Quality in palliative care from the patient perspective

Instrument development, perceptions of care received and the importance of care

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ABSTRACT

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The overall aim was to investigate the quality of palliative care from the patient perspective, to adapt and psychometrically evaluate the Quality from Patients' Perspective instrument specific to palliative care (QPP-PC) and investigate the relationship between the combination of person- and organization-related conditions and patients' perceptions of care quality.

Methods: In the systematic literature review (I), 23 studies from 6 databases and reference lists in 2014 were synthesized by integrative thematic analysis. The quantitative studies (II–IV) had cross-sectional designs including 191 patients (73% RR) from hospice inpatient care, hospice day care, palliative units in nursing homes and home care in 2013–2014. A modified version of QPP was used. Additionally, person- and organization-related conditions were assessed. Psychometric evaluation, descriptive and inferential statistics were used.

Main findings: Patients' preferences for palliative care included living a meaningful life and responsive healthcare personnel, care environment and organization of care (I). The QPP-PC was developed, comprising 12 factors (49 items), 3 single items and 4 dimensions: medical–technical competence, physical–technical conditions, identity–oriented approach, and socio-cultural atmosphere (II). QPP-PC measured patients' perceived reality (PR) and subjective importance (SI) of care quality. PR differed across settings, but SI did not (III). All settings exhibited areas of strength and for improvement (II, III). Person-related conditions seemed to be related to SI, and person- and organization-related conditions to PR, explaining 18–30 and 22-29% respectively of the variance (IV).

Conclusions: The patient perspective of care quality (SI and PR) should be integrated into daily care and improvement initiatives in palliative care. The QPP-PC can measure patients' perceptions of care quality. Registered nurses and other healthcare personnel need awareness of person- and organization-related conditions to provide high-quality person-centred care.

Key words: organization-related conditions, palliative care, patient perspective, person-related conditions, psychometric evaluation, quality of care, QPP-PC, systematic review.

SAMMENDRAG

Kvalitet i palliativ behandling og omsorg fra pasientens perspektiv
Instrumentutvikling, erfaringer med behandling og omsorg og betydningen av denne

Den overordnede hensikten var å undersøke kvalitet i palliativ behandling og omsorg fra pasientens perspektiv, å tilpasse og psykometrisk evaluere spørreskjemaet Kvalitet ut fra Pasientens Perspektiv (KUPP) for palliativ omsorg (KUPP-PO), samt å undersøke sammenhengen mellom person- og organisasjonsrelaterte forhold og pasientenes erfaringer av kvalitet.

Metode: I den systematiske oversiktsartikkelen (I) ble 23 studier fra seks databaser og referanselister syntetisert i 2014 med integrativ tematisk analyse. De kvantitative studiene (II-IV) hadde et tverrsnittsdesign som inkluderte 191 pasienter (svarprosent: 73) fra hospice-døgnavdeling, hospice-dagavdeling, lindrende enheter i sykehjem og hjemmetjeneste i 2013 til 2014. En modifisert versjon av KUPP ble brukt. I tillegg ble person- og organisasjonsorienterte forhold kartlagt. Deskriptiv og inferensiell statistikk, samt psykometrisk evaluering ble anvendt.

Hovedfunn: Pasientene ønsket at palliativ behandling og omsorg skulle omfatte hjelp til å leve et meningsfullt liv og at helsepersonell, omsorgsmiljø og organisering av omsorgen var lydhør for og handlet eller var tilrettelagt i samsvar med deres preferanser (I). KUPP-PO ble utviklet og omfattet 12 faktorer (49 spørsmål), 3 enkeltstående spørsmål og fire dimensjoner; medisinsk-teknisk kompetanse, fysisk-tekniske forhold, identitetsorientert tilnærmingsmåte og sosiokulturell atmosfære (II). KUPP-PO målte pasientenes erfaringer og subjektiv betydning av kvalitet. Pasientens erfaringer av kvaliteten med palliativ behandling og omsorg varierte utfra kontekst, men subjektiv betydning varierte ikke. Alle omsorgskontekstene viste styrker og forbedringsområder (II, III). Personrelaterte forhold så ut til å være forbundet med subjektiv betydning mens person- og organisasjonsorienterte forhold så ut til å være forbundet med erfaring med behandling og omsorg, og forklarte respektivt 18–30 and 22-29 % av variansen (IV).

