supervisor:

Professor Lars Wallin
Karolinska Institutet
Department of Neurobiology, Care Sciences and
Society
Division of Nursing

Co-supervisors:

Associate Professor Jonas Sandberg
Jönköping University
School of Health and Welfare
Department of Nursing Sciences

Professor Carl Johan Fürst
Lund University
Faculty of Medicine
Department of Clinical Sciences

Professor Tomas Brytting
Ersta Sköndal Bräcke University College
The Institute of Organisation and
Worklife Ethics

Opponent:

Associate Professor Anna Milberg
Linköping University
Department of Social and Welfare Studies
Division of Nursing Science

Examination Board:

Professor Christer Sandahl
Karolinska Institutet
Department of Learning, Informatics, Management
and Ethics
Medical Management Centre

Associate Professor Maria Friedrichsen
Linköping University
Department of Social and Welfare Studies
Division of Nursing Science

Associate Professor Johan Thor
Jönköping University
School of Health and Welfare
The Jönköping Academy for Improvement of
Health and Welfare

*”En droppe droppad i Livets älv
har ingen kraft att flyta själv
Det ställs ett krav på varje droppe
Hjälp till att hålla de andra oppe!”*

Tage Danielsson

ABSTRACT

Background and aim: Quality improvement is continuously ongoing at different levels in our healthcare system. In Sweden, as in other countries, guidelines are important for quality improvement in healthcare, since they summarize the best available evidence. Improved living conditions and enhanced treatments for a variety of diseases have resulted in increased longevity and the need for palliative care has therefore also increased. A high proportion of deaths occur in acute care settings, where the care has been described as inadequate for dying patients. In 2013, the National Board of Health and Welfare published *A National knowledge-based guidance for good palliative care in end-of-life care* and just prior to this in 2012, the Regional Cancer Centre published the *National clinical practice guideline for palliative care*. The overarching aim of this thesis was to study implementation of knowledge-based palliative care in acute care settings.

Methods and results of the studies: The first and second studies covered aspects that were to be taken into account for the implementation of the documents described above. In study I, national policy documents in Sweden were reviewed for quality indicators relevant to palliative care and end-of-life care. In study II, perceptions regarding national palliative care guidelines were investigated and obstacles to and opportunities for implementing these guidelines in acute care hospitals were identified through interviews with local politicians, chief medical officers and healthcare professionals. The results showed scarce knowledge of the two documents at all levels of the healthcare organisation. Palliative care was primarily described as end-of-life care. The environment and culture in hospitals, with heavy workload, poor communication and poor teamwork, were described as obstacles for implementation. However, staff emphasised a need for training and support in palliative care through theoretical knowledge and mentoring to develop clinical skills. An implementation strategy for the use of the Integrated Palliative care Outcome Scale (IPOS) was developed. The strategy included information, training and facilitation to support the use of the scale. The implementation was performed at three acute care settings and, to gain a broader understanding of the strategy, it was also tested at a palliative care unit. The evaluation of the strategy, presented in study III and IV, was conducted through multiple methods. The findings showed varying prevalence of completed IPOS, indicating shortcomings in implementation.

Conclusion: The awareness of the two documents on palliative care varied at all levels in the healthcare organisation, being predominantly low among healthcare professionals in acute care settings. The feasibility of the performed implementation strategy was considered questionable and the components need to be further explored to enhance the impact of implementation and thereby improve the use of IPOS in acute care settings.

Keywords: Acute care hospital, Guidelines, Integrated Palliative care Outcome Scale, Implementation, Mixed methods, Palliative Care, Patient-reported Outcome Measure, Process evaluation, Quality indicator, Quality Improvement.

LIST OF SCIENTIFIC PAPERS

- I. **Lind, S**, Adolfsson, J, Axelsson, B, & Fürst, C J. (2013). Quality indicators for palliative and end of life care: a review of Swedish policy documents. BMJ Supportive & Palliative Care. doi: 10.1136/bmjspcare-2012-000390
- II. **Lind, S**, Wallin, L., Brytting, T., Fürst, C. J., & Sandberg, J. (2017). Implementation of national palliative care guidelines in Swedish acute care hospitals: A qualitative content analysis of stakeholders' perceptions. Health Policy. doi: <https://doi.org/10.1016/j.healthpol.2017.09.011>
- III. **Lind, S**, Sandberg, J, Brytting, T, Fürst, C J, & Wallin, L. (2017). (Accepted). Implementation of the Integrated Palliative care Outcome Scale in acute care settings – a feasibility study. Palliative & Supportive Care.
- IV. **Lind, S**, Wallin, L, Fürst, C J, Sandberg, J, Brytting & Beck, I. (In manuscript). Factors related to and experiences of use of the Integrated Palliative Outcome Scale for patients with palliative care needs in acute care settings.

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LIST OF ABBREVIATIONS

AN	Assistant nurse
CFIR	The Consolidated Framework For Implementation Research
EAPC	The European Association for Palliative Care
IPOS	Integrated Palliative care Outcome Scale
NBHW	National Board of Health and Welfare (Socialstyrelsen)
PARIHS	Promoting Action on Research Implementation in Health Services
PROM	Patient Reported Outcome Measures
RN	Registered nurse
SRPC	The Swedish Register of Palliative Care
WHO	World Health Organization

1 FOREWORD

During my work as a registered nurse over more than 30 years I have met many patients with palliative care needs and receiving end-of-life care in different settings. My first employment, as an assistant nurse, was at an oncology unit. Ulla, an assistant nurse with long experience of caring for patients, taught me how to meet and care for severely ill and dying patients and their next of kin with dignity and compassion. In the 1990s, I worked as a registered nurse in a specialised palliative home care team, where I had the opportunity to meet patients in their homes. Being a guest in someone's home whilst carrying out work as a professional nurse is often a challenge. Interpersonal aspects become more important and also natural. Although death is nothing we can influence, we can make life as good as possible.

In the early 2010s, I coordinated the work for the production of the first *National clinical practice guideline for palliative care* in Sweden. It was interesting to work with such a large and varied group of healthcare professionals. They had a passion for palliative care and an ambition to share their knowledge with others. I also participated in the work to produce A *National knowledge-based guidance for good palliative care in end-of-life care*, which was carried out by the National Board of Health and Welfare. When I was presenting these two new documents at meetings, I became interested in and challenged by comments from both nurses and physicians. Questions about when it is ethical to interrupt ongoing therapy and which patients would benefit from palliative care raised many questions for me such as: How will the documents be received by healthcare professionals in different contexts? Would they be able to influence managers at different levels to make changes? Will only the “already converted” use them? What about healthcare professionals working with people in need of palliative care in hospitals, will they use the documents? My thesis will give some answers but there are still a lot of questions waiting to be further researched.

2 INTRODUCTION

Over the last century, reduced child mortality, improved living conditions and enhanced treatments for a variety of diseases have resulted in increased longevity, both globally and in Sweden (1). In 2017, the Swedish population surpassed ten million inhabitants. Of these, two million are 65 years or older and the average life expectancy is estimated to be 84 years for women and 80 years for men (2). Old age is associated with a higher risk of living with chronic diseases, which is reflected in the most common causes of death: ischemic heart diseases and cerebrovascular diseases followed by death caused by cancer in the respiratory organs (3). Due to the change in demographics, the need for palliative care has increased (4, 5), posing a challenge for today's healthcare.

In Sweden, since the middle of the 1990s, the government has given a high priority to palliative care within healthcare through a number of published documents (6, 7). To further promote access to palliative care for everyone in need, particularly at the end-of-life, a national guidance, intended to support governance and management of healthcare, was published in 2013 by the National Board of Health and Welfare (NBHW) (8). The year before, in 2012, the document *National clinical practice guideline for palliative care* was published by the Regional Cancer Centre (9). However, it is well-known that there is a gap between theoretical knowledge and clinical practice, leading to patients not receiving optimal evidence-based care (10). It is also known that there is a lack of follow-up of implementation and compliance to guidelines (11). In this thesis, implementation of national guidelines for palliative care in Sweden is being studied. Two different research- and knowledge areas, quality improvement and palliative care, have been combined and the implementation is performed in the context of acute care settings.

3 BACKGROUND

3.1 QUALITY IMPROVEMENT IN HEALTHCARE

Quality improvement is continuously ongoing at different levels in our healthcare system. An increased awareness of limited resources and complex challenges within healthcare has led to a need for quality management, focusing on different types of processes in the healthcare system. A common description of quality improvement in healthcare is ... *the combined and unceasing efforts of everyone - healthcare professionals, patients and their families, researchers, payers, planners and educators - to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)* (12, p. 2). In accordance with Batalden and Davidoff (12), the NBHW emphasises that healthcare in Sweden, including palliative care, should be knowledge-based, safe and at the same time efficient, i.e. it is, as far as possible evidence-based and available resources are used in the best possible manner. Further, the care should be individualised with respect to the patient's expectations and values and in time for the patients' need (13). Numerous efforts to improve clinical care are made by healthcare professionals in their daily work, initiated by management in the local healthcare organisation or by healthcare professionals themselves.

To ensure good patient care, it is of importance that the care is evidence-based. One of the most commonly used definitions of evidence-based practice (EBP) originates from Sackett et al. (14). They described evidence-based practice as the effort to integrate three components when making decisions about the care of individual patients: the best available scientific facts, the clinician's experience from education and clinical skills and the patients' preferences and values. To promote successful implementation, the evidence should be scientifically robust and experienced by the healthcare professionals as useful and corresponding to the patient's preferences (15). How the evidence as a whole, including research, the healthcare staff and the patient's clinical experiences, is perceived by healthcare professionals in the specific context is of importance (16).

Since the 1990s, different types of guidelines and their recommendations have become increasingly important for achieving evidence-based practice. Such documents have acquired a prominent role in healthcare as tools for translating knowledge gained from research into practice (17, 18). The purposes of guidelines are 1) to provide support so that the patient receives care based on the best available evidence and 2) that health care is provided as equally as possible within the available resources. A structured process is required to identify, appraise and compile the research that the guidelines are based on (19). To ensure broad competence in the development of guidelines, the group involved in the work should be both multi-professional and interprofessional, i.e. include participants from different healthcare professions and different specialties (20). In Sweden, guidelines are developed at several levels in the healthcare organisation. At a national level, the NBHW compiles national guidelines and recommendations for different diseases and conditions, especially those affecting large groups of the population. The guidelines have a top-down perspective, aiming

to define and support healthcare organisations in governance and management of healthcare, i.e. what to do or not to do in accordance with the available evidence and resources (21). The content is often transferred to clinical practice guidelines at national, regional and local level. Clinical practice guidelines could be defined as a bottom-up document, describing how to perform the best evidence-based care according to the national guidelines from the NBHW (22).

3.1.1 Translation of research

A large number of concepts have been used internationally to describe the translation of research into clinical practice, e.g. knowledge translation, knowledge transfer and research utilization (23). McKibbin et al. (24) found about one hundred terms used to describe knowledge translation. The translation of evidence-based healthcare that has been compiled into guidelines is also associated with different concepts. The use of guidelines for improvements in clinical practice is implicit in their preparation. This means that healthcare organisations are expected to make decisions in order to provide care in accordance with the guidelines. Concepts related to implementation are associated with different levels of activities.

Diffusion is a commonly used concept for a passive process as described by Everett Rogers. In 1962, he published the book *Diffusion of innovations*, which has been updated several times (25). In the book, which consists of several theories, Rogers explains how and why an innovation is spread, i.e. the diffusion of an innovation.

Diffusion is the process in which an innovation is communicated through certain channels over time among the members of a social system (25, p. 5).

Rogers further describes five kinds of innovators who adopt an innovation at different times in the process of diffusion. The innovators are individuals who want to and dare to assume new challenges. They are followed by early adopters, who also want new challenges but do not want to take high risks. Early adopters are often seen as individuals whom you can ask for advice. The early majority are people who are careful when taking decisions and the late majority are sceptical to innovations. Finally, the laggards adhere to traditions and do not want to make changes (25). Furthermore, five phases of the adoption process of an innovation, e.g. a guideline, have been described by Rogers: knowledge, persuasion, decision, implementation and confirmation. During the first step, the individual receives information and knowledge about the innovation, e.g. by reading or hearing other people talk about the innovation. If the individual finds the innovation interesting, they move to the next step: seeking more information and knowledge, i.e. to say seeking persuasion. The individual makes a decision, depending on the experienced pros and cons of the innovation, either to reject or to accept it. If the individual experiences benefits of the innovation as being predominant, the individual will try to use it to different degrees and search for further information and knowledge. Finally, the individual will make a decision as to whether to continue to use the innovation or not (25).

The concept of dissemination describes a translation when planned activities are performed. The aim is to increase the adoption of a proposed activity, i.e. what treatment and methods are to be used for certain diseases (26). The activities consist of information and communication with selected recipients about, e.g. medical treatment and care of patients with a specific disease. The activities could be in writing, e.g. different kind of guidelines, and orally, such as conferences and workshops. The next step, implementation includes planned and structured activities to ensure that the content of a guideline is put into use. Several issues need to be taken into account when planning the implementation of a new guideline and questions such as *What should be transferred?* and *To whom should research knowledge be transferred?* are important to consider (27, p. 2-3). Even if a structured plan is used, it can take a long time before recommendations in guidelines are adopted and used in clinical practice. How to facilitate translation of knowledge into clinical practice depends on e.g. the context in which the implementation is supposed to occur, which groups are to be addressed and what the culture is like (16). However, knowledge about how to overcome barriers for implementation is still not determined and further research is necessary (27).

In Sweden, as in other countries, guidelines are an important factor for quality improvement in healthcare in that they summarize the best available evidence. When the NBHW publishes guidelines, they are mainly disseminated as written publications of different kinds and through conferences and regional/local seminars (18). In recent years, the NBHW has published guidelines related to specific diseases, e.g. different cancer diagnoses (28), cardiac care (29) and care of multiple sclerosis and Parkinson's disease (30). Furthermore, guidelines for general conditions such as palliative care have been published (8). In Sweden, patients with palliative care needs are cared for in a diversity of care settings: acute care hospitals, nursing homes and specialised palliative care settings. Accordingly, there are a large number of intended recipients of the guidelines for palliative care. For the recommendations in the guidelines to benefit the patients, the recipients must also make a decision to adopt them.

3.2 PALLIATIVE CARE

3.2.1 Definition of palliative care

In the 1960s, Dame Cicely Saunders significantly contributed to the development of the modern hospice movement. To clarify the complexity and inseparability of pain, Saunders introduced the concept of *total pain*, including physical, psychological, social and spiritual dimensions. Further, Saunders stressed the importance of including next of kin when caring for patients at the end-of-life (31).

The World Health Organization (WHO) emphasises palliative care as an approach to improve quality of life for patients with life-threatening illnesses and their next of kin and the care is neither intended to prolong life nor to hasten death (32). Palliative care aims is to promote quality of life for the patient with as effective relief from pain and other distressing symptoms as possible. Further, WHO emphasis to palliative care as being “*applied as early as possible in the course of any chronic, ultimately fatal illness*” (32, p. 83). In line with

Saunders, The European Association for Palliative Care (EAPC) defines palliative care as active and total care, aiming to improve quality of life for the patient. Holistic perspectives in palliative care entail seeing the whole person, including social, physiological and existential perspectives. It also includes the next of kin's perspective, especially when caring for patients at the end-of-life who may no longer be able to express their wishes (33).

The benefits of palliative care being used early in the care of a life-threatening disease, regardless of the underlying disease, have emerged during the last decades. Early integration of palliative care in oncology has been emphasised for patients with cancer and is highlighted in guidelines from the American Society of Clinical Oncology (34). There is a need to ensure the same for patients with other life-threatening diseases, such as chronic obstructive pulmonary diseases and chronic heart diseases.

In Sweden, the definition of palliative care complies with the definition by WHO, (32), in that holistic palliative care aims to achieve the best possible quality of life for the patient, without prolonging or shortening life. Palliative care is emphasised as inherently holistic and subsequently articulated in four fundamental prerequisites: symptom relief, teamwork, communication and relationship, and support to next of kin (8, 35).

Teamwork is an essential part of palliative care. Teamwork has been defined as involving members of at least two different healthcare professions (36). The complexity of palliative care from the perspectives of the variety of needs, and the inclusion of next of kin, requires knowledge that cannot be obtained from one single healthcare profession, rather there is a need for a diversity of healthcare professionals in the team. This has been described as especially important when caring for patients with complex needs (33). Communication in palliative care refers to conversations with the patient and the next of kin about, e.g. decision-making regarding the goals of care and treatment of symptoms, topics which can be difficult to talk about (33). Furthermore, to enhance the holistic approach of palliative care, functioning constructive communication is imperative, especially among team members from different health care professions working together (37).

3.2.2 Place of death

The most common place of death varies between different countries, but institutions are consistently described as having a high proportion of deaths. Around half of all deaths (42 %) in Sweden occur in hospitals (38), which is similar to other European countries (39-42). In contrast to this, home has been described as the most common preferred place of death expressed by the general public (43, 44) and by patients (43).

Patients described home as being their preferred place of death when home was their place of care at the time of being asked (45). The preferred place of death may vary during the disease trajectory (43), which is important to take into account when caring for patients with life-threatening diseases.

Patients with cancer were, to a larger extent, more aware of a forthcoming death compared to patients with chronic diseases, making it possible for them to express their wishes and be able to die in their preferred place. A large number of patients have not expressed a preference as to where they want to die, which makes it difficult to meet their wishes (46). It has been suggested that the availability of hospital beds near to where a patient lives is related to a higher risk of their death occurring in hospital (41). The most common place of death differs worldwide but cannot be entirely explained by demographic differences or access to palliative care. Rather, the existence of policies and guidelines for palliative care and end-of-life care has been proposed as an influence on place of death (47).

3.2.3 Symptom relief

In accordance with Saunders, the WHO (32) and the EAPC (33) highlight the importance of taking into account the four different dimensions of total pain in the care of patients with palliative care needs as well as care of next of kin. Nonetheless, it is still common with high levels of perceived distressing symptoms in advanced stages of life-limiting diseases and at the end-of-life (48, 49). Although there is a large variation in the prevalence of described symptoms (48), pain is still the most common symptom in end-of-life regardless of the underlying disease (49-53). No differences were found when comparing the prevalence of symptoms between different diseases: cancer, chronic heart failure and chronic obstructive pulmonary disease (53). However, patients with chronic obstructive pulmonary disease and dementia have been reported to be less relieved from pain compared to patients with cancer (50). Dyspnoea and secretions/death rattles are other distressing symptoms related to breathing that are commonly reported at the end-of-life (48, 49). These symptoms are often associated with pulmonary diseases, but may occur in connection with many other diseases, such as chronic heart failure and neurological disorders. Most of the research on symptoms at the end-of-life has focused on physical symptoms, but according to Saunders' concept of total pain, many other symptoms and problems may bother the patient. It can be difficult to distinguish between different symptoms, such as those of anxiety and physical pain. Hence, from the perspective of *total pain*, i.e. physical, psychological, social and spiritual issues, the description of anxiety (51) and confusion (48) as being common symptoms at the end-of-life is of importance so that an opportunity is provided to relieve patients from distressing symptoms.

3.2.4 Patient reported outcome measures

The use of patient reported outcome measures (PROM) gives patients the possibility to communicate their experiences of symptom burden, wellbeing and functional status. It is of importance to use validated tools and select an appropriate PROM for the intended group of patients (54, 55). A structured use of PROM has been shown to improve the care of patients with palliative care needs: the symptoms identified and treatment of symptoms was based on the patient's perceived quality of life to a greater degree and can contribute to improved communication between the patient and healthcare professionals (56).

In the past 20-25 years, several assessment tools have been developed and made available for patients with palliative care needs. The Edmonton Symptom Assessment Scale was one of the first assessment tools to be used in palliative care settings. It was developed in the early 1990s, initially focusing on symptom burden among patients with advanced cancer diseases. The scale has been psychometrically validated and translated into several languages (57). Later, the Palliative care Outcome Scale was developed (58). This tool also focused on palliative care for patients with advanced cancer diseases being cared for in palliative care settings. Two versions were developed, one intended for the patient and one for healthcare professionals, which enabled proxy estimation. The Palliative care Outcome Scale has also been validated and widely translated (58) and has proven to be comprehensive (59, 60). It has been further developed to ensure the adequate measurement of symptoms in patients suffering from a variety of diseases who have palliative care needs. The refined tool, the Integrated Palliative care Outcome Scale (IPOS), is available in several languages and is validated for this group of patients (61).

Few assessment tools for patients in palliative care have been validated in Swedish. Pain and pain relief have commonly been assessed using the Visual Analogue Scale and Numeric Rating Scale. Both scales consist of a pointed line, often ten-pointed, where the patient can rate their pain, from “not at all” to “as bad as it could be”. In line with the description of palliative care as holistic care, pain is only one of the symptoms that can affect patients. In order to include the assessment of other distressing symptoms, the Edmonton Symptom Assessment System has been used, even though it was only recently culturally adapted and evaluated in a Swedish context (62). The Edmonton Symptom Assessment Scale includes assessment of both physical symptoms, e.g. breathlessness, as well as psychological, social and spiritual issues, such as anxiety and well-being. It has been used for a rather long time both in clinical care and in research (57, 63). Recently, the Integrated Palliative care Outcome Scale (IPOS), both the patient version and the staff version, were translated and culturally adapted into Swedish. The Swedish version is named Integrated Patient care Outcome Scale (64).

3.2.5 Different levels of palliative care

According to the EAPC (33), a palliative care approach should be provided regardless of where the care takes place. General palliative care should be provided in settings caring for patients with diseases that will eventually lead to death. The main task of the care is usually provided in settings where the focus is on the cure and treatment of diseases. Traditionally, oncology and geriatric settings belong to healthcare settings providing general palliative care. Healthcare professionals in such settings are expected to have good knowledge of basic palliative care. The extensive inclusion of other conditions within palliative care implies that patients with general palliative care needs are cared for in a large variety of care settings, e.g. those caring for patients with chronic pulmonary diseases and heart diseases.

Specialised palliative care is required for patients with life-threatening diseases who have complex and difficult needs. These needs may be due to complex symptoms, including

physical and psychological issues as well as a complex life situation. Providing specialised palliative care requires healthcare professionals who have extensive knowledge of palliative care. Further, this care places high demands on teamwork, where nurses and physicians constitute the base complemented by other healthcare professionals depending on the needs of the patient and next of kin (33). In Sweden, the same premises for delivering of palliative care as those of the EAPC are applied (8, 9). General palliative care ought to be provided in the majority of healthcare settings, e.g. in acute care as well as in nursing homes. Specialised palliative care is provided by healthcare professionals with extensive knowledge of palliative care in specialised palliative care settings, either in inpatient units or by home care teams. The organization of specialised palliative care varies throughout Sweden, partly because of demographic conditions and regional county council governance.

Compared to patients with non-malignant diseases, patients with cancer traditionally have had good access to specialised palliative care, with improved quality of life in terms of symptom control and being cared for in the place of their preference (65). Patients with chronic diseases are often cared for at departments with specialist knowledge in the specific diseases, acute care organisations. In such units, palliative care at a general level should be possible to provide (33). Nevertheless, the awareness of the benefits of integration of palliative care in the treatment of severe diseases has increased (66, 67).

3.2.6 Palliative care in acute care hospitals

The high proportion of deaths occurring in hospitals of patients with heart diseases and cerebrovascular diseases indicates that deaths in hospitals may, to a certain extent, be expected. Patients with severe, life-threatening diseases are cared for in nearly all kinds of units in the acute care setting. The main assignment of acute care organisations is to save lives, e.g. injured patients and patients with life-threatening diseases, which is therefore in contrast to the care of patients with chronic diseases with more or less life-threatening symptoms (68).

The acute care hospital has been described as an inadequate place for the care of patients with palliative care needs. The culture in acute care hospitals raises expectations on healthcare professionals to focus on active treatment to cure the patient (69, 70). Several studies have indicated difficulties in identifying patients in need of palliative care in acute care hospitals, leading to decisions concerning end-of-life care being made late in the disease trajectory (71-73). However, in contrast to acute care settings being an inadequate setting for dying, they may also be experienced by patients and their next of kin as *a safe haven*. Dying and death may cause feelings of fear and uncertainty about how to deal with the situation (74). This is, in a sense, confirmed by Gomes, Calanzani (43), who asked patients about their preferred place of death. Although home was the most common preferred place of death, they found differences between preferred place of care and preferred place of death, with advantages of being cared for at home compared to dying at home (43). Several studies report a need for further education in palliative care to improve the care in hospitals, e.g. about management of

pain and other symptoms (75, 76). It has been concluded that there is a constant need for education in palliative care (71).

3.3 QUALITY IMPROVEMENT IN PALLIATIVE CARE IN SWEDEN

Since access to palliative care was perceived as not being uniform throughout Sweden (77, 78), the NBHW was assigned to develop guidelines in the area. This resulted in the 2013 publication *A National knowledge-based guidance for good palliative care in end-of-life care* (8). Previously, in 2012, the *National clinical practice guideline for palliative care* (9) was published by the Regional Cancer Centre. In this thesis, a distinction is made between national guidelines from the authority, the National Board of Health and Welfare, referred to as guidance, and clinical practice guidelines developed by healthcare professionals, referred to as guidelines.

3.3.1 A national knowledge-based guidance for good palliative care in end-of-life care

In addition to officials from the NBHW, a large number of participants, including healthcare professionals with knowledge and clinical experience in palliative care, contributed to different aspects of the work to develop the guidance. The recipients of the guidance were defined as decision-makers at different levels in the healthcare organisation such as politicians and official managers. Healthcare professionals were also expected to be recipients. The concept of *evidence-based* in the provision of healthcare in Sweden is emphasised in publications from the NBHW. Ten recommendations are described in the guidance which have priorities from one to ten or not to do. Conversations about the goal of care at the end-of-life are a recommendation with a high priority (priority 1) as is the assessment of pain at the end-of-life (priority 2). High priority is also given to training and tutorials in palliative care and the assessment of symptoms using assessment tools at the end-of-life (priority 3) (8).

3.3.2 National clinical practice guideline for palliative care

The clinical guideline for palliative care was developed by a group of about 70 healthcare professionals. In accordance with palliative care being teamwork, staff from different professions was represented. As a supplement, a short version of the guideline was published, designed to support healthcare professionals in their clinical work (9). The content consists of theoretical knowledge combined with clinical implications. Concepts that were defined in the guidance from the NBHW are further developed. Concrete suggestions and advice for translating theory into practice are given, e.g. how to communicate with patients with severe illnesses and their next-of-kin, and the treatment of common symptoms. Furthermore, caring measures to promote wellbeing, e.g. oral health, and how to create a calm and comfortable care environment for the patient and the next of kin is emphasised. As with the national guidance from the NBHW, the national clinical guideline was spread through dissemination, i.e. written and oral information and communication.

3.3.3 Measurement of the quality of palliative care

Measurement of the results of activities is a basic requirement for structured improvement work. There is an increasing awareness of the importance of quality assurance as a basis for improvement work aimed to achieve good care. There are several types of measures that are relevant to use, depending on the section and level of the healthcare system the evaluation is supposed to highlight. Quality indicators are increasingly used to assess quality of care (79). As described by Campbell et al. (80), three kinds of indicators focusing on different aspects of quality can be defined: *structure*, *process* and *outcome*. A structure measure refers to the available prerequisites in the healthcare system. These could be related to physical aspects, e.g. access to technical equipment, as well as the characteristics of healthcare professionals, e.g. management and access to healthcare professionals with disease specific knowledge. Process indicators are intended to reflect actual actions and answer the questions of when, where and how care has been delivered, e.g. the time that has passed between a decision to treat and when the patient receives the treatment. Finally, the results effects of the care given on the patient's health and well-being are captured by outcome measures. In Sweden, quality indicators for specific areas are often formulated by the NBHW in connection with the development and publication of new guidelines (21). Such indicators reflect the content of the guidelines and might be used to measure adherence to guideline recommendations.

As with indicators for specific diseases, those for palliative care have to be valid, reliable and provide both sensitivity and specificity to be able to measure what they are supposed to measure. The content of an indicator might be easy to describe but developing a valid outcome measure is often challenging (81) and further efforts are needed to continue the development (82). An overview of indicators for palliative care made by Pasman et al. (83) revealed the problem of defining indicators for palliative care. They found a total of 142 indicators for palliative care, some of them overlapping. Most of the indicators referred to processes ($n=82$) and outcomes of care ($n=57$) (83). An update of the review showed that the number of quality indicators had increased by an additional 187 indicators, giving a total of 326 indicators. The majority still reflected the process of care ($n=199$) followed by the outcome of care ($n=117$) (84).

Nine quality indicators were defined in conjunction with the development of the guidance from the NBHW (8). Six of the indicators could be used immediately. Four of them reflected processes and two structure and result. The structure indicator is defined as the ratio of registration of expected deaths in the Swedish Register of Palliative Care (SRPC) and the indicator for result is the prevalence of pressure ulcers in patients at their time of death. The four indicators reflecting processes refer to 1) inpatient care on two or more occasions during the last 30 days in life, 2) documented oral health assessment, 3) prescription of opioid for pain when required and 4) medication for anxiety when required. In addition, three indicators were suggested for further development: end-of-life conversations, pain analysis and the structured assessment of pain and other symptoms.

In order to report and evaluate results, data can be gathered in quality registers. Sweden has just over a hundred quality registers capturing data related to specific diseases or conditions, of which the SRPC is one. This register was established in 2005 and, like the clinical guidelines, the register was developed by healthcare professionals. The objective of the register is to improve end-of-life care (85). Care units, regardless of their responsible authority, have the opportunity to join the register and input data on line. After the patient's death, healthcare professionals answer about thirty questions concerning the care in the patient's last week of life. The questions concern the presence of symptoms such as pain and pressure ulcers as well as the care provided to the patient and the next of kin. Each participating unit can use their data for evaluation and improvement of care. Furthermore, data is available for public access on a website (86). The use of the register has been shown to contribute to improvements in quality of care in participating units, indicating that registration in itself generate improvements (87). Another objective of the register is to create opportunities for research in this area. Studies have been undertaken using register data about the end-of-life of patients with different diseases, e.g. patients suffering from stroke (88) and chronic pulmonary disease (89). Registration in SRPC is defined as a quality indicator for palliative care by the NBHW, assessing adherence to the guidance (8).

Approximately 1 year after the publication of the *National knowledge-based guidance for good palliative care in end-of-life care*, statistics from the SRPC showed that patients who died in acute care settings were not adequately treated in end-of-life. Of 4,099 registered patients, 23 % had documented pain assessment during last week and 66 % were totally relieved from pain. This indicates that the dissemination of the two described documents and/or the uptake of the knowledge in acute care settings were unsatisfactory.

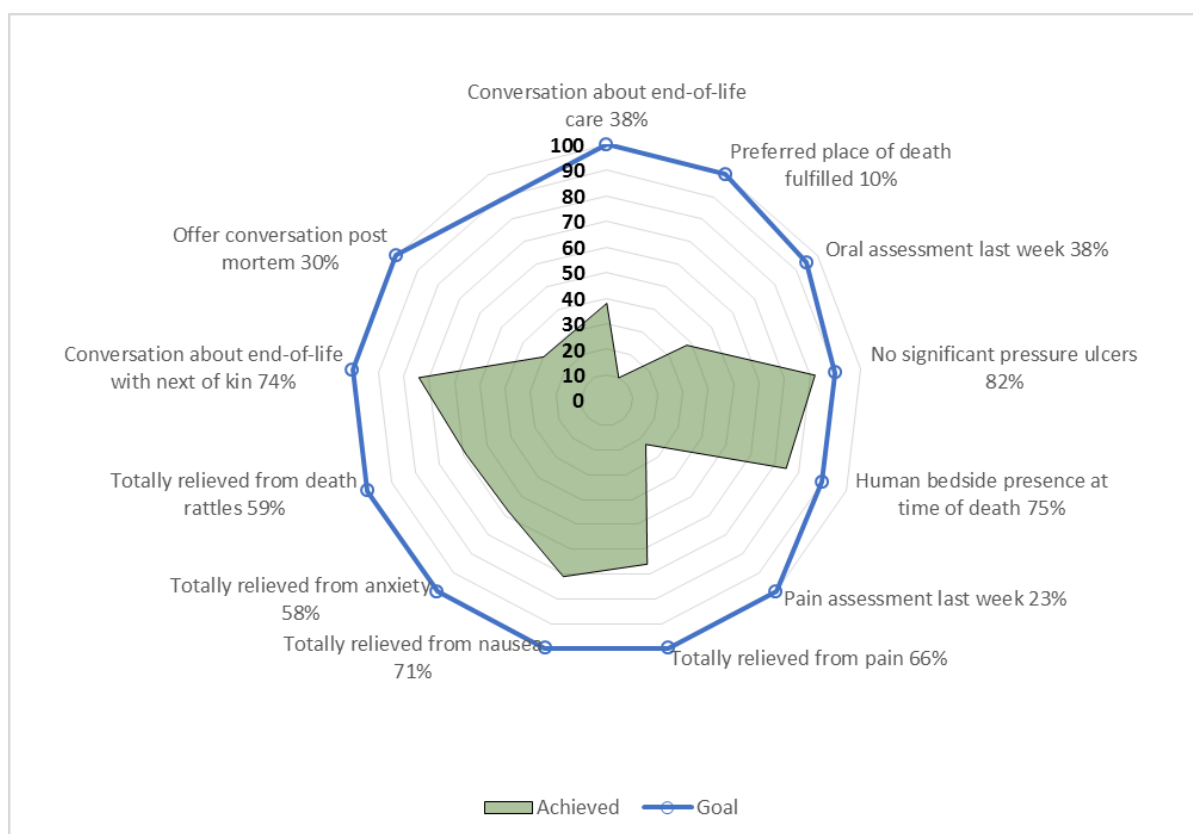


Figure 1. End-of-life care for reported expected hospital deaths 1 April 2014 – 30 June 2014, Sweden. Green colour depicts percentage of achieved goals. Source SRPC, <http://palliativ.se/>

4 RATIONALE

It has been proposed that a palliative approach should be an integrated part of the care of patients with severe life-threatening diseases, regardless of where the care takes place (33). In Sweden, approximately 90,000 people die annually and the most common causes of death are related to chronic diseases, such as heart failure and cancer. There is an increasing awareness of the importance of integration of palliative care early in disease trajectories for patients with chronic diseases, including not only cancer, but also for patients with chronic heart failure, chronic obstructive pulmonary disease and degenerative neurological diseases. The main mission for acute care hospitals is to care for patients with life-threatening conditions related to emergencies and acute injuries as well as for patients with acute impairment due to chronic diseases and elective care. As in other countries in Europe, Sweden has a high proportion of deaths occurring in hospitals. End-of-life care in hospitals has been described as unsatisfactory with problems related to communication, decision-making late in disease trajectories and inadequate symptom control and treatment.

Implementation in healthcare is often referred to as a complex and difficult undertaking because it involves several interacting components (90). Two Swedish documents concerning palliative care were published in 2012 and 2013: *A National knowledge-based guidance for good palliative care in end-of-life care* (8) by the NBHW and the *National clinical practice guideline for palliative care* by the Regional Cancer Centre (9). The documents were expected to be adopted through current decision-making and dissemination processes. These expectations required that the intended recipients at different organisations levels were aware of the publications, perceived them as useful and thereby decided to implement them.