Konklusjon: Kvalitet fra pasientens perspektiv (subjektiv betydning og erfaring) bør integreres i daglig behandling og omsorg og i forbedringstiltak i palliativ omsorg. KUPP-PO kan måle pasientenes erfaringer i kvalitetsutviklingsarbeid. Sykepleiere og annet helsepersonell trenger å være bevisst person- og organisasjonsrelaterte forhold for å utføre personsentrert behandling og omsorg av høy kvalitet.

Nøkkelord: organisasjonsrelaterte forhold, palliative behandling og omsorg, pasient perspektiv, personrelaterte forhold, psykometrisk evaluering, kvalitet, QPP-PC, systematisk oversikt.

'For i Sandhed at kunne hjælpe en Anden, maa jeg forstaae mere end han - men dog vel først og fremmest forstaae det, han forstaaer'.

Søren Kierkegaard 1859

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PAPERS I-IV

Abbreviations

ALS	Amyotrophic lateral sclerosis
ANCOVA	Analysis of covariance
COPD	Chronic obstructive pulmonary disease
EAPC	European Association for Palliative Care
ESAS	Edmonton Symptom Assessment System
EQ-VAS	EuroQol-Visual Analogue Scale
GP	General practitioner
HC	Home care
HDC	Hospice day care
HF	Heart failure
HIC	Hospice inpatient care
ID	Identity–oriented approach
MS	Multiple sclerosis
MT	Medical–technical competence
PCA	Principal component analysis
PCC	Person-centred care
PR	Perceived reality (care received)
PT	Physical–technical condition
PUNH	Palliative units in nursing homes
QPP	Quality from the Patient's Perspective
QPP-PC	Quality from the Patient's Perspective specific to palliative care
RN	Registered nurse
RRN	Registered nurse responsible for recruiting patients
SC	Socio-cultural atmosphere
SI	Subjective importance
SOC	Sense of coherence
WHO	World Health Organization

Original papers

This thesis is based on the following papers, which will be referred to by their Roman numerals:

I. Sandsdalen, T., Hov, R., Høye, S., Rystedt, I., & Wilde-Larsson, B. (2015). Patients' preferences in palliative care: A systematic mixed studies review. *Palliative Medicine, 29*(5), 399–419.

II. Sandsdalen, T., Rystedt, I., Grøndahl, V.A., Hov, R., Høye, S., Wilde-Larsson, B. (2015). Patients' perceptions of palliative care: adaptation of the Quality from the Patient's Perspective instrument for use in palliative care, and description of patients' perceptions of care received. *BMC Palliative Care*, (*14*)54.

III. Sandsdalen, T., Grøndahl, V.A., Hov, R., Høye, S., Rystedt, I., Wilde-Larsson, B. (2016). Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: a cross sectional study. *BMC Palliative Care (15)*79.

IV. Sandsdalen, T., Høye, S., Rystedt, I., Grøndahl, V.A., Hov, R., Wilde-Larsson, B. The relationships between the combination of person- and organization-related conditions and patients' perceptions of palliative care quality. In manuscript.

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Introduction

In developed countries more and more people are living longer, often with chronic illnesses and cancer over long periods of time (World Health Organization (WHO), 2004). Consequently, the number of patients with life-threatening illnesses who need palliative care will continue to increase.

Patients with life-threatening illnesses facing death may struggle with progressive losses, increased disability and often complex symptoms (Murray et al., 2002). As the illness gets worse, patients may need to put themselves in the hands of others (Ek, Sahlberg-Blom, Andershed, & Ternestedt, 2011; Murray et al., 2002). Feelings of social isolation and worries about how their family will cope with their illness and after their death (Murray et al., 2002) are common and existential issues may arise about the meaning of the past and the remaining life ahead (Ternestedt, Österlind, Henoch, & Andershed, 2012).

The provision of palliative care of high quality includes relieving the patients' 'total pain' and increasing their quality of life, founded on the holistic view that suffering is physical, psychosocial and spiritual (WHO, 2000;Clark, 1999). A multiprofessional approach is emphasized, within which registered nurses (RNs) have a crucial role, often being in close and continuous contact with patients.

Patients should be confident that, when faced with a life-threatening illness that needs palliative care, they will receive care according to their needs and that the care received is of high quality. However, patients have identified several areas for improvement of existing palliative care, e.g., symptom control, communication and shared decision-making (Bélanger, Rodríguez, & Groleau, 2011; Robinson, Gott, & Ingleton, 2013; Ventura, Burney, Brooker, Fletcher, & Ricciardelli, 2014). In particular challenges are related to the unequal care provided for patients without cancer (Brännström, Hägglund, Fürst, & Boman, 2011; Murray et al., 2002; Rocker, Dodek, & Heyland, 2008) and older people (WHO, 2011), and geographical differences with regard to accessing palliative care (Andershed, Ternestedt, & Håkanson, 2013). In addition, the policy of reducing hospital beds (Eurostat, 2015) and extending the care for palliative care patients, often with complex needs, in the community (Ministry of Health and Care Services, 2013) challenges the maintenance of care quality. This emphasizes that healthcare systems are in need of urgent and fundamental change for further development of palliative care to meet the needs of future patients and their families (European Association for Palliative Care (EAPC), 2009, 2010).

Healthcare services aim to provide high-quality care to all patients (Departement of Health, 2008b; Ministry of Health and Care Services, 2012). Patient preferences and perceptions of care are considered an important component for quality work by identifying potential areas for improvement and defining indicators for quality of health care (Crow et al., 2002; Ministry of Health and Care Services, 2012; Sofaer & Firminger, 2005; WHO, 2006). National health services are required to systematically collect patients' experiences of the care received (Departement of Health, 2008b; Ministry of Health and

Care Services, 2012). To guide such an assessment, an approach has been developed to measure patients' experiences according to; structure, process and outcome (Departement of Health, 2008a; Donabedian, 1966; Lindblom, 2013), and a theoretical framework concerning the concept 'quality of care from the patient perspective, and how to measure this, is available (Wilde, 1994; Wilde, Starrin, Larsson, & Larsson, 1993). However, these are not fully implemented in palliative care.

Inclusion of patients' perceptions about the quality of palliative care in research is still rare. The reason for this may be a result of methodological and ethical challenges regarding, for example, the vulnerability of the patients (Casarett & Karlawish, 2000), and difficulties in recruiting and identifying patients in a palliative phase of their illness (Hanson et al., 2014; Jordhøy et al., 1999; Van Mechelen et al., 2013). Therefore, patient preferences for and perceptions of quality of care have often been collected via patients' relatives and healthcare personnel. However, the patients' view may differ from the perceptions of relatives or healthcare personnel (Henoch, Lövgren, Wilde-Larsson, & Tishelman, 2011; Heyland et al., 2006; Sofaer & Firminger, 2005; Virdun, Luckett, Davidson, & Phillips, 2015; Wilde Larsson, Larsson, & Carlson, 2004).

In my work with patients with life-threatening illnesses in nursing homes, hospitals wards and intensive care units, and when teaching students about cancer nursing and intensive care nursing, I have been concerned with patients' opinions about the care and what is of importance to them. According to a nursing model of care (Ternestedt et al., 2012) and my personal beliefs, patients' perceptions of their situation and what is important to them should be the foundation of nursing care, and thereby the starting point for good care from the patient perspective. The intention of this thesis is therefore to increase the knowledge of and illuminate the patient's voice with regard to the patients' preferences for and experience of palliative care, and to include this further in quality work.