Data from the SRPC showed several areas where palliative care given in acute care hospitals was deficient, e.g. regarding the assessment of pain and other distressing symptoms and the low proportion of patients who were offered end-of-life conversations. The gap between knowledge of palliative care and clinical practice, and how to bridge this gap, i.e. how palliative care could be integrated in acute care settings, has been sparsely explored in Sweden. There is a need for research on the implementation of palliative care in acute care settings, which can provide important knowledge for improvements in this area.

5 AIMS

The overarching aim of this thesis is to study implementation of knowledge-based palliative care in acute care settings.

5.1 SPECIFIC AIMS

Study I

To review existing national policy documents in Sweden for quality indicators relevant to palliative care and end-of-life care.

Study II

To investigate the perceptions of local politicians, chief medical officers and healthcare professionals regarding national palliative care guidelines, and to identify obstacles to and opportunities for implementing these guidelines in acute care settings.

Study III

To explore the feasibility of a pilot version of an implementation strategy for introducing IPOS in acute care settings. The strategy was also tested in a palliative care unit to gain additional understanding of the implementation process.

Study IV

To explore factors contributing to or hindering patients with palliative care needs having their symptoms assessed through IPOS and to describe healthcare staffs' experiences of what prevents and/or facilitates systematic use of IPOS in acute care settings.



Figure 2. Overview of the studies in the thesis including the development and performance of the implementation strategy

6 DESIGN AND METHODS

6.1 DESIGN

This thesis has an implementation research design, i.e. the intention is to study methods promoting actions that improve quality of care (91). When planning for implementation in healthcare settings, especially if it is expected to be complex, it can be beneficial to start with identifying obstacles and opportunities for the enterprise. If possible, this should be carried out at different levels in the intended organization and include decision-makers as well as a variety of healthcare professionals (92). The first and the second studies cover aspects to be taken into account for the development of the implementation strategy. Descriptive and qualitative analyses were used to gain a deeper understanding of obstacles and opportunities (90). The implementation strategy, in this case the support of the implementation of the Integrated Palliative care Outcome Scale, was subsequently carried out in clinical care settings. The third and fourth studies refer to the evaluation of the process of the implementation. Since implementation is most often a complex intervention (90), a combination of qualitative and quantitative methods was used (93).

Table 1. Overview of studies in the thesis

Study	Design	Materials and participants	Data collection	Data analysis
I	Quantitative descriptive design	National and regional/local guidelines and an annual report of the Swedish Register of Palliative Care.	Review of existing policy documents.	Quantitative descriptive analysis
II	Explorative qualitative design	Six local politicians in different county councils, five chief medical officers at different acute care hospitals and healthcare professionals, (physicians, nurses, assistant nurses) at three acute care units.	Interviews, individual and in groups.	Qualitative directed content analysis
III	Explorative design with qualitative and quantitative data	Three acute care units, one inpatient palliative care unit and one specialised palliative home care team.	Interviews, individual and in groups, and review of patient health records.	Process evaluation with quantitative descriptive analysis and qualitative content analysis.
IV	Explorative design with qualitative and quantitative data	Three acute care units (The same as in study III).	The same as in study III.	A mixed methods approach with regression analysis and qualitative content analysis.

6.2 THEORETICAL FRAMEWORKS AND METHODS

Implementation, i.e. interventions with the intention of achieving changes in practice, often includes several components. A number of frameworks have been developed to guide and support implementation in healthcare. The framework *Promoting Action on Research Implementation in Health Services* (PARIHS) has, in various ways, influenced this thesis (15, 16). In addition, another framework for implementation, the *Consolidated Framework for Implementation Research* (CFIR), was used to frame the data analysis in study II (94). The analysis of the feasibility of the implementation strategy (study III), which included several components, was guided by the description of process evaluation of complex interventions by Moore et al. (95). In the fourth study, a mixed methods approach was used (96).

6.2.1 Promoting Action on Research Implementation in Health Services

Evidence, context and facilitation, the main features in the conceptual framework PARIHS, guided the development of the implementation strategy (16). PARIHS has been used in many studies and in different contexts (97).

As described above, *evidence-based* practice is the combination of scientific facts, research, and the clinician's as well as the patient's experiences. In PARIHS, a broader interpretation of the concept evidence-based is emphasised. Beyond research, healthcare and patients' experiences, local data and information about where the change is intended to occur are included in the concept of evidence (16). Such information could be the prevailing culture and the presence of collaboration in different internal networks as well as existing local policies and guidelines.

The *context* in which the implementation is intended to occur could affect the prerequisites for a successful implementation. Both the physical place and the type of healthcare organisation should be part of this concept (97). As described by Damschroder et al. (94), the inner setting, i.e. the place where the implementation is intended to make a change and the individuals involved in the implementation, have to be considered (94). Leadership, the contexts' readiness for an implementation process of the intended change and the possibilities for feedback are of importance (16). The discussion regarding the differences between leadership and management have been ongoing for a long time, but an unambiguous definition is hard to find. A common description of management is a formal position with defined tasks at some level of an organisation, while a leader could be anyone in a group of staff who is involved in supporting activities to achieve specific aims and goals (98). A transformative leadership inspires employees to find new solutions and ways of carrying out tasks to enable development and innovation to be achieved to a larger extent. This kind of leadership has also been described as important for successful implementation (99).

Facilitation can be defined as components in a strategy that enable and promote the intended change, while a facilitator is as an organisation or an individual assigned to support the implementation in different ways (97). Knowledge about facilitation as a pivotal component in implementation has increased. This is emphasised in a recently revised version of PARIHS (100). A facilitator could be internal, working within the organisation, or external, belonging to another organisation with knowledge in the specific change that is planned to occur. Further, Kitson et al. (101) distinguish between facilitators role depending on their skills: *novice*, *experienced* and *expert*. By gaining experience of leading changes and knowledge about e.g. their own organisation, a facilitator can build his/her capacity to act as a facilitator on a higher level (101). With implementation at local levels, i.e. clinical care settings, the skills needed to act as a facilitator and manage implementation could be supported or hindered by formal and informal leadership, how the team works and the experiences of earlier implementation processes (100).

6.2.2 Consolidated Framework for Implementation Research

The Consolidated Framework for Implementation Research (CFIR) was developed through a compilation of the content of several implementation frameworks, models and theories.

CFIR is a conceptual framework, i.e. a structured description of factors that may affect implementation, and thereby important to take into account when planning, implementing and evaluating interventions and improvements in healthcare (94). CFIR encompasses five domains: the intervention characteristics, outer and inner setting, characteristics of the individuals involved and the process of implementation. Each domain has a number of defined underlying constructs, in total 39, including inclusion as well as exclusion criteria (Table 2). CFIR has been used in many studies, especially for data analysis (102).

The first domain, the intervention characteristics, focuses on the intervention. An intervention usually consists of several components, which may have to be adapted to the specific context where it is supposed to produce change. This domain intends to illuminate the stakeholder's perceptions of the intervention from different perspectives. The second and the third domain, outer and inner setting, reflect organisational viewpoints concerning the intervention. Clinical practice, management and organisational factors of healthcare systems in a specific context are affected by political and financial conditions, which are reflected in the outer setting. These in turn can affect the inner setting in various ways. The inner setting also concerns the specific internal context, e.g. norms and values and implementation climate. The fourth domain, characteristics of individuals, reflects the individuals' perceptions and expectations of the intervention. The fifth domain focuses on the implementation process and associated activities: planning, engaging, executing, and finally evaluating and reflecting. The authors of CFIR underline that there is no need to use every domain and construct: instead, CFIR is to be viewed as an overview of potentially impacting factors to consider in implementation activities. CFIR was used to guide the analysis in study II to enhance the understanding of obstacles and opportunities for implementation of palliative care in acute care settings at different levels in the healthcare organisation.

Table 2. Overview of the Consolidated Framework for Implementation Research (CFIR)

Intervention characteristics	Outer setting	Inner setting	Characteristics of individuals	Process
Intervention Source	Patient Needs & Resources	Structural Characteristics	Knowledge & Beliefs about the Intervention	Planning Engaging
Evidence Strength & Quality	Cosmopolitanism Peer Pressure	Networks & Communication	Self-efficacy	Executing
Relative Advantage	External Policy & Incentives	Culture Implementation Climate	Individual Stage of Change	Reflecting & Evaluating
Adaptability		Readiness for Implementation	Individual Identification with Organization	
Trialability			Other Personal Attributes	
Complexity				
Design Quality and Package				
Cost				

Source: Damschroder et al. (2009) (94).

6.2.3 Process evaluation

The aim of a process evaluation is to understand why a complex intervention, such as an implementation intervention, succeeded or failed (95). The Medical Research Council's framework for complex intervention describes the importance of designing, testing and evaluating complex interventions (103). As suggested in the framework, the development of an implementation strategy has to be carried out systematically. Thus, development and evaluation of a strategy requires several steps. Pilot testing and investigation of the feasibility of a strategy are recommended (95). It is important to scrutinize the intervention, both as a whole as well as each included part and the selected outcome. A combination of qualitative and quantitative research methods should preferably be used for the evaluation due to the complexity of an intervention. This kind of evaluation covers key process factors: implementation, mechanisms of impact and context. Further, an outcome has to be defined to enable evaluation of whether the objective of the strategy has been achieved or not. The evaluation of the implementation is supposed to answer questions about fidelity, dose and reach. Was it possible to deliver the strategy as expected and to what extent was it delivered? What adaptations of the implementation were required to fit the context? Factors related to mechanisms of impact are supposed to contribute understanding of how the delivered strategy produced change. The last question to be answered in a process evaluation is how factors

related to the context affected the implementation, mechanisms of impact and the outcome (95).

6.2.4 Mixed methods

To illuminate a research question from different perspectives, a mixed methods approach can be used. As suggested by Creswell (104), a combination of research methods gives an opportunity to fully understand what and why something is, or is not, happening. A combination of different data, such as qualitative and quantitative data, and different analysis methods, could contribute to the illumination of the results in a study. This is especially important in implementation research where you want to gain an understanding of the change process: what works in the specific context and why and how does it work or not works (105). In accordance with the description of mixed methods by Creswell (104), quantitative data was combined with qualitative data in study IV.

6.3 STUDY I – IDENTIFYING OBSTACLES AND OPPORTUNITIES FOR IMPLEMENTATION AT GOVERNING LEVEL

6.3.1 Design

Study I focused on identifying obstacles and opportunities for implementation of palliative care and in end-of-life care at the governing level in Swedish healthcare. The research question was: *Which quality indicators for palliative care and end-of-life care are described in existing national policy documents in Sweden?* In order to obtain an overview of existing quality indicators for palliative care and end-of-life care in governing documents, a quantitative descriptive design was used.

6.3.2 Sample

Based on the report *National indicators for good care* from the NBHW (106) were guidelines related to diseases associated with forthcoming death identified and included in the review. Furthermore, by reading the chapter on existing practice guidelines at regional and local level in county councils in the report *End-of-life care* from the NBHW (77), additional guidelines were identified. Finally, to gain supplementary knowledge regarding the prevalence of defined quality indicators for palliative care, the 2010 annual report from the SRPC (107) was included. The inclusion of guidelines was complemented by a manual search on the internet. Guidelines for palliative care and end-of-life care in municipalities were not included in the review.

6.3.3 Data collection

The definition of a quality indicator as described by the NBHW & Swedish Association of Local Authorities and Regions (108) was used in this review. A distinction was made between national guidelines which were defined as coming from the authority (NBHW) and clinical practice guidelines as developed by healthcare professionals. The search for documents was performed from March to April 2010. An updated search was made in

January 2011 and, finally, the 2010 annual report from the SRPC was included in the analysis.

6.3.4 Data analysis

A quantitative content analysis guided by Krippendorff (109) was performed. The documents were read and explicit palliative care quality indicators were marked. In total, eleven national guidelines from the NBHW and ten regional clinical guidelines were included. Data were tabulated regarding the source, the total number of quality indicators and the number of indicators relevant for our study. Moreover, a matrix over numerators and denominators, as well as the quality area the included palliative indicators referred to, was organized according to the definition by NBHW (108).

6.4 STUDY II – IDENTIFYING OBSTACLES AND OPPORTUNITIES FOR IMPLEMENTATION OF PALLIATIVE CARE IN ACUTE CARE HOSPITALS

6.4.1 Design

The study had an explorative qualitative design using content analysis guided by the Consolidated Framework for Implementation Research (94). Obstacles and opportunities for implementation can occur at different levels in healthcare organisations. Hence, it was important to interview participants representing different levels about their perceptions of the two recently published documents *A National knowledge-based guidance for good palliative care in end-of-life care* (8) and *National Clinical Practice Guideline for palliative care*, (9) but also the *Swedish Register of Palliative Care* (86). Furthermore, we were interested in their views regarding obstacles and opportunities for implementation of palliative care guidelines in acute care hospitals.

6.4.2 Sample and participants

Participants in this study were purposefully selected aiming to include regional politicians as well as managers and healthcare professionals in acute care hospitals. Six local politicians with responsibility for healthcare in as many county councils were invited to participate. The selected county councils represented all six healthcare regions in the current division of Sweden. Further, the county councils were selected to represent different demographic conditions in terms of geography, population and political governance. In addition, six chief medical officers in as many acute care hospitals were invited to the interviews. One chief medical officer declined participation late, and it was, unfortunately, not possible to substitute.

Similar to the selection of politicians, a purposeful sample of hospitals was made, located in both urban and rural areas. They were of different sizes and represented local as well as university hospitals. A specific requirement for the inclusion of hospitals was having an emergency room and the possibility of round-the-clock hospitalisation.

Staff at several acute care hospitals were invited to participate in interviews regarding obstacles and opportunities for implementation of palliative care according to the palliative care guidelines. However, there was little interest in participation, either because palliative care in the hospital was described as working well or that palliative care was not so common in the hospital. Finally, healthcare professionals at three medical units in an acute hospital in central Sweden volunteered to participate in interviews. Similar to the hospitals the chief medical officers represented, this hospital had an emergency room and a variety of departments with round-the-clock hospitalisation. Approximately 130, 000 patients with emergency care needs visited the hospital annually. Participating staff came from units that cared mainly for patients with neurological and pulmonary diseases and most of the patients were admitted from the emergency room.

6.4.3 Data collection

An interview guide was developed and all interviews began with the question “What does palliative care mean to you in relation to your work as a politician/chief medical officer/staff member?” Further, questions were asked regarding the interviewee’s knowledge and perceptions of the governing document, the clinical guidelines and the *Swedish Register of Palliative Care*. Finally, the participants were asked about their perceptions regarding opportunities and obstacles for implementation of palliative care in acute care hospitals. Participating healthcare professionals were also asked to answer a questionnaire regarding e.g. profession, number of years in their profession and number of years at current workplace.

Before the interviews with healthcare professionals were conducted, I made field visits to the units. It had been several years since I had worked as a clinical nurse. To gain an understanding of the daily work and to get to know the healthcare professionals in the units, I attended three work shifts in each unit. In addition, the visit helped me to ask probing questions during the interviews.

Individual interviews were conducted with politicians and chief medical officers. All interviews with the chief medical officers and two with politicians were conducted at their workplaces: the remaining interviews were conducted by telephone. The interviews lasted between 12 and 43 minutes, with a mean time of 26 minutes. The interviews were conducted from April to June 2013. A total of 37 healthcare professionals participated in the interviews, represented by five physicians, twenty registered nurses (RNs) and nine assistant nurses (ANs). The physicians were interviewed individually while the RNs and ANs participated in group interviews. Additionally, three nurse managers, responsible for each of the participating units, participated in individual interviews. The interviews with healthcare professionals were conducted in a separate room at the units or in nearby rooms in the hospital. They lasted between 27 and 56 minutes, with a mean time of 39 minutes. The interviews were conducted between March and April 2014.

6.4.4 Data analysis

All interviews in the study were audio recorded and transcribed verbatim by an external person. To become familiar with the content in the interviews, I listened to them and read the text concurrently several times. The texts were thereafter organised in the software NVivo10. Qualitative content analysis with a deductive approach as described by Elo and Kyngäs (110) was performed which meant that words, sentences and paragraphs (meaning units) were marked. A deductive approach was suitable for incorporating the theoretical framework CFIR (94) to guide the analysis. Since CFIR consists of domains and constructs, directed content analysis as described by Hsieh et al. (111) was conducted. This requires meaning units to be sorted initially into relevant domains and constructs. The meaning units and the content in the domains and the constructs were read through several times during the analysis. All five domains of CFIR were useful in the analysis but not all constructs: nine out of 39 constructs were used.

6.5 DEVELOPMENT AND DELIVERY OF THE IMPLEMENTATION STRATEGY

The goal of the implementation strategy, and thereby the outcome of the evaluation, was the clinical use of the Integrated Palliative care Outcome Scale (IPOS), a PROM developed for patients with palliative care needs. IPOS is available in two versions: one for self-reporting by the patient (Appendix 1) and one for proxy-estimation by healthcare professionals (Appendix 2). IPOS begins with an open question “What have been your main problems or concerns over the past three days?” followed by statements about various symptoms to be answered on a 5-point Likert Scale. A version for asking about problems or concerns over the past seven days is also available, but not used in this strategy (61, 64). Symptom assessment does not imply that the goal of the patient’s care needs to be defined as curative or palliative. Rather, the discussion with the patient, and/or next of kin, about the experienced symptoms could facilitate integration of palliative care early in a disease trajectory, as requested by healthcare professionals in study II. They were aware of the importance of prioritising symptom relief and providing psychosocial support. However, dying patients, particularly unconscious ones, were not prioritised in terms of symptom relief.

A description of the types of patients being cared for at the acute care hospitals and with a presumed need for palliative care was compiled. The description was consistent with patients who were to be offered assessment of their symptoms using IPOS. The assessment was preferably to be performed by the patient her/himself. If this was not possible due to e.g. unconsciousness, proxy assessment could be performed by healthcare professionals preferably in cooperation with next of kin. The assessment was to be performed during the third day of care on the unit. This day was chosen so as not to cause stress for either the patient or the healthcare professionals since it was likely that the patient would undergo a number of medical examinations and treatments during the first days of care in the hospital. Assessment on the seventh day of care was proposed for evaluation and follow-up. The completed IPOS forms were expected to be scanned into the patient’s electronic health record or saved in the paper-based health record.