Background

Palliative care

Palliative care – concept and context

In developed countries the number of patients in need of palliative care will continue to increase because more people are living longer, often with complex needs as a consequence of chronic illness or cancer over long periods of time (EAPC, 2009; WHO, 2004). Each year, about 56 million people die worldwide, 5 million people in the EU and 40 000 in Norway (Clark & Graham, 2011; Eurostat, 2016; Folkehelseinstituttet, 2015). It has been described that around 60% of all these people could benefit from palliative care; however, only a small proportion of those in need receive such care (Clark & Graham, 2011). The challenges are especially related to patients with illnesses other than cancer (Clark & Graham, 2011; WHO, 2004), older people (WHO, 2011), and integration of palliative care earlier in the illness trajectory and more widely across all healthcare services (WHO, 2004). Last, the number of hospital beds has decreased (Eurostat, 2015) with an increase in patients with complex needs being cared for in the community e.g., in nursing homes or home-care (Ministry of Health and Care Services, 2013, 2015). This challenges the healthcare systems and services to develop palliative care and ensure its availability to all in need of such care.

Modern palliative care, developed by Balford Mount, from the hospice philosophy founded by Cicely Saunders aims to improve the quality of life for patients with life-threatening illnesses, meet individual needs, prevent and provide relief of physical, psychosocial and spiritual suffering, and care for patients' families (WHO, 2002). Based on the definition of palliative care (WHO, 2002), four cornerstones (Nationella rådet för Palliativ Vård, 2010) describe the content of good palliative care. These are symptom relief (holistic), communication and relationships to enhance quality of life, a multiprofessional team approach and support for relatives.

The concept of 'total pain' as a holistic approach to relieving patient's suffering has been a fundament in the development of hospice philosophy and palliative care (Clark, 1999). 'Total pain' comprises patient's pain being viewed as physical, physiological, social and spiritual, and in this way involves placing the whole patient at the centre of care (Strømskag, 2012). This in turn involves preserving the patient's identity and values, in a community with family, staff and other patients occupying a homely environment (Andershed et al., 2013; Clark, 1999; Husebø, 2014; Strømskag, 2012). Central to the hospice philosophy is that care for patients' 'total pain' should be founded on clinical practice, education and research (Strømskag, 2012).

Through the focused holistic, individualized, family and team view of care, palliative care incorporates principles of person-centred care (PCC), that involves acknowledgement of the individual patient being at the centre of care, being respectful of and responsive to patient's circumstances in life, life story, preferences, needs and values, and integrating knowledge of the patient and the competence of the healthcare personnel to give the best for the patient (Edvardsson, 2009; Institute of Medicine, 2001; Kvåle & Bondevik, 2008; Ternestedt et al., 2012). PCC was first developed in the care of patients with dementia

(Kitwood, Høeg, & Johnsen, 1999). Since then, PCC has been emphasized as an important area for improvement in all areas of health care (Institute of Medicine, 2001). More recently, models have been introduced to integrate PCC into nursing care (McCormack & McCance, 2006) and palliative care (Ternestedt, Andershed, Eriksson, & Johansson, 2002), and PCC interventions have been developed and assessed (Dwamena et al., 2012; McMillan et al., 2013). The terms 'patient centred' and 'person centred' have both been used frequently to describe the concept. Ekman et al. (2011) distinguish these terms as follows: the 'patient' objectifies the person as being a receiver of care and not an active partner. When the term 'patient' is used in palliative care and in this thesis, it involves the patient's rights and the obligations of the healthcare personnel when receiving and providing palliative care. However, this does not exclude the view that all patients are persons.

The target population of palliative care has changed within the WHO's definitions of palliative care. In 1990, the WHO (p. 11) defined palliative care as 'the active total care of patients whose disease is not responsive to curative treatment', with a focus on patients with cancer. Later, in 2002, patients facing physical, psychosocial, spiritual and existential problems associated with life-threatening illnesses and their families were defined as the patient population in need of palliative care (WHO, 2002). This is a wider definition initiating early integration of palliative care and not exclusively for patients with cancer. Included in this patient population are patients with advanced, incurable cancer and non-cancer illnesses (EAPC, 2009), e.g., advanced chronic obstructive pulmonary disease (COPD), heart failure, and neurological illnesses such as amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS) and Parkinson's disease. The development of palliative care as a discipline led to the integration of palliative care into earlier illness trajectories and for patients in different settings, compared with hospice care which mainly cared for people who were dying, often in voluntary free-standing facilities (Clark & Graham, 2011). However, the palliative care movement has been faced with the criticism of its strong focus on patients' diseases and symptom control and reducing the focus on essential hospice values (Strømskag, 2012). This focus on hospice values is therefore still relevant.

The European Association for Palliative Care (EAPC) (2009) distinguishes between two levels of palliative care: general or non-specialized and specialized palliative care. Non-specialized palliative care requires basic competence in palliative care and occasionally serves patients in the palliative phases of their illnesses, e.g., general hospital wards, nursing homes or home care. Specialized palliative care services have professionals with specialized training who often provide palliative care exclusively, with a multidisciplinary approach and mainly to patients with complex needs, e.g., palliative care units in hospitals, palliative care units in nursing homes, palliative care teams, hospice inpatient care or hospice day care. Hence, palliative care comprises different types of services, although the structure of these services may differ from one country to another (Centeno, Lynch, Donea, Rocafort, & Clark, 2013).

In Norway, palliative care is provided in primary or community care and specialist healthcare contexts (Norwegian Directorate of Health, 2015a). The responsibility for community care involves care for patients both in nursing homes and at home, via home

care or their general practitioner (GPs) (Kaasa, Jordhøy, & Haugen, 2007). The state is responsible for patients in specialist health care and serves patients in hospitals and specialist services, (Norwegian Directorate of Health, 2015a). Non-specialized palliative care (general palliative care) is an integrated part of the services in both specialist- and community care and, in addition, specialized palliative care services are offered within community care and specialist health care. Specialized palliative care within the specialist healthcare is provided through palliative centres, palliative units in hospitals and palliative care teams, and within the community, through palliative units or beds in nursing homes, and cancer nurses and/or coordinators in the community (Norwegian Directorate of Health, 2015a).

As part of the palliative care services, hospice services are organized within community care as palliative units in nursing homes, and within the specialist healthcare system as palliative care units, palliative care teams or day-care centres led by the hospitals. The understanding of what constitutes hospice care is not common (EAPC, 2009). Hospice care in some countries, e.g., the USA, means care for those agreeing to no curative treatment (Payne, Seymour, & Ingleton, 2008) whereas, in the Norwegian context, it equals palliative care, and may be provided at earlier stages, often parallel to active treatment organized (Norwegian Directorate of Health, 2015a, 2015b). Hospice care services can be described as specialized palliative care services using 'hospice' by name, indicating special dedication to the hospice philosophy and values (Norwegian Directorate of Health, 2015b).

Patients in palliative care

Patients with life-threatening illnesses who face death may suffer physically, psychosocially and spiritually (WHO, 2002). Patients have described experiences of progressive losses, increased disability, a struggle to cope with symptoms and uncertainties about prognosis (Murray et al., 2002). Increased disability can lead to a feeling of being controlled by a sick body, again causing frustration and tiredness, and restricting the opportunities to live a normal life (Ek et al., 2011). In addition, as the illness progresses, patients may experience progressive losses (Murray et al., 2002), and the balance between control of their own lives and putting themselves in the hands of others increases the importance of 'protecting significant values of identity' (Ek et al., 2011). The constant present of illness, and episodes of worsening illness are a persistent reminder of forthcoming death and can lead to feelings of fear (Ek et al., 2011; Murray et al., 2002). However, death can also be looked on as liberating (Socialstyrelsen, 2007). Patients may experience social isolation and worries about their family, how they would cope with their illness and after their death (Murray et al., 2002), but being with their families is experienced as of the utmost important (Socialstyrelsen, 2007). Existential issues may arise, but, additional to the suffering, patients may experience meaning and enjoyment in life (Socialstyrelsen, 2007).