The healthcare professionals also expressed a need for palliative care training in the interviews in study II. Training is a common component in implementation strategies of palliative care (112) and has been noted to be important especially when implementing PROM (113-115). Thereby, training became a natural part of the implementation strategy.

As pointed out by all stakeholders in study II, and emphasised by e.g. Harvey and Kitson (97) formally appointed implementation leaders and champions are important for successful implementation. As suggested by the stakeholders, use of internal and external facilitators was included in the implementation strategy. Lastly, leadership has been described as an important component of implementation (16, 99) and a specific assignment for the nurse managers was therefore included. They were asked to identify one or two RNs who could act as internal facilitators. The nurse managers were also asked to support the facilitators during the implementation period. The internal facilitators were assigned to remind and encourage their colleagues to use IPOS. I myself acted as the external facilitator providing support and feedback to healthcare professionals and the internal facilitators in their use of IPOS. Contacts between me, as an external facilitator, and the internal facilitators were scheduled in the project plan (Figure 3).



Figure 3. Overview of the implementation strategy

Information meetings were planned to be carried out at all units at the start of the implementation. The information meetings, held by me, introduced the aim of the project, the content of the training course, the facilitation approach, the data collection and ethical issues. A leaflet was distributed with information about the project, ethical approval and contact details.

All healthcare professionals at the units were invited to participate in the training course. Six sessions were developed giving information and knowledge related to the use of IPOS and palliative care to support the healthcare professionals in the use of IPOS (Table 3). The content was based on the *National clinical practice guideline for palliative care* (9). Learning

outcomes were defined for each session. A session lasted 15 minutes and the units were allowed to set their own schedule. The participants received Power-Point handouts and the basic and pocket versions of the clinical guidelines were distributed to the units after the training period. Thereafter followed 12 weeks of clinical use of IPOS.

Table 3. Overview of the content and the learning outcomes in the training sessions

Training session	Learning outcomes
Session 1. Palliative care: The meaning of the concept of palliative care	The learning outcome for the session was knowledge about palliative care as an approach and as an active total care of patients with life-threatening diseases. The session aimed to prepare healthcare professionals to identify patients who were to be offered the use of IPOS. Further, it underlined the need to ask the patient about their symptoms and introduced the use of IPOS as a tool for symptom assessment and communication.
Session 2. The Integrated Palliative care Outcome Scale (IPOS): Background and clinical use	The learning outcome for the session was knowledge concerning the clinical use of IPOS. The session aimed to introduce IPOS as a tool for assessment of symptoms. Further, it aimed to prepare healthcare professionals to identify patients who were to be offered the use of IPOS and when and how to ask the patient or their next of kin to carry out assessment using IPOS. Healthcare professionals were supported with regard to discussing completion of IPOS with the patient and their next of kin. They were also instructed to discuss the outcome of IPOS and initiate actions in cooperation with the patient and other healthcare professionals. The completed IPOS forms were expected to be scanned into the patient's electronic health record or saved in the paper-based health record.
Session 3. Communication/information: The meaning of communication and possibilities/ obstacles for communication	The learning outcome for the session was knowledge concerning communication related to the clinical use of IPOS. The session aimed to prepare healthcare professionals to identify patients who were to be offered the use of IPOS and when and how to ask the patient or their next of kin to use IPOS. The session aimed to support healthcare professionals in how to use IPOS as a guide for conversation with the patient and their next of kin. Further, factors promoting or inhibiting good communication were elucidated.
Session 4. Symptom relief: Pain, breathlessness and rattles	The learning outcome for the session was knowledge concerning how to translate the patient's assessment of different symptoms in IPOS to treatment and other activities, in cooperation with the patient, their next of kin and other healthcare professionals. This session focused on pain, breathlessness and rattle.
Session 5. Symptom relief: Anxiety and terminal distress	The learning outcome for the session was knowledge about how to translate the patient's assessment of different symptoms in IPOS to treatment and other activities in cooperation with the patient, their next of kin and other healthcare professionals. This session focused on anxiety and terminal distress.
Session 6. Symptom relief: Nausea/vomiting, infusions at end-of-life and oral healthcare	The learning outcome for the session was knowledge about how to translate the patient's assessment of different symptoms in IPOS to treatment and other activities in cooperation with the patient, their next of kin and other healthcare professionals. This session focused on nausea/vomiting, infusions at the end-of-life and oral healthcare.

The implementation strategy was developed based on theoretical assumptions and research on implementation. In addition, the results in study I and II contributed to the tailoring of the strategy to fit the specific context i.e. that of acute care hospitals in Sweden. The lack of quality indicators for diseases other than cancer and care of the elderly found in study I, and the opportunities expressed and the obstacles found in study II, were carefully considered in planning the strategy. The implementation components, assessment of pain and other symptoms and training in palliative care, were consistent with proposed recommendations for palliative care with high priority in the guidance from the NBHW (8). Assessment of pain was given the next highest priority (2) and assessment of other symptoms and training in care were prioritised with 3. The recommendation with the highest priority (1), end-of-life conversations, could be initiated and performed using IPOS.

6.5.1 Settings

The implementation strategy was performed at three acute care units in two hospitals in an urban area in central Sweden. Two of the units were the same as in study II but had undergone some reorganisations and had moved to other premises. These units received most of their patients from the hospitals' emergency rooms, which implied that patients with acute care needs and palliative care needs were cared for on the units. In addition, a gastro-surgery unit participated in the study. This unit cared for patients with upper gastrointestinal diseases and admitted patients for both acute and elective treatment. Similar to the two other acute care units, the gastro-surgery unit cared for patients with acute care needs and those with palliative care needs, particularly related to cancer diseases.

According to the definition of palliative care by EAPC (33), a general level of palliative care should be offered patients in acute care settings, while patients with palliative care needs suffering from complex and severe diseases should be cared for in hospitals with knowledge in specialised palliative care. To strengthen the evaluation of the feasibility of the implementation strategy, the implementation of IPOS was also performed at a palliative care setting at a smaller hospital in central Sweden. A palliative inpatient unit and a team providing specialised palliative home care participated in the study. The implementation strategy was performed from November 2015 to February 2016 in the palliative care unit and from January 2016 to June 2016 in the acute care units.

6.6 STUDY III AND IV – EVALUATION OF THE IMPLEMENTATION STRATEGY

6.6.1 Design

Studies III and IV were both designed to evaluate the performance of the strategy used for supporting implementation of IPOS in the different settings. Study III had an explorative design and a process evaluation was used to explore the feasibility of the implementation strategy.

Similar to study III, study IV had an explorative design but focused on factors contributing to or hindering patients from having their symptoms assessed using IPOS, and also described healthcare professionals' experiences of using IPOS. To gain an understanding of what prevents or enables the use of IPOS, a mixed methods approach combining quantitative and qualitative data was used.

6.6.2 Data collection and participants

Data collection for study III and IV was conducted at the same time. Quantitative data were collected through reviewing patients' health records for their reason for admission and the presence of completed IPOS. Furthermore, notes were made during the implementation period regarding number of participants in the training sessions and contacts between internal and external facilitators.

Qualitative data was gathered through interviews with nurse managers, internal facilitators and healthcare professionals at the participating units. An interview guide was developed with open-ended questions focusing on the different parts of the implementation strategy: information meetings, training sessions, internal and external facilitation and nurse managers' assignments. Questions regarding the healthcare professionals' experiences of using IPOS were also asked. In total, twelve interviews were conducted, whereof eight were performed in the acute care settings. The interviews were conducted either individually, in pairs or in groups depending on the practical circumstances at the units. Nurse managers and the majority of internal facilitators (nine out of eleven) participated in the interviews. Available nurses and assistant nurses as well as one physician in the palliative unit participated in interviews. None of the physicians in the acute care units participated, even though they were invited. In study III, all units were included, while study IV focused on the three acute care units. All interviews were conducted in rooms close to the units. Two research team members, who had not been involved in the implementation activities, conducted the interviews which lasted between 22 and 53 minutes.

Table 4. Overview of participants in study III and study IV

	Total	Nurse managers	Internal facilitators	Registered nurses/assistant nurses	Physicians
Study III	30	7	9	13	1
Study IV	19	3	6	10	0

6.6.3 Data analysis common to study III and IV

The quantitative data from the health records were organised in the software IBM SPSS Statistics 22. The same dataset was used for study III and IV. The sample consisted of 1,153 patients whereof 400 patients were considered relevant to be offered assessment of their symptoms using IPOS. The interviews were audio recorded and transcribed verbatim by an external person. The texts were thereafter organised in the software NVivo10 for the analysis in study III while the analysis in study IV was performed in Microsoft Word 2010.

6.6.4 Data analysis study III

In study III, descriptive data on the prevalence of completed IPOS and descriptive data regarding number of performed activities in the implementation strategy were compiled. Content analysis of the interviews, as described by Elo et al. (110) was performed. The texts were read several times and meaning units were marked and inductively coded into categories and subcategories. These in turn were deductively sorted (111) based on the components of the process evaluation: context, implementation, mechanisms of impact and outcome (95).

6.6.5 Data analysis study IV

In study IV, data from the sample of 309 patients eligible to be offered to complete IPOS were used. Descriptive statistics were used for demographic data of the patients: gender, age, diagnosis and death on unit during the study. Further, frequency of healthcare professionals' participation in the training sessions during the implementation period was calculated. Multivariable logistic regression analyses were performed for identifying factors contributing to or hindering patients from completion of IPOS. The prevalence of IPOS in patients' health records was selected as the dependent variable and was categorised as yes or no. The independent variables consisted of patient demographic data ($n=4$) and healthcare professionals' participation in training sessions ($n=4$). The patient related variables were gender (woman/male), age (≤ 65 years, 66-74 years or ≥ 75 years), diagnosis (cancer disease/other chronic disease) and patients' death on unit during the duration of the project (yes/no). The variables related to healthcare professionals' participation in training sessions were categorised in the same way for RN/AN, internal facilitators and physicians (not at all, 1- 50 % in two or more training sessions, 51-100 % in two or more training sessions). The categories for the nurse managers' participation differed due to the low number of nurse managers (not at all, 1-3 sessions, > 4 sessions).

Similar to study III, qualitative content analysis as described by Elo et al. (110) was performed for the eight interviews with healthcare professionals in the acute care settings. The texts were read several times, meaning units were marked and labelled with codes. Thereafter the codes were sorted into subcategories and finally organised into two main categories.

6.7 ETHICAL APPROVAL AND CONSIDERATIONS

Palliative care research is strongly associated with ethical issues such as vulnerable study populations. Ethical considerations according to the principles of the World Medical Association Declaration of Helsinki (116) have been taken into account during the entire process of this thesis. Study I was not regulated by the Swedish Act concerning Ethical Review of Research Involving Humans (117) since it was a literature study. The interviews with politicians, chief medical officers and healthcare professionals in study II-IV were also not regulated by the law, but an advisory statement from a regional ethical review board was obtained (2013/875-31/1). A complementary application was approved (2015/2197-32) for the review of health records in study III and IV. Furthermore, all department managers gave written permission for access to healthcare professionals for the interviews, for the implementation and for access to the health records. To ensure autonomy and non-maleficence (118), written as well as verbal information was given to the participants in the interviews in study II-IV. The information emphasised that participation was voluntary and participants could discontinue the interview at any time. Written informed consent was obtained. Moreover, to give participants the opportunity to talk freely, the interviews for study III and IV were performed by two research team members who had not been involved in the clinical part of the implementation project.

The patients were not directly involved in the studies but some ethical issues are important to discuss in relation to symptom assessment with IPOS and the review of the health records. Assessment of symptoms is not only important in palliative care since, e.g. pain and nausea can occur in any medical condition. It can be argued that not using assessment tools for patients with palliative care needs could cause unnecessary suffering and thus be seen as unethical. After gaining written permission from the department managers, IPOS was used as an ordinary assessment tool at the participating units during the study period.

7 RESULTS

7.1 MAIN FINDINGS STUDY I

A total of 240 quality indicators were detected in the review of guidelines for healthcare and of these, eleven indicators were appropriate to palliative and end-of-life care (Table 5). Of these eleven, three were general and common for cancer care, one was related to prostate cancer and four were related to lung cancer. Three of the described indicators in the guidelines were clearly related to end-of-life care: *assessment of pain with numeric rating scale during the palliative phase*, *prescription of opioid as required* and *registration in the SRPC*. *Documentation of the patients' transition to the palliative phase* was referred to as a development indicator in the guidelines for lung cancer. No indicator relevant for palliative or end-of-life care was found in the guidelines for cardiology, diabetes, dementia, pulmonary diseases and stroke. Moreover, in the document *The care and nursing of the elderly*, three indicators that were general for palliative care were found: *fraction of people aged 65 years and older with assessment of pain with a numeric rating scale during the last week of life*, *the use of guidelines for offering informed counselling to terminally ill people* and *counselling to relatives after death*.

Only a limited number of indicators were described in the regional/local documents. One guideline included *use of numeric rating scale for assessment of pain* and one *registration in the SRPC* as a quality indicator. Another guideline referred to the same quality indicators as in the overall national guideline for cancer. The annual report for 2010 from SRPC included quality indicators which corresponded to the indicators described in the general guidelines for cancer as well as in the document regarding care of the elderly.

Most of the indicators found (10/11) were referred to as measuring processes. The indicator *pain assessment by numeric rating scale* was generally referred to as a process measure, but in the document for overall indicators for cancer care it was referred to as a process as well as a structure measure. Seven of the eleven quality indicators had defined numerators and denominators. Two out of three indicators specific to lung cancer and the three overall indicators for cancer care included numerators and denominators: *use of numeric rating scale*, *prescription of opioid when required* and *registration in the SRPC*.

The indicators in the document *The care and nursing of the elderly* were not referred to as specific measures, but two out of three indicators had defined numerators and denominators. None of the indicators defined in the regional/local documents and in the SRPC had defined numerators and denominators.

Table 5. Overview of quality indicators in national and regional guidelines and the Swedish Register of Palliative Care

National guidelines from the National Board of Health and Welfare including the document “The care and nursing of the elderly”				
	Use of numeric rating scale (NRS) for the assessment of pain	Prescription of an injectable opioid as required	Registration in the SRPC	Other indicator relevant for palliative care and end-of-life care
Breast cancer care 2007	X	X	X	
Colorectal cancer care 2007	X	X	X	
Lung cancer care 2010	X	X	X	*Palliative radiation therapy for incurable lung cancer * Palliative chemotherapy for lung cancer *Stent in case of vena cava superior syndrome * Documentation of the patient’s transition to the palliative phase
Overall indicators for cancer care 2007	X	X	X	
Prostate cancer care 2007	X	X	X	*Age-normalised incidence of palliative radiation therapy for skeletal metastases in prostate cancer
The care and nursing of the elderly 2009				*Guidelines and procedures used for end-of-life care and nursing that describe, among other things, how informed counselling can be offered to terminally ill people aged 65 years and older. * Fraction of people aged 65 years and older who have died, for whom pain was estimated with the aid of a scientifically evaluated instrument such as a numeric rating scale or a visual analogue scale, during the final week of life. * Fraction of relatives offered counselling for survivors.
Regional clinical practice guidelines				
Clinical guideline for the Mölndal area 2006	X			
Palliative care in Östergötland 2009	X	X	X	
Swedish Register of Palliative Care				
	X (including other symptoms)	X		* Patient received information about their imminent death * Death in a preferred place * Did not die alone * Next of kin offered follow-up appointment

7.2 MAIN FINDINGS STUDY II

The results of study II are presented using all five domains in CFIR. However, not all constructs were relevant for the data. The findings below are presented using only the domains.

Regarding the **intervention characteristics**, knowledge about the *National clinical practice guideline for palliative care* and the *National knowledge-based guidance for good palliative care in end-of-life care* was scarce among stakeholders at all levels. However, politicians and chief medical officers pointed out the importance of the documents concern the patient's right to equitable health and medical care and for further improvement of palliative care. The concept of palliative care was mainly expressed as a holistic approach for patients at the end-of-life and the care provided by specialised palliative care units. Knowledge about the documents among staff was mainly restricted to the short version of the clinical guidelines. Staff described palliative care in their everyday work as related to sudden disease and difficulties in predicting impending death.

The **outer setting** was in this study, interpreted as being located outside the hospital. Stakeholders, especially chief medical officers, described the aging population living with chronic diseases as leading to an increasing need for palliative care. This was described as posing a challenge for healthcare services in the future. The knowledge and perceptions of the SRPC were, similar to that of the documents, of varying degrees among all stakeholders. The register was to some extent experienced as not being adapted to acute care organisations.

All stakeholders described the **inner setting**, interpreted as being located within the hospital, as an obstacle to the provision of palliative care. Heavy workloads and feelings of lack of time were experienced as an obstacle for palliative care. The decision to end ongoing life-sustaining treatment and focus on palliative care was experienced as difficult by all healthcare professionals. Lack of internal collaboration was described, especially by ANs, and all stakeholders described external inter-professional collaboration as insufficient.

Poor work continuity among healthcare professionals as well as poor communication and teamwork were additional obstacles for providing palliative care. Nevertheless, healthcare professionals emphasised a readiness for the improvement of palliative care. They requested training and support, both theoretically and in their clinical work.

Regarding the **characteristics of the individuals involved**, the gender distribution among interviewees was uneven in all groups except for the politicians. Among the participating chief medical officers, one was a woman, while among the healthcare professionals, women were in the majority. All nurse managers were women. Physicians participating in the interviews had at least 15 years experience in their profession compared to participating RNs, where twelve out of 20 had worked less than five years in their profession. Four out of nine of the participating ANs had less than five years experience as ANs. The level of formal and informal training regarding palliative care was low among all professionals.