Despite the definitions of palliative care made by the WHO and EAPC, there is no consensus about the definition of the patient population in palliative care (Van Mechelen et al., 2013). This makes it difficult to define the patient population in clinical practice as well as in research, and to know when, in the illness trajectory, patients are in need of

palliative care. For a better description to target the patient group and the timing of palliative care, initiatives have been made to describe palliative care in terms of phases and trajectories of patients' illnesses. The *early phase* comprises patients with incurable illnesses with a low symptom burden and active curative treatment and palliative care; the *late palliative phase* comprises patients with incurable illnesses and a life expectancy of less than a year, more progressive symptoms, and curative treatment may be offered together with palliative care; the *terminal phase* includes those for whom death is expected within days or weeks, curative treatment has been finished and palliative care is provided (Grov, 2014; Jarlbæk, Tellervo, & Timm, 2014). For better provision of high-quality palliative care, the Gold Standard Framework (GSF) developed three prognostic indicators for GPs to identify patients in the last year of life (12 months) (Thomas et al., 2011). These involved: (1) the surprise question 'Would you be surprised if this patient were to die within the next few months, weeks or days?', (2) general indicators of decline and (3) specific indicators related to certain conditions.

Patients' legal rights have strengthened the patient's position and voice in health care, and given patients the right by law to equal access to services of god quality (Ministry of Health and Care Services, 1999b). Within this the right to emergency, necessary and dignified health care, to have an individual care plan, and to receive information and participate in their care is highlighted. Despite all patients having equal rights to receive necessary care (Ministry of Health and Care Services, 1999b), most (95%) of those receiving specialized palliative care services have cancer (EAPC, 2009; Norwegian Directorate of Health, 2015a). Consequently, the care for patients with other life-threatening illnesses does not equal the care for patients with cancer (Brännström et al., 2011; Hyasat & Sriram, 2016; Murray et al., 2002). Unequal palliative care has also been described according to geography, age, gender, socioeconomic factors, physical or psychological disabilities, drug abuse, sexual orientation and cultural aspects (Andershed et al., 2013). Future palliative care has a responsibility to develop specialized services further to include all patients in need of such care and to ensure high-quality palliative care in non-specialized services.

Palliative care nursing

Historically and to the present day, registered nurses (RNs) have been engaged with, and played a central role in care for, patients with life-threatening illnesses (Henderson, 1997). Palliative care involves a multidisciplinary team-based approach that addresses patients' multidimensional needs in a holistic way (WHO, 2002), and this requires availability of competent healthcare personnel from multiple professions, e.g., RNs, physicians, physiotherapists, occupational therapists, nursing assistants, priests, social workers, nutritional physiologists (Norwegian Directorate of Health, 2015a). RNs play an important role in the multidisciplinary team due to their holistic approach to patients and of all professions they often have the closest and most continuous contact with the patients (Payne et al., 2008). In this thesis, the term 'nurse' is used to describe RNs.

Nursing care is regulated by ethical guidelines and legal legislation. Nurses' legal responsibilities include and highlight areas such as acting and caring according to competence, cooperation with other healthcare professionals, provision of information, duty of confidentiality and documentation of care (Ministry of Health and Care Services),

all of which are intended to ensure the care quality. The International Council of Nurses (ICN) (2012) states that the four fundamental responsibilities for nursing care are: to promote health, to prevent illness, to restore health and to alleviate suffering; in addition nurses are ethically responsible for promoting high-quality care and quality work is highlighted.

Akre (2014) argues that general nursing is equal to palliative care, in that the delivery of good nursing care is fundamental to the relief of suffering. Core competencies for nursing state that nurses should possess and deliver patient-centred care, work in interdisciplinary teams, emphasizing evidence-based practice, apply quality improvement and safety, and utilize informatics (American Association for Colleges of Nursing (AACN), 2012; Cronenwett et al., 2007). These competencies illuminate nurses' specific competence and responsibility to deliver person-centred care, including care according to patients' individual preferences and needs. According to these competencies, nurses are responsible for acquiring knowledge, skills and attitudes to monitor and continuously improve the care quality. However, nurses in home care and nursing homes often lack competence in caring for patients in need of palliative care (Haukelien, Vika, & Vardheim, 2015); the need for increased competencies to ensure high-quality palliative care based on changes in the palliative care population has been emphasized (Ministry of Health and Care Services, 2013).