Prior to upcoming **process of implementation**, all stakeholders described the use of internal facilitators with formal assignments as an important factor for successful implementation of palliative care in acute care settings.

7.3 MAIN FINDINGS STUDY III

A total of 1,153 patients were admitted to the units during the study period. Of these, 400 were relevant for offering assessment of their symptoms using IPOS. The **primary outcome** in the study, the prevalence of completed IPOS in patients' health records, varied widely between the units. In the pulmonary unit and the inpatient palliative care unit about half of the patients had a completed IPOS (53 % and 44 %) in their health records. The lowest prevalence was found in the gastro-surgery unit (6 %) followed by the neurological unit (9 %), while the result in the home care team was 35 %. The **context** in the acute care units was described as having *A need for an improved culture regarding palliative care*. It was further depicted as focusing on curative therapy and the teamwork between healthcare professionals when caring for patients with palliative care needs was perceived as insufficient.

The **implementation** started with information meetings, which were held at all units except for the gastro-surgery unit. The number of performed training occasions and the number of participants varied between the units. The pulmonary unit had the highest prevalence of participating RNs/ANs, where 83 % of them participated in \geq two sessions, followed by the palliative care unit where nearly three quarters (72 %) of RNs/ANs participated in \geq two sessions. In the gastro-surgery unit 60 % of RNs/ANs participated in \geq two sessions and in the neurological unit 49 % of RNs/ANs in \geq two sessions. Nurse managers at all units participated in \geq two sessions, except the nurse manager at the neurological unit who did not participate at all. Only a few of the physicians in the acute care units participated in training sessions, claiming that the strategy was questionable and of less interest to them. The content of the training sessions was perceived in divergent ways: in the acute care units staff stated that it was *related to everyday work*, whilst staff in the palliative unit perceived it as *nothing in it for us*. The visits/contacts between the internal and external facilitators were, to a large extent carried out, although not completely, in accordance with the project plan.

Several **mechanisms of impact** were identified. Feelings of *constantly increasing workload* and *constantly on-going changes* were described at all units. Caring for severely ill patients with a need for advanced care, in combination with endless changes of different kinds were leading to feelings of *change fatigue*. However, healthcare professionals emphasised the importance of quality improvement regarding patient care. Concerning the components of the implementation strategy, the importance of *the internal facilitator* as well as *the impact of nurse managers' support* were described as crucial for the use of IPOS. A perceived barrier that was reported for the implementation of IPOS was *unclear documentation of the IPOS form*. Since it was not possible to complete IPOS forms in the digital health record, healthcare professionals at all units described uncertainty about how to record IPOS.

7.4 MAIN FINDINGS STUDY IV

A total of 309 patients were included in the study, whereof 126 were cared for on the pulmonary unit, 101 on the neurological unit and the remaining 82 on the gastro-surgery unit: a total of 22 % of the patients had completed IPOS. The largest age category was those aged ≥ 75 years (58 %), followed by just over a quarter of those aged 66 to 74 years and the gender distribution was even. Nearly three quarters of the included patients (72 %) suffered from severe chronic diseases and 6 % died on the units during the duration of the project.

Chi-square tests of the variables regarding patient demographics showed a significant association for patients with completed IPOS and chronic diseases other than cancer ($p = 0.001$) when compared with patients with cancer. Fisher's Exact Test was used for the variables related to healthcare staff participation in training sessions due to cell counts smaller than 5. The tests showed a significant association between healthcare staff's participation and patients having completed IPOS ($p \leq 0.001$), regardless of profession.

Also the two models tested in the logistic regression analyses showed a significant association between patients having completed IPOS and healthcare staff's participation in training sessions, regardless of profession. In the first model, the strongest determinant for patients having completed IPOS was the participation of more than 50 % of the internal facilitators (OR = 15.8; 95 % CI = 3.18-78.53) and, in the second model, participation of more than 50 % of the physicians at the unit (OR = 15.8; 95 % CI = 3.18-78.53).

Healthcare professionals' experiences of using IPOS fell into two main categories: *IPOS acting as a facilitator* and *barriers for use of IPOS*. The use of IPOS contributed to *person-centred care of patients with palliative care needs* as well as to *improvement of the quality of care*. Healthcare professionals described IPOS as making it easier to communicate with patients. Moreover, they experienced IPOS as contributing to increased teamwork and awareness on how to integrate palliative care. Healthcare professionals also described that the use of IPOS *contributed to and inspired to improvement of routines* in that the content of IPOS made the documentation in health records easier. However, there were also barriers and *insecurity regarding the use of IPOS*. The healthcare professionals described lack of knowledge in palliative care and limited clinical experience of caring for patients with palliative care needs as factors hindering them in the use of IPOS. This was described as giving them feelings of *uncertainty on how to approach severely ill patients and their next of kin*. Further, they expressed *an uncertainty on how to integrate palliative care* in the care of patients affected by severe chronic diseases. Another barrier to using IPOS was *difficulties in finding new routines for the use of IPOS*. Contextual factors, such as a sense of high workload and feelings of time pressure in their daily work, contributed to IPOS being omitted. Further, insufficient teamwork contributed to difficulties in finding new routines for the use of IPOS.

8 DISCUSSION

Taken together, the findings in this thesis contribute with 1) knowledge about obstacles and opportunities for the implementation of palliative care in acute care settings, 2) information about the feasibility of a specific implementation strategy for IPOS and 3) healthcare professionals' experiences of using IPOS. Interviews with politicians, chief medical officers and healthcare professionals in study II detected several factors which could act as obstacles or opportunities for implementation. These findings, in combination with theoretical assumptions and research on implementation, contributed to the tailoring of a strategy to support the implementation of IPOS. The process evaluation of the implementation showed a large variation of completed IPOS, indicating a strong influence of contextual factors, but also that the strategy appeared less relevant for achieving successful implementation.

Some implementations efforts succeed in fully reaching the expected change, however many others fail. Implementation in healthcare is most often a complex undertaking because it includes several interacting components. Each component may have the possibility to influence the outcome of the implementation (90). According to the Medical Research Council framework on complex intervention (119), an intervention may be defined as complex based on five different aspects, each one contributing to the complexity. The *number of interacting components* and the *number of behaviour changes* that the receiver/participant in the intervention are expected to undertake contributes to the complexity, as well as if the expected change is experienced as difficult. The *number of groups* and if the groups are at different levels in the healthcare organisation also make a contribution. Finally, the *number of outcomes* and opportunities for *tailoring the intervention* to the context influence the complexity (119). It can be argued that the implementation of palliative care is a complex intervention due to its holistic approach including several perspectives, and because the emotional challenge of death.

8.1 THE PREVALENCE OF QUALITY INDICATORS

Findings in study I showed a scarce presence of quality indicators, relevant to the palliative care of patients with disease other than cancer, in guidelines for healthcare. As described by Mizuno et al. (120), quality indicators for the palliative care of patients with heart diseases have not yet been developed, indicating a need for further development to enable measurement of the quality of palliative care of patients with diseases other than cancer. The quality indicators found in the SRPC were not specified for particular diseases and could be applied to palliative care regardless of disease. In 2016, the NBHW evaluated end-of-life care in Sweden based on the *National knowledge-based guidance for good palliative care in end-of-life care* (121). Data from the SRPC was used as one source for the evaluation. This showed, among other things, that the use of pain assessment tools during the last week of life has increased in recent years. However, assessment of pain is still unequal considering patient demographics, such as age, gender and diagnosis, and geographical location. To promote quality of life for patients at the end-of-life, the NBHW has set a target level for the use of assessment tools for pain in the last week of life at 100 % (122).

8.2 THE CONCEPT OF PALLIATIVE CARE

Findings in study II, scarce knowledge among stakeholders at all levels about the two national guiding documents on palliative care, indicate that the documents have not reached recipients in acute care organisations to a proper extent. Moreover, the findings add knowledge about perceptions concerning the concept of palliative care. Uncertainty regarding the relevance of palliative care in acute care was to some extent, underlined by the chief medical officers questioning of the appropriateness and usefulness of the *Swedish Register of Palliative Care*. Research in palliative care has a short history compared to other areas of healthcare, it has only been an academic topic for a short time. There might be uncertainty about the evidence for providing palliative care in acute care, which may also have affected the implementation of IPOS as reported in study III and IV.

Palliative care is still frequently described in the literature in terms of end-of-life care (123, 124). It has been suggested that the unclear definition of the concept creates confusion regarding care (71). Gatekeeping to avoid research on palliative care has been described to occur on different levels in healthcare organisations, from ethical boards to the direct contact with patients and their next of kin (125). The topic itself may be experienced to cause discomfort leading to a fear of burdening both the patient and the next of kin in a situation where they are considered vulnerable (125, 126). However, research in palliative care has grown in areas such as symptom assessment and symptom management. Even though the awareness of the importance of good palliative care has increased, healthcare professionals' perceptions of and access to knowledge about palliative care are probably crucial for whether they want to be influenced and change their behaviour, particularly when working in acute healthcare organisations.

8.3 FEASIBILITY OF THE IMPLEMENTATION STRATEGY

The huge variation of completed IPOS shown in study III indicates that the strategy was not working that well for supporting the implementation of IPOS.

The interviews in study II enhanced the opportunities to **tailor** the strategy to the context, that of acute care settings. Since two of the units, the pulmonary and the neurological units were the same in the pre-implementation study II and the implementation study III and IV, the strategy could be considered relatively well adapted to the context of these units. The inclusion of the gastro-surgery unit in study III and IV added the perspective of the surgical specialty in hospitals. The inclusion of the palliative care unit, with an inpatient unit and a specialised palliative home care team, brought a broader understanding of the process and outcome of the strategy. However, it is possible that the design of the strategy would have been differently designed if preceding interviews had been conducted in these additional units.

8.3.1 Outcome – IPOS

The **object** of the implementation, IPOS, has recently been translated into Swedish. For this reason it was not a well-known assessment tool. Previous research has highlighted problems related to practical issues creating barriers for the use of PROM (115) and the findings in study III and IV show similar barriers. One reason for the variation of completed IPOS could be previous experience of using assessment tools. The units' previous experiences of using assessment tools were not investigated prior to implementation. Little experience of using assessment tools may have contributed to the healthcare staffs' feelings of insecurity regarding the use of IPOS. Perhaps there was too little theoretical education on IPOS and practicing the tool in the training sessions. The study period over twelve weeks of clinical use of IPOS may also have been too short for the healthcare professionals being able to feel comfortable using IPOS and establish routines for its use. However, they also experienced IPOS as a facilitator for the care of patients with palliative care needs. Previous research on experiences of using PROMs has shown similar results, in that the PROMs acted as complements to clinical assessment of the patients. By combining these information sources, the care of the patient was improved (115).

8.3.2 Mechanisms of impact

The findings in study III and IV provide important knowledge about factors related to the context that affected the implementation. Nurse managers support, i.e. **leadership**, and support from **internal facilitators** in using IPOS were highlighted as important by healthcare professionals. However, the conditions for managers and internal facilitators to support staff were in turn affected by contextual factors, e.g. staff shortage and high workload. The **culture** in the acute care hospitals, and thereby the conditions for good care, was also described as hindering the introduction of IPOS. All these three factors are closely intertwined and probably affecting each other. Previous research on implementation has made similar findings, suggesting that circumstances as in the current project are commonly occurring (127-129).

Leadership was a prominent finding in study III being an important factor for support or non-support of the internal facilitators and healthcare professionals in the use of IPOS. The support from nurse managers was perceived as either very supportive or lacking depending on the unit. Their participation in training sessions varied and none of them participated in all training sessions. However, the nurse managers also reported an awareness of their lack of involvement in the project. A previous study showed that even though healthcare professionals were positively persuaded about the use of guidelines on cardiovascular diseases, lack of leadership acted as a barrier for implementation (129). This was pronounced for staff of younger age and working in hospitals. According to Zheng et al. (130), caring for patients at the end-of-life is an emotional challenge for newly graduated nurses. Nurses experienced a variety of unpleasant feelings, e.g. nervousness and helplessness, and performing nursing care alone made them feel uncomfortable. Since participants in study II indicated that RNs in the acute care units in general were young and newly graduated one

may assume that the combination of young nurses working in acute care settings and the lack of leadership affected the implementation of IPOS.

The findings regarding leadership and facilitation suggest that the assignments for the nurse managers and the internal facilitators in the performed strategy worked deficient. Further measures to strengthen the engagement of the nurse managers and preparations of the internal facilitators would probably have improved the preconditions for a more successful implementation. Training the facilitators and nurse managers in the use of IPOS before training the healthcare professionals would have prepared them in a better way. Additional contacts between the external facilitator and the nurse managers during implementation may also have improved the nurse managers' engagement in changing practice.

The role of a **facilitator** has increasingly been described as an important but complex undertaking in supporting implementation (97). It is an active role with the objective to motivate and support in making change. According to Cranley et al's (131) description of different kinds of facilitator roles, the internal facilitators in the used implementation strategy are to be considered as *coaches*, while the role of the external facilitator, the one that I had, is to be viewed as an *outreach facilitator*. The internal facilitators had ambitions to support healthcare professionals in the use of IPOS, but contextual factors, e.g. lack of time and work schedules, hindered them. This also impacted their opportunities to meet the external facilitator. Nevertheless, the findings in study III showed that support from the internal facilitator was perceived as important, indicating that further efforts to strengthen the internal facilitators in their roles should be considered in future implementation endeavours. Regular group meetings between internal and external facilitators with opportunities to discuss experiences and support each other may strengthen the internal facilitators in their roles.

As found in study IV, **participation in training sessions**, regardless of profession, was significantly contributing to patients completing IPOS. Furthermore, healthcare professional's experienced the education as helpful when caring for patients. Nevertheless, they also expressed insecurity in their use of IPOS and uncertainty in how to approach the patients and next of kin. Moreover, healthcare professionals experienced lack of specific knowledge concerning IPOS. This indicates that the content in the education was not sufficient for a more extensive use of IPOS. Previous research has highlighted education as an important component in the implementation of PROMs (113-115). The units had huge opportunities to influence the time and number of training sessions, but the 2-4 weeks time period for the training sessions may have been too short. A longer period may have resulted in higher proportions of participants in the training sessions and, thereby, increased knowledge about IPOS, which in turn may have strengthen the group in their support of each other.

One of the four fundamental prerequisites in palliative care is **multi-professional teamwork** (8). A clear limitation in the strategy was the fact that I, as a nurse, performed the education and acted as external facilitator without co-workers from other healthcare professions. This may have affected the credibility of the training sessions in being intended and useful for also

professions other than nurses and assistant nurses. Participation in training sessions by the physicians was low. An underlined reason for this was that the project was perceived to be of less interest for them while being regarded as a nursing project. Since teamwork is an essential part of palliative care, it is unfortunate that the physicians did not recognise the project as important for improving palliative care in the units. However, previous research has described lack of a functional team as a barrier for implementation. The importance of everyone in the team getting the same information has been highlighted as necessary to be able to make changes (128), suggesting the need for a longer period of time for training and facilitation in an upscaled implementation effort. Further, findings in previous research have shown that insufficient teamwork could hinder implementation of guidelines (127). Since completed IPOS in our strategy required cooperation between, at least, nurses and physicians in order to initiate or change treatment to achieve symptom relief for the patient, the insufficient teamwork described in study IV may have contributed to the low prevalence of completed IPOS.

The focus on IPOS may have been a contributing factor to **physicians' participation** in the project. A previous study found that physicians in acute care may feel hesitant about using PROMs. The role of PROM in the specific context was questioned and uncertainty in interpretation of the findings of the PROM contributed to the distrust (132). This reinforces the importance of implementation strategies for palliative care in acute care should be carried out by a multi-professional team. Also having a physician as an internal facilitator may strengthen the implementation and demonstrate teamwork as a fundamental part of the concept of palliative care.

In study II, factors related to the **environment in acute care settings** were described as obstacles to the provision of palliative care. A high workload was described to contribute to feelings of lack of time. In addition, poor work continuity among healthcare professionals and poor communication contributed to feelings of insufficient teamwork and thereby acting as obstacles for providing palliative care. It was not surprising that the same factors appeared in study III and IV, described as obstacles for using IPOS, indicating that the strategy did not overcome these barriers. Staff shortages, especially among nurses, high workload, and time pressure contributed to IPOS not being used, as well as feelings of always ongoing changes.

Previous research has highlighted lack of time as an important barrier for implementation of guidelines (127, 129) and for the use of quality indicators for palliative care (128). Furthermore, time constrains is a well-known barrier for use of PROM (114). Time shortage has also been shown to contribute to nurses leaving care *left undone*. For example, communication has been described as a prominent activity not being performed (133). In the qualitative findings in study IV, healthcare professionals described feelings of uncertainty on approaching severely ill patients and their next of kin. Probably these patients were perceived as vulnerable, which is a reason for gatekeeping (125). Since communication is a prerequisite for use of IPOS, healthcare professionals' uncertainty in talking with patients and feelings of lack of time, one may assume that using IPOS may have been *left undone* as described by

Ball et al. (133). In future research on implementation of IPOS further efforts are needed to support healthcare professionals in communicating with severely ill patients.

8.3.3 Theoretical assumptions

The **components** in the strategy were based on theoretical assumptions on implementation taken from the PARIHS framework: evidence, context and facilitation (16). Nevertheless, a more extensive use of theoretical assumptions could probably have contributed to better feasibility, which is of importance for a potential upscaling of the implementation strategy. Different types of theories could be useful depending on whether the intention of the implementation is to change behaviour or affect attitudes and awareness regarding different ways of working. Implementation of PROMs implies changes in behaviour, e.g. on how to integrate palliative care in acute care, and awareness of ways of working, e.g. teamwork and routines for the use of PROM. Consequently, theoretical assumptions developed for such objectives are needed (134). Several types of theories may then be relevant to take into account, such as theories on communication and teamwork (26).

8.4 METHODOLOGICAL CONSIDERATIONS

In order to fulfil the evaluation of the implementation design, a mixed methods approach was used. Both qualitative and quantitative data were collected and qualitative and quantitative analysis methods were used. This means that trustworthiness needs to be discussed from several perspectives. Trustworthiness is reflected by different concepts depending on whether qualitative or quantitative methods have been used. Credibility, dependability, conformability and transferability are important for qualitative studies, while reliability and validity are relevant to discuss for quantitative studies.

A major strength is the overall design of the doctoral project, with studies I and II illustrating obstacles and opportunities for implementation, followed by the use of the results in the development of the implementation strategy and finally the evaluation of implementation as presented in study III and IV. In study I and II, where obstacles and opportunities for implementation of palliative care were investigated, data were collected from several levels of the healthcare organisation, from the authority NBHW, to politicians in county councils, different levels of managers in acute care and also clinically practising healthcare professionals. The variation of the sample thereby strengthens the credibility.

To strengthen the transferability of the implementation strategy, a project plan was developed. The components of the strategy were described in detail, such as the assignments for the nurse managers and the internal and external facilitators. Furthermore, learning outcomes were developed for each training session. However, adaptations needed to be made continuously during the implementation process based on the specific situations that emerged, e.g. follow-up of questions that arose during the training sessions. The description of the context of the participating units strengthens the transferability, while the small number of participating units is a limitation. At the same time, it is appropriate to conduct smaller studies to understand feasibility before conducting a larger implementation intervention.

Previous research has shown that a bottom-up perspective on implementation of clinical guidelines is preferred by healthcare professionals (135). This indicates a need for integrated knowledge translation, i.e. researchers and user of guidelines working close together (136). Workshops with healthcare professionals could provide opportunities to set a common benchmark for tailoring of future implementation strategies.

In connection with the interviews in study II and during the work with the implementation study, a close cooperation was established between myself as a nurse researcher and the study participants: healthcare professionals, facilitators and nurse managers. Interactive research approaches have both pros and cons. It is important to maintain a proper distance between the researcher and the participants. On the other hand, acting as an external facilitator in the implementation strategy required an ability to enthuse the participants. By keeping a diary and continuously discussing with my co-authors, my objectivity during the implementation and its evaluation was strengthened.

In study I, data were collected through a review of guidelines searching for quality indicators related to diseases associated with forthcoming death. The inclusion of guidelines was mainly based on the reports *National indicators of good care* (106) and *End-of-life care* (77) from the NBHW, which may have limited the search and thereby the result. It cannot be excluded that further guidelines existed at the time of the search, primarily concerning municipally organised healthcare, such as nursing homes.

In study II, the length of the interviews with the politicians and chief medical officers varied widely. The shortest duration was 12 minutes and the longest 43 minutes. Although the shortest interview only lasted for 12 minutes, it provided important information. The findings regarding interviewees not knowing that much about the national documents add a dimension to the problems of diffusion of knowledge and are a result in itself. A limitation is that four out of eleven of the interviews were conducted by telephone. This may have affected the conversation, since it is not as personal as a face-to-face interview.

In study II, III and IV, healthcare professionals were recruited according to their availability during their working shifts. It was therefore not possible to achieve an equal distribution of participants from the different units or heterogeneity in terms of age, gender and years in profession.

In study II, the number of participants in the group interviews with healthcare professionals varied, from three to six, while nurse managers and physicians were interviewed individually. The field notes I made before the interviews contributed to the probing questions asked during the interviews. Trustworthiness in study II was strengthened by the moderation of one co-author (JS) in three of the group interviews.

Similar to study II, the numbers of participants at each interview occasion for study III and IV varied from individual interviews to groups of two to four participants due to the recruitment procedure being the same as in study II. To strengthen the relevance of content in the

interviews, an interview guide had been developed. While I had supported the implementation in the units, it was not appropriate for me to conduct these interviews. To enable the participants to talk freely, all the interviews were performed by a co-author (JS) except for one interview which was conducted by another co-author (TB). The small number of participants in the groups may have influenced the interaction during the conversations and thereby affecting the credibility. In order to inspire the participants to share their experiences, open-ended questions were asked, followed by probing questions. A limitation of the interviews might be that no pilot interview was conducted.

The use of the framework CFIR (94) in study II, and the guidance from the Medical Research Council (95) in study III, contributed to the focus of the research questions in the analyses. However, it was important not to be completely guided by the framework in the analysis process, as this can lead to lack of attention to the content in the text. CFIR was helpful in ensuring focus on the research questions: the participants' perceptions of the guidelines, and the obstacles and opportunities for their implementation. To increase the credibility of the content analyses in study II-IV, regular discussions took place among the researchers involved in the analysis. In the initial part of the analysis process, I had continuous discussions about the findings with the current last author. Later, the findings were discussed with the whole research group on several occasions. Citations have been used to illustrate statements and make the analysis transparent.

To structure a process evaluation, the investigation and its findings might be sorted into the following main components: context, implementation and mechanisms of impact (95). The evaluation in study III focused on the implementation process and, thereby, on the strengths and weaknesses of the design and performance of the implementation support. However, it can be difficult to cover all aspects contributing to the results. The interpretation of the statements in the interviews in study III was a challenge in having an open mind to what the interviewees described and at the same time the distinguish between the main components in the process evaluation. Although a description of the components is available in the guidance from the Medical Research Council, it was not obvious how to separate between statements, primarily in sorting it to context or mechanisms of impact. A further limitation of process evaluations, as described in the guidance, is that there is no consensus regarding how to distinguish between the different concepts fidelity, reach, and dose (95). This means an uncertainty in the comparability between projects evaluated with this approach.

Aspects of reliability and validity are of importance when dealing with quantitative data. Although a description was compiled regarding types of patients with a presumed need for palliative care and thereby relevant to be offered to complete IPOS, there may be a difference in how I viewed relevance and how the healthcare professionals viewed relevance. Further, the healthcare professionals experienced storing the completed IPOS in the patient health records as a barrier for the use of IPOS, which may have affected the number of completed IPOS found in the health records. The sample in study IV ($n=309$) strengthened the logistic regression analyses.

9 CONCLUSIONS

In conclusion, the findings from the four studies in this thesis add important knowledge about the obstacles and opportunities for implementation of palliative care in acute care settings in general, and specifically on implementation of the assessment tool IPOS.

There was a lack of quality indicators relevant for palliative care and end-of-life care in national guidelines for diseases other than cancer and care of the elderly. The most common quality indicators were the use of a numeric rating scale for the assessment of pain, prescription of an injectable opioid as required and registration in the SRPC.

The knowledge about the *National knowledge-based guidance for good palliative care in end-of-life care* among local politicians as well as chief medical officers and healthcare professionals in acute care settings was scarce. Palliative care was referred to as a holistic approach for patients in end-of-life. Demographic changes with an aging population living with chronic diseases were described as a challenge for healthcare services.

Providing palliative care in acute care settings was associated with obstacles related to the context. A heavy workload and a feeling of lack of time as well as poor communication and teamwork among healthcare professionals were described as obstacles for providing palliative care. They emphasised training and support in their desire to improve palliative care.

A strategy to support implementation of IPOS, based on the healthcare professionals' descriptions of obstacles and opportunities for implementation of palliative care and theoretical assumptions for implementation, was developed. It included information, training and symptom assessment using IPOS. Internal facilitators and nurse managers were assigned to support the implementation. An external facilitator provided support to healthcare professionals and the internal facilitators. The strategy was performed at three acute care units, one palliative inpatient unit and a specialised palliative home care.

Findings from the evaluation imply that the strategy was not feasible to fully support implementation of IPOS. The components in the strategy had limitations, e.g. the training sessions were performed by a nurse instead of a team, and contextual factors relating to acute care settings, e.g. lack of teamwork and a high workload, were not possible to overcome. There was a positive association between healthcare professionals' participation in training sessions and patients completing IPOS. The use of IPOS was found to act as a facilitator for improvements in the care of patients with palliative care needs, but healthcare professionals also described uncertainty in how to approach severely ill patients and how to integrate palliative care for these patients.

10 IMPLICATIONS AND FUTURE RESEARCH

Demographic changes with an aging population living with chronic diseases will increase the need for palliative care. Patients with palliative care needs will be cared for in a diversity of settings, including hospitals. Palliative care as an approach to improve quality of life for patients with life-threatening diseases should be offered to everyone person who needs it, regardless of place of care. The scarce awareness of the two documents on palliative care, *A National knowledge-based guidance for good palliative care in end-of-life care* and *National clinical practice guideline for palliative care* shows a continuing need for dissemination of knowledge about palliative care in acute care settings. Although the findings in this thesis indicate that the strategy for supporting implementation of IPOS was not that successful as we had hoped for, the findings add important knowledge that can be used in clinical practice and future research. The thesis highlights the need for more research on implementation of palliative care in hospitals in general and of PROMs, such as IPOS, more specifically.

11 SWEDISH SUMMERY/SVENSK SAMMANFATTNING

11.1 BAKGRUND

Kvalitetsarbete genomförs kontinuerligt och systematiskt inom hälso- och sjukvården. Ett vanligt sätt att sammanställa den evidens som finns för vård genom forskning och utveckling inom ett visst område, är att publicera olika former av riktlinjer och vårdprogram. För att kunskapen ska spridas och användas behöver dokumenten implementeras, vilket sker med varierande resultat. Ett flertal faktorer kan påverka en implementeringsprocess, t.ex. vilka evidens som finns för åtgärden, vilka personer som berörs av förändringen och i vilken kontext/sammanhang förändringen ska genomföras.

I Sverige avlider cirka 90 000 personer årligen och vanligtvis orsakas dödsfallen av kroniska sjukdomar, t.ex. kronisk obstruktiv lungsjukdom och neurologiska sjukdomar. Palliativ vård, dvs. att lindra lidande och främja livskvalitet, är en viktig del av hälso- och sjukvården. En tredjedel av dödsfallen i Sverige sker på akutsjukhus, dvs. i en högteknologisk miljö vars främsta uppdrag att rädda liv. Tidigare studier visar på problem med palliativ vård inom akutsjukvården såsom svårigheter med ställningstagandet att patienten befinner sig i livets slutskede och att ge information till patienten/närstående om vårdens mål och inriktning.

Som all hälso- och sjukvård ska palliativ vård och vård i livets slutskede vara evidensbaserad. Socialstyrelsen publicerade 2013 nationella riktlinjer - *Nationellt kunskapsstöd för palliativ vård i livets slutskede* - och 2012 publicerades ett nationellt vårdprogram - *Nationellt vårdprogrammet för palliativ vård* från Regionala cancercentrum i samverkan. Genom registrering i *Svenska Palliativregistret* ges möjligheter till uppföljning av vården. Det övergripande syftet med avhandlingen var att studera implementering av kunskapsbaserad palliativ vård inom akutsjukvården.

11.2 SYFTE OCH METOD

Studie I och II fokuserade på att identifiera hinder och möjligheter för implementering av palliativ vård inom olika organisationsnivåer. Resultaten användes i utarbetandet av en strategi för att stödja implementeringen av symtomskattningsformuläret *Integrated Patient Outcome Scale* (IPOS). I studie III och IV utvärderades genomförandet av strategin.

Syftet i **studie I** var att beskriva vilka kvalitetsindikatorer relevanta för palliativ vård och vård i livets slutskede som kunde återfinnas i befintliga nationella policydokument publicerade av Socialstyrelsen. Därutöver granskades regionala/lokala vårdprogram för palliativ vård samt årsrapporten för Svenska Palliativregistret 2010. En kvantitativ deskriptiv analys genomfördes.

Syftet i **studie II** var att undersöka landstingspolitikernas, chefläkarens och vårdpersonalens uppfattning om dokumenten *Nationellt kunskapsstöd för palliativ vård i livets slutskede* och *Nationellt vårdprogram för palliativ vård* samt att identifiera hinder och möjligheter för att implementera dessa inom akutsjukvården. Sex politiker i lika många landsting samt fem

chefs-läkare på olika akutsjukhus intervjuades. Därutöver intervjuades läkare, sjuksköterskor och undersköterskor vid tre vårdavdelningar på ett akutsjukhus om sin kännedom om dokumenten samt hinder och möjligheter för implementering. En kvalitativ riktad innehållsanalys genomfördes. Vid analysen användes *The Consolidated Framework for Implementation Research (CFIR)*, ett teoretiskt ramverk som kan användas för att stödja och utvärdera implementeringsprocesser.

En strategi för implementering av IPOS utarbetades, baserad på teoretiska antaganden i ramverket *Promoting Action on Research Implementation in Health Services (PARIHS)*, tidigare implementeringsforskning samt resultaten i delstudie I och II. Strategin bestod av information, utbildning samt klinisk användning av symtomskattningsformuläret IPOS under 12 veckor. En beskrivning av patienter med allvarliga sjukdomstillstånd och palliativa vårdbehov som torde erbjudas att skatta sina symtom utarbetades. För att ytterligare stödja implementeringen ombads respektive chefsjuksköterska att utse 1-2 sjuksköterskor som kunde agera som interna faciliterare, dvs. stödja övrig personal i användandet av IPOS. Chefsjuksköterskorna ombads även att stödja de interna faciliteterna under projektiden. För att ytterligare stödja implementeringen agerade jag själv som extern faciliterare. All vårdpersonal erbjöds att delta i sex utbildningsmoduler á 15 minuter. Innehållet i utbildningen bestod av information och kunskap om palliativ vård, symtomlindring, kommunikation samt symtomskattningsformuläret IPOS. Utbildningen var baserad på *Nationellt vårdprogram för palliativ vård* och genomfördes på enheterna utifrån respektive enhets önskemål. Under den kliniska användningen genomfördes kontinuerliga kontakter, inledningsvis som möten och senare via mail mellan de interna faciliterarna och mig som extern faciliterare.

Syftet i **studie III** var att utforska genomförbarheten av strategin för att implementera IPOS inom akutsjukvården. Strategin genomfördes på tre akutsjukvårdsavdelningar. För att få ytterligare kunskap om genomförbarheten av strategin genomfördes den även på en vårdavdelning för specialiserad palliativ vård samt ett hemsjukvårdsteam för specialiserad palliativ vård.

Syftet i **studie IV** var att undersöka vilka faktorer som bidrog till eller förhindrade att patienter med behov av palliativ vård fick sina symtom skattade med hjälp av IPOS samt att beskriva vårdpersonalens erfarenheter av vad som förhindrar och/eller underlättar systematisk användning av IPOS inom akutsjukvården.

Datainsamlingen för studie III och IV genomfördes vid samma tillfälle. Som utfallsmått användes förekomsten av IPOS i patientjournaler. Kvantitativ data insamlades genom att undersöka förekomsten av IPOS i journaler för de patienter som borde erbjudits att använda IPOS. Deskriptiv data angående deltagare i utbildningarna och genomförda möten med interna och extern faciliterare insamlades genom dagboksanteckningar. Kvalitativ data insamlades genom intervjuer med vårdpersonalen och chefsjuksköterskor vid de deltagande vårdavdelningarna. I delstudie III genomfördes en processutvärdering där alla deltagande vårdenheter ingick. I delstudie IV ingick data från de tre akutvårdsavdelningarna. Delstudie

IV har en mixed-metod ansats med deskriptiv statistik, regressionsanalyser och kvalitativ innehållsanalys.

11.3 RESULTAT

Resultatet i **delstudie I** visar överlag att endast ett fåtal (11/240) av de kvalitetsindikatorer som återfanns i de granskade dokumenten var relevanta för palliativ vård och vård i livets slutskede. Dessa indikatorer fanns beskrivna för vården vid cancersjukdomar samt för vård och omsorg av äldre personer. Den vanligaste indikatorn var registrering i Svenska Palliativregistret och därefter skattning av smärta med skattningsinstrument samt vid behovsordination av opioid.

Intervjuerna i **delstudie II** visade generellt en låg kännedomen om dokumenten *Nationellt kunskapsstöd för palliativ vård i livets slutskede* och *Nationellt vårdprogram för palliativ vård* och kännedomen om *Svenska Palliativregistret* varierade. Begreppet palliativ vård beskrevs som ett holistiskt förhållningssätt vid vård av patienter i livets slutskede. Vårdpersonalen beskrev palliativ vård som vanligt förekommande i det dagliga arbetet. Vårdkontexten inom akutsjukvården, med hög arbetsbelastning och otillräcklig kommunikation och teamarbete, beskrevs som hinder för att kunna ge god palliativ vård. Vårdpersonalen efterfrågade kunskap om palliativ vård, både teoretiskt och praktiskt.

Processutvärderingen av genomförandet av implementeringsstrategin i **delstudie III** visade att förekomsten av IPOS i patientjournalerna varierade stort: från 6 % till 53 %. Även deltagandet i utbildningen varierade: av alla sjuksköterskor/undersköterskor vid respektive avdelning deltog från 83 % till 49 % i ≥ 2 utbildningsmoduler. Alla utom en av chefsjuksköterskorna deltog i ≥ 2 utbildningsmoduler. Endast ett fåtal läkare deltog då de ansåg att strategin inte var intressant ut deras perspektiv. Flera faktorer beskrevs påverka användningen av IPOS, varav flera av dem beskrevs som hinder för implementering i delstudie II: hög arbetsbelastning samt otillräcklig kommunikation och teamarbete. Ledarskap och stöd från faciliterarna beskrevs som viktiga faktorer för att IPOS skulle användas. Oklarheter i dokumentationen av IPOS, som inte var möjlig att göra i det digitala journalsystemet, var en hindrande faktor.

I **delstudie IV**, där data från de tre akutavdelningarna analyserades, visade de kvantitativa analyserna en signifikant association mellan vårdpersonalens deltagande i utbildningsmodulerna och förekomsten av IPOS i patientjournalerna. De kvalitativa analyserna visade att användning av IPOS bidrog till ett personcentrerat förhållningssätt i vården av patienter med palliativa behov. Användning av IPOS bidrog också till kvalitetsförbättringar av vården. Vårdpersonalen upplevde dock osäkerhet i att närma sig svårt sjuka patienter och deras närstående samt osäkerhet hur palliativ vård kan integreras inom akutsjukvården.

11.4 SLUTSATSER

Resultaten visar att spridningen av de publicerade nationella dokumenten om palliativ vård, *Nationellt kunskapsstöd för palliativ vård i livets slutskede* och *Nationellt vårdprogram för palliativ vård* inte är tillfredsställande inom akutsjukvården. Begreppet palliativ vård beskrevs som ett förhållningssätt, framför allt för patienter som vårdas i livets slutskede. Resultaten visar också på svårigheter att ge palliativ vård inom akutsjukvården beroende på faktorer i vårdkontexten: hög arbetsbelastning, otillräcklig kommunikation och otillräckligt teamarbete.

Resultaten visar att den framtagna strategin inte vara tillräckligt stödjande för att implementera symtomskattningsformuläret IPOS inom akutsjukvården, men att användningen av IPOS bidrog till kvalitetsförbättringar av palliativ vård. Ytterligare studier bör genomföras för att stödja implementering av palliativ vård inom akutsjukvården.

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13 REFERENCES

1. World Health Organization (WHO). World Health Statistics 2016: monitoring health for the SDGs. 2016.
2. Statistics Sweden. (Statistiska Centralbyrån). The future population of Sweden 2017–2060 (Sveriges framtida befolkning 2017–2060). 2017.
3. World Health Organization (WHO). The global burden of disease 2004 update. 2008.
4. Morin L, Aubry R, Frova L, MacLeod R, Wilson DM, Loucka M, et al. Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative medicine*. 2017 Jun;31(6):526-36. PubMed PMID: 27683475.
5. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative medicine*. 2014 Jan;28(1):49-58. PubMed PMID: 23695827.
6. Swedish Government Official Reports. Death concerns us all: worthy care at the end of life: final report (Döden angår oss alla: värdig vård vid livets slut : slutbetänkande). Stockholm: Socialdepartementet. Stockholm: Fritzes offentliga publikationer; 2001.
7. In Swedish: Statens offentliga utredningar. Utredningen om prioriteringar inom hälso- och sjukvården Vårdens svåra val : slutbetänkande. Stockholm: 1995. 1995:5.
8. National Board of Health and Welfare (NBHW). A national knowledge-based guidance for End-of-life palliative care. (Nationellt kunskapsstöd för god palliativ vård i livets slutskede: vägledning, rekommendationer och indikatorer : stöd för styrning och ledning). Stockholm: National Board of Health and Welfare (Socialstyrelsen); 2013.
9. Regional cancer center Stockholm Gotland. National clinical practice guidelines for palliative care 2012-2014 (Nationellt vårdprogram för palliativ vård 2012-2014). Västerås: Ed. Regional cancer center in cooperation, (Regionala cancercentrum i samverkan,); 2012.
10. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. *Lancet*. 2003 Oct 11;362(9391):1225-30. PubMed PMID: 14568747.
11. Lugtenberg M, Burgers JS, Westert GP. Effects of evidence-based clinical practice guidelines on quality of care: a systematic review. *Quality & safety in health care*. 2009 Oct;18(5):385-92. PubMed PMID: WOS:000270515300013. English.
12. Batalden PB, Davidoff F. What is "quality improvement" and how can it transform healthcare? *Quality & safety in health care*. 2007 Feb;16(1):2-3. PubMed PMID: 17301192. Pubmed Central PMCID: 2464920.
13. Minister of Health & Social Affairs. Health and Medical Services Act. (Hälso- och sjukvårdslagen) HSL 2017:30. Socialdepartementet; (2017).
14. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *Bmj*. 1996 Jan 13;312(7023):71-2. PubMed PMID: 8555924. Pubmed Central PMCID: 2349778.
15. Kitson A, Harvey G, McCormack B. Enabling the implementation of evidence based practice: a conceptual framework. *Qual Health Care*. 1998;7(3):149 - 58.
16. Rycroft-Malone J, Kitson A, Harvey G, McCormack B, Seers K, Titchen A, et al. Ingredients for change: revisiting a conceptual framework. *Quality & safety in health care*. 2002 Jun;11(2):174-80. PubMed PMID: 12448812. Pubmed Central PMCID: 1743587.

17. Woolf SH, Grol R, Hutchinson A, Eccles M, Grimshaw J. Clinical guidelines: potential benefits, limitations, and harms of clinical guidelines. *Bmj*. 1999 Feb 20;318(7182):527-30. PubMed PMID: 10024268. Pubmed Central PMCID: 1114973.
18. Legido-Quigley H, Panteli D, Brusamento S, Knai C, Saliba V, Turk E, et al. Clinical guidelines in the European Union: mapping the regulatory basis, development, quality control, implementation and evaluation across member states. *Health Policy*. 2012 Oct;107(2-3):146-56. PubMed PMID: 22939646.
19. Shekelle PG, Woolf SH, Eccles M, Grimshaw J. Clinical guidelines: developing guidelines. *Bmj*. 1999 Feb 27;318(7183):593-6. PubMed PMID: 10037645. Pubmed Central PMCID: 1115034.
20. Eccles MP, Grimshaw JM, Shekelle P, Schunemann HJ, Woolf S. Developing clinical practice guidelines: target audiences, identifying topics for guidelines, guideline group composition and functioning and conflicts of interest. *Implementation science : IS*. 2012 Jul 04;7:60. PubMed PMID: 22762776. Pubmed Central PMCID: 3523009.
21. National Board of Health and Welfare (NBHW). National guidelines: What are national guidelines? (Vad är nationella riktlinjer?). www.socialstyrelsen.se/publikationer: Edita Västra Aros, Västerås; 2013.
22. Hupe H. Implementing Public Policy: An Introduction to the Study of Operational Governance: SAGE, 2008; 2008.
23. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof*. 2006 Winter;26(1):13-24. PubMed PMID: 16557505.
24. McKibbin KA, Lokker C, Wilczynski NL, Ciliska D, Dobbins M, Davis DA, et al. A cross-sectional study of the number and frequency of terms used to refer to knowledge translation in a body of health literature in 2006: a Tower of Babel? *Implementation science : IS*. 2010 Feb 12;5:16. PubMed PMID: 21080976. Pubmed Central PMCID: 2834600.
25. Rogers EM. Diffusion of innovations. New York: Free press; 2003.
26. Grol R. Improving patient care : the implementation of change in health care. Chichester, West Sussex: Wiley Blackwell; 2013.
27. Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. *Implementation science : IS*. 2012;7:50. PubMed PMID: 22651257. Pubmed Central PMCID: 3462671. Epub 2012/06/02. eng.
28. National Board of Health and Welfare (NBHW). National Guidelines for breast, prostate, colon- and rectal cancer, (Nationella riktlinjer för bröst-, prostata-, tjocktarms- och ändtarmscancervård 2014 : stöd för styrning och ledning,). Stockholm: National Board of Health and Welfare, (Socialstyrelsen); 2014.
29. National Board of Health and Welfare S. National Guidelines for Cardiac Care, (Nationella riktlinjer för hjärtsjukvård 2015: stöd för styrning och ledning). Stockholm: National Board of Health and Welfare, (Socialstyrelsen); 2015.
30. National Board of Health and Welfare (NBHW). Care in multiple sclerosis and Parkinson's disease, (Vård vid multipel skleros och Parkinsons sjukdom : stöd för styrning och ledning). Stockholm: National Board of Health and Welfare, (Socialstyrelsen); 2016.
31. Lutz S. The history of hospice and palliative care. *Curr Probl Cancer*. 2011 Nov-Dec;35(6):304-9. PubMed PMID: 22136703.

32. World Health Organization (WHO). National cancer control programmes : policies and managerial guidelines. Geneva 2002.
33. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 1, recommendations from the European Association for Palliative Care. *European Journal of Palliative Care* 2009;16(6):278-89.
34. Ferrell BR, Temel JS, Temin S, Alesi ER, Balboni TA, Basch EM, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2017 Jan;35(1):96-112. PubMed PMID: 28034065.
35. The Committee on Care in End of life. Death concern us all, worthy care in end of life: final report, (Döden angår oss alla värdig vård vid livets slut: slutbetänkande). Stockholm; SOU 2001:6.
36. Xyrichis A, Lowton K. What fosters or prevents interprofessional teamworking in primary and community care? A literature review. *Int J Nurs Stud*. 2008 Jan;45(1):140-53. PubMed PMID: 17383655.
37. Moore AR, Bastian RG, Apenteng BA. Communication Within Hospice Interdisciplinary Teams: A Narrative Review. *Am J Hosp Palliat Care*. 2016 Dec;33(10):996-1012. PubMed PMID: 26518351.
38. Håkanson C, Öhlén J, Morin L, Cohen J. A population-level study of place of death and associated factors in Sweden. *Scandinavian journal of public health*. 2015 July 20, 2015.
39. Dasch B, Blum K, Gude P, Bausewein C. Place of Death: Trends Over the Course of a Decade: A Population-Based Study of Death Certificates From the Years 2001 and 2011. *Dtsch Arztebl Int*. 2015 Jul 20;112(29-30):496-504. PubMed PMID: 26249252. Pubmed Central PMCID: 4555061.
40. Gao W, Ho YK, Verne J, Glickman M, Higginson IJ, project GUC. Changing patterns in place of cancer death in England: a population-based study. *PLoS Med*. 2013;10(3):e1001410. PubMed PMID: 23555201. Pubmed Central PMCID: 3608543.
41. Houttekier D, Cohen J, Pepersack T, Deliens L. Dying in hospital: a study of incidence and factors related to hospital death using death certificate data. *Eur J Public Health*. 2014 Oct;24(5):751-6. PubMed PMID: 24367064.
42. Loucka M, Payne SA, Brearley SG, Euro I. Place of death in the Czech Republic and Slovakia: a population based comparative study using death certificates data. *BMC Palliat Care*. 2014;13(1):13. PubMed PMID: 24650214. Pubmed Central PMCID: 3994490.
43. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*. 2013 Feb 15;12:7. PubMed PMID: 23414145. Pubmed Central PMCID: 3623898.
44. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of oncology : official journal of the European Society for Medical Oncology / ESMO*. 2012 Aug;23(8):2006-15. PubMed PMID: 22345118.
45. Hoare S, Morris ZS, Kelly MP, Kuhn I, Barclay S. Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLoS One*. 2015;10(11):e0142723. PubMed PMID: 26555077. Pubmed Central PMCID: 4640665.

46. Hunt KJ, Shlomo N, Addington-Hall J. End-of-life care and achieving preferences for place of death in England: results of a population-based survey using the VOICES-SF questionnaire. *Palliative medicine*. 2014 May;28(5):412-21. PubMed PMID: 24292157.
47. Pivodic L, Pardon K, Morin L, Addington-Hall J, Miccinesi G, Cardenas-Turan M, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*. 2016 Jan;70(1):17-24. PubMed PMID: 26202254.
48. Kehl KA, Kowalkowski JA. A Systematic Review of the Prevalence of Signs of Impending Death and Symptoms in the Last 2 Weeks of Life. *American Journal of Hospice and Palliative Medicine®*. 2013;30(6):601-16. PubMed PMID: 23236090.
49. Kobewka D, Ronksley P, McIsaac D, Mulpuru S, Forster A. Prevalence of symptoms at the end of life in an acute care hospital: a retrospective cohort study. *CMAJ Open*. 2017 Jan-Mar 03/09;5(1):E222-E8. PubMed PMID: PMC5378541.
50. Romem A, Tom SE, Beauchene M, Babington L, Scharf SM, Romem A. Pain management at the end of life: A comparative study of cancer, dementia, and chronic obstructive pulmonary disease patients. *Palliative medicine*. 2015 May;29(5):464-9. PubMed PMID: 25680377.
51. Öhlen J, Russell L, Hakanson C, Alvariza A, Furst CJ, Arestedt K, et al. Variations in Care Quality Outcomes of Dying People: Latent Class Analysis of an Adult National Register Population. *J Pain Symptom Manage*. 2017 Jan;53(1):13-24. PubMed PMID: WOS:000396502600005.
52. Wilkie DJ, Ezenwa MO. Pain and symptom management in palliative care and at end of life. *Nurs Outlook*. 2012 Nov-Dec;60(6):357-64. PubMed PMID: 22985972. Pubmed Central PMCID: 3505611.
53. Steinhäuser KE, Arnold RM, Olsen MK, Lindquist J, Hays J, Wood LL, et al. Comparing three life-limiting diseases: does diagnosis matter or is sick, sick? *J Pain Symptom Manage*. 2011 Sep;42(3):331-41. PubMed PMID: 21276704. Pubmed Central PMCID: 3597229.
54. Bausewein C, Daveson BA, Currow DC, Downing J, Deliens L, Radbruch L, et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services - Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement. *Palliative medicine*. 2015 Jan;30(1):6-22. PubMed PMID: 26068193.
55. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. *Br Med J*. 2010 Jan;340. PubMed PMID: WOS:000273951100003.
56. Etkind SN, Daveson BA, Kwok W, Witt J, Bausewein C, Higginson IJ, et al. Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review. *J Pain Symptom Manage*. 2015 Mar;49(3):611-24. PubMed PMID: 25135657.
57. Hui D, Bruera E. The Edmonton Symptom Assessment System 25 Years Later: Past, Present, and Future Developments. *J Pain Symptom Manage*. 2017 Mar;53(3):630-43. PubMed PMID: 28042071. Pubmed Central PMCID: 5337174.
58. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Palliative Care Core Audit Project Advisory*

- Group. Qual Health Care. 1999 Dec;8(4):219-27. PubMed PMID: 10847883. Pubmed Central PMCID: PMC2483665. Epub 2000/06/10. eng.
59. Kearns T, Cornally N, Molloy W. Patient reported outcome measures of quality of end-of-life care: A systematic review. *Maturitas*. 2017 Feb;96:16-25. PubMed PMID: 28041590.
 60. Catania G, Beccaro M, Costantini M, Ugolini D, De Silvestri A, Bagnasco A, et al. Effectiveness of complex interventions focused on quality-of-life assessment to improve palliative care patients' outcomes: A systematic review. *Palliat Med*. 2015 Jan;29(1):5-21. PubMed PMID: WOS:000346427300002.
 61. Schildmann EK, Groeneveld EI, Denzel J, Brown A, Bernhardt F, Bailey K, et al. Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the Integrated Palliative care Outcome Scale. *Palliative medicine*. 2016 Jun;30(6):599-610. PubMed PMID: 26415736. Pubmed Central PMCID: 4873725.
 62. Lundh Hagelin C, Klarare A, Fürst CJ. The applicability of the translated Edmonton Symptom Assessment System: revised [ESAS-r] in Swedish palliative care. *Acta Oncol*. 2017;1-2.
 63. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991 Summer;7(2):6-9. PubMed PMID: 1714502.
 64. Beck I, Möller UO, Malmström M, Klarare A, Samuelsson H, Hagelin CL, et al. Translation and cultural adaptation of the Integrated Palliative care Outcome Scale including cognitive interviewing with patients and staff. *BMC Palliat Care*. 2017;16(1):49.
 65. Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative medicine*. 1998 Sep;12(5):317-32. PubMed PMID: 9924595.
 66. Siouta N, van Beek K, Preston N, Hasselaar J, Hughes S, Payne S, et al. Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliat Care*. 2016 Feb 13;15:18. PubMed PMID: 26872741. Pubmed Central PMCID: 4752742.
 67. Siouta N, Van Beek K, van der Eerden ME, Preston N, Hasselaar JG, Hughes S, et al. Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC Palliat Care*. 2016 Jul 08;15:56. PubMed PMID: 27391378. Pubmed Central PMCID: 4939056.
 68. Hirshon JM, Risko N, Calvillo EJ, Stewart de Ramirez S, Narayan M, Theodosios C, et al. Health systems and services: the role of acute care. *Bull World Health Organ*. 2013 May 1;91(5):386-8. PubMed PMID: 23678202. Pubmed Central PMCID: 3646345.
 69. Reid C, Gibbins J, Bloor S, Burcombe M, McCoubrie R, Forbes K. Healthcare professionals' perspectives on delivering end-of-life care within acute hospital trusts: a qualitative study. *BMJ Support Palliat Care*. 2015 Dec;5(5):490-5. PubMed PMID: 24644187.
 70. Willard C, Luker K. Challenges to end of life care in the acute hospital setting. *Palliative medicine*. 2006 Sep;20(6):611-5. PubMed PMID: 17060254.
 71. Bloomer M, Moss C, Cross W. End-of-life care in acute hospitals: an integrative literature review. *J Nurs Healthc Chronic Illn*. 2011;3:165-73.

72. Bloomer MJ, Endacott R, O'Connor M, Cross W. The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative medicine*. 2013 Sep;27(8):757-64. PubMed PMID: 23442881.
73. Sheward K, Clark J, Marshall B, Allan S. Staff perceptions of end-of-life care in the acute care setting: a New Zealand perspective. *J Palliat Med*. 2011 May;14(5):623-30. PubMed PMID: 21486146.
74. Reyniers T, Houttekier D, Cohen J, Pasman HR, Deliens L. The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers. *Health & place*. 2014 May;27:77-83. PubMed PMID: 24577161.
75. Frey R, Gott M, Raphael D, O'Callaghan A, Robinson J, Boyd M, et al. Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. *BMJ Support Palliat Care*. 2014 Dec;4(4):381-9. PubMed PMID: 24644167.
76. McCourt R, James Power J, Glackin M. General nurses' experiences of end-of-life care in the acute hospital setting: a literature review. *Int J Palliat Nurs*. 2013 Oct;19(10):510-6. PubMed PMID: 24162282.
77. National Board of Health and Welfare (NBHW). End -of-life care: The assessment by the National Board of Health and Welfare of development in county councils and municipalities (Vård i livets slutskede, Socialstyrelsens bedömning av utvecklingen i landsting och kommuner). 2006.
78. Williams R. A National Cancer Strategy for the Future : summary : report of the. Stockholm: Fritze; 2009.
79. Carinci F, Van Gool K, Mainz J, Veillard J, Pichora EC, Januel JM, et al. Towards actionable international comparisons of health system performance: expert revision of the OECD framework and quality indicators. *Int J Qual Health Care*. 2015 Apr;27(2):137-46. PubMed PMID: 25758443.
80. Campbell SM, Braspenning J, Hutchinson A, Marshall M. Research methods used in developing and applying quality indicators in primary care. *Quality & safety in health care*. 2002 Dec;11(4):358-64. PubMed PMID: 12468698. Pubmed Central PMCID: 1758017.
81. Payne S, Leget C, Peruselli C, Radbruch L. Quality indicators for palliative care: debates and dilemmas. *Palliative medicine*. 2012 Jul;26(5):679-80. PubMed PMID: 22733962.
82. Dy SM, Lupu D, Seow H. Progress towards systems of quality measurement that capture the essence of good palliative care. *Palliative medicine*. 2012 Jun;26(4):291-3. PubMed PMID: 22585596.
83. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage*. 2009 Jul;38(1):145-56. PubMed PMID: 19615636. Epub 2009/07/21. eng.
84. De Roo ML, Leemans K, Claessen SJ, Cohen J, Pasman HR, Deliens L, et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage*. 2013 Oct;46(4):556-72. PubMed PMID: 23809769.
85. Lundstrom S, Axelsson B, Heedman PA, Fransson G, Furst CJ. Developing a national quality register in end-of-life care: the Swedish experience. *Palliative medicine*. 2012 Jun;26(4):313-21. PubMed PMID: 21737480.

86. The Swedish Register of Palliative Care (SRPC). www.palliativ.se [accessed 2017 28 September].
87. Martinsson L, Furst CJ, Lundstrom S, Nathanaelsson L, Axelsson B. Registration in a quality register: a method to improve end-of-life care--a cross-sectional study. *BMJ Open*. 2012;2(4). PubMed PMID: 22936818. Pubmed Central PMCID: 3432841.
88. Eriksson H, Milberg A, Hjelm K, Friedrichsen M. End of Life Care for Patients Dying of Stroke: A Comparative Registry Study of Stroke and Cancer. *PLoS One*. 2016;11(2):e0147694. PubMed PMID: 26845149. Pubmed Central PMCID: 4742254.
89. Ahmadi Z, Lundstrom S, Janson C, Strang P, Emtner M, Currow DC, et al. End-of-life care in oxygen-dependent COPD and cancer: a national population-based study. *Eur Respir J*. 2015 Oct;46(4):1190-3. PubMed PMID: 26250490.
90. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, et al. Framework for design and evaluation of complex interventions to improve health. *Bmj*. 2000 Sep 16;321(7262):694-6. PubMed PMID: 10987780. Pubmed Central PMCID: 1118564.
91. Eccles MP, Mittman BS. Welcome to Implementation Science. *Implementation Science*. 2006;1. PubMed PMID: WOS:000206717500001.
92. Grol R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. *The Medical journal of Australia*. 2004 Mar 15;180(6 Suppl):S57-60. PubMed PMID: 15012583.
93. Creswell JW. *Research design : qualitative, quantitative, and mixed methods approaches*. Thousand Oaks: SAGE Publications; 2014.
94. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science*. 2009 Aug;4. PubMed PMID: WOS:000269819300001. English.
95. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. *Bmj*. 2015;350:h1258. PubMed PMID: 25791983. Pubmed Central PMCID: 4366184.
96. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research*. Los Angeles: SAGE Publications; 2011.
97. Harvey G, Kitson A. *Implementing evidence-based practice in healthcare : a facilitation guide*. London ;; Routledge/Taylor & Francis Group; 2015.
98. Yukl GA. *Leadership in organizations*. Boston: Pearson; 2013.
99. Gifford W, Davies B, Edwards N, Griffin P, Lybanon V. Managerial leadership for nurses' use of research evidence: an integrative review of the literature. *Worldviews Evid Based Nurs*. 2007;4(3):126-45. PubMed PMID: 17850494.
100. Harvey G, Kitson A. PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice. *Implementation science : IS*. 2016 Mar 10;11:33. PubMed PMID: 27013464. Pubmed Central PMCID: 4807546.
101. Kitson AL, Harvey G. Methods to Succeed in Effective Knowledge Translation in Clinical Practice. *J Nurs Scholarsh*. 2016 May;48(3):294-302. PubMed PMID: 27074390.

102. Kirk MA, Kelley C, Yankey N, Birken SA, Abadie B, Damschroder L. A systematic review of the use of the Consolidated Framework for Implementation Research. *Implementation science : IS*. 2016 May 17;11:72. PubMed PMID: 27189233. Pubmed Central PMCID: 4869309.
103. Craig P, Petticrew M. Developing and evaluating complex interventions: reflections on the 2008 MRC guidance. *Int J Nurs Stud*. 2013 May;50(5):585-7. PubMed PMID: 23159017.
104. Creswell JW. *Educational research : planning, conducting, and evaluating quantitative and qualitative research* 4th ed. ed. Boston: Pearson Education, Inc.,; 2012.
105. Peters DH, Adam T, Alonge O, Agyepong IA, Tran N. Implementation research: what it is and how to do it. *Bmj*. 2013 Nov 20;347:f6753. PubMed PMID: 24259324.
106. National Board of Health and Welfare (NBHW). National indicators for good care—Comprehensive indicators in health and medical care—Indicators in the national guidelines (Nationella indikatorer för God vård – Hälso- och sjukvårdsövergripande indikatorer – Indikatorer i Socialstyrelsens nationella riktlinjer). 2009.
107. Swedish Register of Palliative Care. Annual report for Swedish Register of Palliative Care, 2010 (Årsrapport för Svenska Palliativregistret verksamhetsåret 2010). 2011.
108. National Board of Health and Welfare & Swedish Association of Local Authorities and Regions. Model for development of quality indicators: Report from the Info-VU project's network for quality indicators (Modell för utveckling av kvalitetsindikatorer Rapport från Info-VU-projektets nätverk för kvalitetsindikatorer) 2005.
109. Krippendorff K. *Content analysis : an introduction to its methodology*. Thousand Oaks, Calif. SAGE; 2013.
110. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107-15. PubMed PMID: 2009880550. Language: English. Entry Date: 20080530. Revision Date: 20120302. Publication Type: journal article.
111. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research*. 2005 Nov;15(9):1277-88. PubMed PMID: 16204405.
112. van Riet Paap J, Vernooij-Dassen M, Sommerbakk R, Moyle W, Hjerstad MJ, Leppert W, et al. Implementation of improvement strategies in palliative care: an integrative review. *Implementation science : IS*. 2015;10(1):103. PubMed PMID: 26210499. Pubmed Central PMCID: PMC4515317. Epub 2015/07/27. eng.
113. Antunes B, Harding R, Higginson IJ, Euroimpact. Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliat Med*. 2014 Feb;28(2):158-75. PubMed PMID: WOS:000329687600007.
114. Bausewein C, Simon ST, Benalia H, Downing J, Mwangi-Powell FN, Daveson BA, et al. Implementing patient reported outcome measures (PROMs) in palliative care - users' cry for help. *Health and Quality of Life Outcomes*. 2011 Apr;9. PubMed PMID: WOS:000291560100001. English.
115. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf*. 2014 Jun;23(6):508-18. PubMed PMID: WOS:000336914900010. English.
116. World Medical Association (WMA). Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects <https://www.wma.net/policies-post/wma->

declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/: World Medical Association (WMA); [accessed 2017 18 September].

117. Swedish Act about Ethical Review of research Involving Humans (Lag om etikprövning av forskning som avser människor). (2003).

118. Beauchamp TL, Childress JF. Principles of biomedical ethics. New York: Oxford University Press; 2013.

119. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *Bmj*. 2008;337:a1655. PubMed PMID: 18824488. Pubmed Central PMCID: 2769032.

120. Mizuno A, Miyashita M, Hayashi A, Kawai F, Niwa K, Utsunomiya A, et al. Potential palliative care quality indicators in heart disease patients: A review of the literature. *J Cardiol*. 2017 Oct;70(4):335-41. PubMed PMID: 28427868.

121. National Board of Health and Welfare (NBHW). Palliative care in end-of life: Summary with improvement areas: national guidelines - evaluation 2016., (Palliativ vård i livets slutskede : sammanfattning med förbättringsområden : nationella riktlinjer - utvärdering 2016). Stockholm: Socialstyrelsen; 2016.

122. National Board of Health and Welfare (NBHW). Palliative care in end-of-life: target levels for indicators, (Palliativ vård i livets slutskede: Målnivåer för indikatorer,. 2017.

123. Hui D, De La Cruz M, Mori M, Parsons HA, Kwon JH, Torres-Vigil I, et al. Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Support Care Cancer*. 2013 Mar;21(3):659-85. PubMed PMID: 22936493. Pubmed Central PMCID: 3781012.

124. Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, et al. The lack of standard definitions in the supportive and palliative oncology literature. *J Pain Symptom Manage*. 2012 Mar;43(3):582-92. PubMed PMID: 22104619. Pubmed Central PMCID: PMC3818788. Epub 2011/11/23. eng.

125. Kars MC, van Thiel GJ, van der Graaf R, Moors M, de Graeff A, van Delden JJ. A systematic review of reasons for gatekeeping in palliative care research. *Palliative medicine*. 2016 Jun;30(6):533-48. PubMed PMID: 26577927.

126. Chen EK, Riffin C, Reid MC, Adelman R, Warmington M, Mehta SS, et al. Why is high-quality research on palliative care so hard to do? Barriers to improved research from a survey of palliative care researchers. *J Palliat Med*. 2014 Jul;17(7):782-7. PubMed PMID: 24885960. Pubmed Central PMCID: 4082348.

127. Bayley MT, Hurdowar A, Richards CL, Korner-Bitensky N, Wood-Dauphinee S, Eng JJ, et al. Barriers to implementation of stroke rehabilitation evidence: findings from a multi-site pilot project. *Disabil Rehabil*. 2012;34(19):1633-8. PubMed PMID: 22631218.

128. Leemans K, Van den Block L, Vander Stichele R, Francke AL, Deliens L, Cohen J. How to implement quality indicators successfully in palliative care services: perceptions of team members about facilitators of and barriers to implementation. *Support Care Cancer*. 2015 Dec;23(12):3503-11. PubMed PMID: 25832893.

129. McKee G, Kerins M, Hamilton G, Hansen T, Hendriks J, Kletsios E, et al. Barriers to ESC guideline implementation: results of a survey from the European Council on Cardiovascular Nursing and Allied Professions (CCNAP). *Eur J Cardiovasc Nurs*. 2017 Dec;16(8):678-86. PubMed PMID: 28498092.

130. Zheng R, Lee SF, Bloomer MJ. How new graduate nurses experience patient death: A systematic review and qualitative meta-synthesis. *Int J Nurs Stud*. 2016 Jan;53:320-30. PubMed PMID: 26493131.
131. Cranley LA, Cummings GG, Profetto-McGrath J, Toth F, Estabrooks CA. Facilitation roles and characteristics associated with research use by healthcare professionals: a scoping review. *BMJ Open*. 2017 Aug 11;7(8):e014384. PubMed PMID: 28801388. Pubmed Central PMCID: 5724142.
132. Dainty KN, Seaton B, Laupacis A, Schull M, Vaillancourt S. A qualitative study of emergency physicians' perspectives on PROMS in the emergency department. *BMJ Qual Saf*. 2017 Sep;26(9):714-21. PubMed PMID: 28183828. Pubmed Central PMCID: 5574389.
133. Ball JE, Murrells T, Rafferty AM, Morrow E, Griffiths P. 'Care left undone' during nursing shifts: associations with workload and perceived quality of care. *BMJ Quality & Safety*. 2014;23(2):116.
134. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? *Soc Sci Med*. 2005 Feb;60(4):833-43. PubMed PMID: 15571900.
135. Bahtsevani C, Willman A, Stoltz P, Ostman M. Experiences of the implementation of clinical practice guidelines--interviews with nurse managers and nurses in hospital care. *Scand J Caring Sci*. 2010 Sep;24(3):514-22. PubMed PMID: 20070594.
136. Gagliardi AR, Berta W, Kothari A, Boyko J, Urquhart R. Integrated knowledge translation (IKT) in health care: a scoping review. *Implementation science : IS*. 2016 Mar 17;11:38. PubMed PMID: 26988000. Pubmed Central PMCID: 4797171.

14 APPENDICES

Appendix 1

Personnummer:

IPOS Patientversion



www.pos-pal.org

Namn:

Datum (dd/mm/åååå) / /

Vänligen texta tydligt, en bokstav eller siffra per ruta. Dina svar kommer att hjälpa oss att fortsätta förbättra vården för dig och för andra.

F1. Vilka har dina huvudsakliga problem eller bekymmer varit de senaste 3 dagarna?

1.

2.

3.

F2. Nedan finns en lista över symtom som du kan ha upplevt. Vänligen markera den ruta som bäst beskriver hur varje symtom har påverkat dig de senaste 3 dagarna.

	Inte alls			Mycket	Överväldigande
Smärta	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Andfåddhet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Svaghet eller brist på energi	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Illamående	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Kräkningar	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Dålig aptit	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Förstoppning	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Ont eller torr i munnen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Dåsighet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nedsatt rörlighet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Vänligen skriv ner eventuella andra symtom som inte nämns ovan och markera en ruta för att visa hur de har påverkat dig de senaste 3 dagarna.

1. 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

2. 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

3. 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

Under de senaste 3 dagarna:

	<i>Nej, inte alls</i>	<i>Vid enstaka tillfällen</i>	<i>Ibland</i>	<i>Ofta</i>	<i>Ja, hela tiden</i>
F3. Har du känt ångest eller oro över din sjukdom eller behandling?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
F4. Har någon i din familj eller vänskapskrets känt oro eller varit bekymrad för dig?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
F5. Har du känt dig deprimerad?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>Ja, hela tiden</i>	<i>Ofta</i>	<i>Ibland</i>	<i>Vid enstaka tillfällen</i>	<i>Nej, inte alls</i>
F6. Har du känt dig tillfreds?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
F7. Har du i den utsträckning du önskat kunnat dela med dig av hur du mår till din familj eller dina vänner?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
F8. Har du fått den information du önskat?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>Problemen har bemötts/ Inga problem</i>	<i>Problemen har mestadels bemötts</i>	<i>Problemen har delvis bemötts</i>	<i>Problemen har knappast bemötts</i>	<i>Problemen har inte bemötts</i>
F9. Har några praktiska frågor som uppkommit på grund av din sjukdom bemötts? (antingen ekonomiska eller personliga)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	<i>På egen hand</i>	<i>Med hjälp av en vän eller släkting</i>	<i>Med hjälp av vårdpersonal</i>
F10. Hur besvarade du detta frågeformulär?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Om du känner dig orolig över någon av frågorna som tagits upp i frågeformuläret, vänligen tala med din läkare eller sjuksköterska.

Patientens personnummer:

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IPOS Personalversion



www.pos-pal.org

Patientens namn:

Datum (dd/mm/åååå)

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F1. Vilka har patientens huvudsakliga problem eller bekymmer varit de senaste 3 dagarna?

1. _____
2. _____
3. _____

F2. Vänligen markera den ruta som bäst beskriver hur patienten har påverkats av nedanstående symtom de senaste 3 dagarna?

	<i>Inte alls</i>	<i>Lite</i>	<i>Måttligt</i>	<i>Mycket</i>	<i>Överväldigande</i>	<i>Kan inte bedömas (t.ex. medvetslös)</i>
Smärta	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andfåddhet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Svaghet eller brist på energi	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Illamående	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kräkningar	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Dålig aptit	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Förstoppning	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Ont eller torr i munnen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Dåsighet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Nedsatt rörlighet	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

Vänligen skriv ner eventuella andra symtom som inte nämns ovan och markera en ruta för att visa hur du upplever att dessa symtom har påverkat patienten de senaste 3 dagarna.

1. _____ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ ☐
2. _____ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ ☐
3. _____ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ ☐

Under de senaste 3 dagarna:

	<i>Nej, inte alls</i>	<i>Vid enstaka tillfällen</i>	<i>Ibland</i>	<i>Ofta</i>	<i>Ja, hela tiden</i>	<i>Kan inte bedömas (t.ex. medvetslös)</i>
F3. Har han/hon känt ångest eller oro över sin sjukdom eller behandling?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
F4. Har någon i hans/hennes familj eller vänskapskrets känt oro eller varit bekymrad för patienten?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
F5. Anser du att han/hon känt sig deprimerad?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

	<i>Ja, hela tiden</i>	<i>Ofta</i>	<i>Ibland</i>	<i>Vid enstaka tillfällen</i>	<i>Nej, inte alls</i>	<i>Kan inte bedömas (t.ex. medvetslös)</i>
F6. Anser du att han/hon känt sig tillfreds?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
F7. Har patienten i den utsträckning som han/hon önskat kunnat dela med sig av hur han/hon mår till sin familj eller sina vänner?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
F8. Har patienten fått så mycket information som han/hon önskat?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

	<i>Problemen har bemötts/ Inga problem</i>	<i>Problemen har mestadels bemötts</i>	<i>Problemen har delvis bemötts</i>	<i>Problemen har knappast bemötts</i>	<i>Problemen har inte bemötts</i>	<i>Kan inte bedömas (t.ex. medvetslös)</i>
F9. Har några praktiska frågor som uppkommit på grund av hans/hennes sjukdom bemötts? (antingen ekonomiska eller personliga)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>