Based on Weisman's six questions (as cited in Ternestedt et al., 2002, p. 154) for retrospective assessment of a good death, a person-centred nursing model for palliative care called 'The 6 S key words' was developed (Hermansson & Ternestedt, 2000; Ternestedt et al., 2002) to guide nurses in providing palliative care of high quality. The core intention of the model is to acknowledge the patient as a person with history and values, to allow patients to be involved in their care, and to incorporate the patient's situation and preferences as the starting point for care. The model concretizes the WHO definition of what constitutes good palliative care and includes the following care areas: self-image, symptom control, self-determination, social relationships, synthesis/coherence and choice of strategies. Of these, self-image is central and reflects the goal of care – to promote person-centred care. Symptom control reflects the physical aspects of care, self-determination reflects the psychological aspects of care and the need to be an active part of their care and social relationship reflects patients' social needs, whereas coherence and choice of strategies reflect spiritual and existential needs (Ternestedt et al., 2012). However, in clinical practice, these aspects influence each other and are connected as a whole. The model has been introduced and implemented in the Swedish palliative care context.

In summary, ethical guidelines, legal legislation and areas of competence concern nurses' specific responsibilities and competencies in providing palliative care of high quality. However, changes in the palliative care population challenge nurses further to develop their competencies. A model has been developed to guide high-quality palliative nursing care.

Quality of palliative care

Quality of care in general

The National Academy, Institute of Medicine (2001) in the USA, states that health care too frequently causes harm and fails to be beneficial for patients, arguing that the healthcare systems are in need of urgent and fundamental change. The WHO (2006) considers the care quality to be a serious concern even in well-developed healthcare systems, especially related to wide variance in care delivered within and between healthcare systems. The importance of high-quality care, more knowledge about quality in health care and building systems to systematically monitor patients' evaluation of the care has been emphasized in a report from the Norwegian Ministry of Health and Care Services (2012).

According to the Institute of Medicine (2001, pp. 5-6), quality of care can be considered within six dimensions:

- Safe – avoiding injuries to patients from the care that is intended to help them.
- Effective – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
- Patient-centred – providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- Timely – reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Efficient – avoiding waste, including waste of equipment, supplies, ideas, and energy.
- Equitable – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

These dimensions have been adapted by the WHO (2006), as well as the Norwegian government (Norwegian Directorate of Health, 2005), as definitions of quality of care. They have led to the development of the nursing competencies previously presented, to deliver nursing care of high quality and to have knowledge, skills and attitudes for a systematic and continuous improvement in the quality of work (AACN, 2012; Cronenwett et al., 2007). In the Norwegian strategy for improving the quality of care (Norwegian Directorate of Health, 2005), patient-centred care includes involving patients in both planning and development of care services, as well as in the provision of care, based on patients' experiences and points of view. In addition, systematic assessment of patients' experiences of care quality should be used for quality improvement initiatives.

Donabedian (1966), as one of the leading developers of the concept and provider of quality-of-care research, identified three indicators of quality of care: structure, process and outcome. Structure includes the physical environment and resources, e.g., provider qualifications and equipment, and administration of care. Process refers to the performance of the care related to the consequences for the patient, the interpersonal

interactions, e.g., information, procedures, empathy and competence. Assessment of outcome includes the results of the process measured by changes in the patient's condition.

Quality of care is considered to be a multidimensional concept (Crow et al., 2002). The meaning of what constitutes quality of care may differ according to time and cultures, whether it is at an individual, organizational or societal level, and who defines the concept: patients, relatives, healthcare personnel, leaders, policy-makers or researchers (Donabedian, 1980; Wilde, 1994). This thesis focuses further on patients' perceptions of care quality.

Quality of palliative care from the patient perspective and Theoretical framework for this thesis

Patients' preferences and perceptions of care are considered to be important components for quality work, through identification of potential areas for improvement and defining indicators of quality of health care (Crow et al., 2002; Ministry of Health and Care Services, 2012; Sofaer & Firminger, 2005; WHO, 2006).

According to Donabedian (1980), quality of care from the patient perspective involved the quality of technical care, interpersonal care and amenities in the care environment. More recently, a review by Sofaer and Firminger (2005) to determine patients' own definition of quality of care found that the categories defining quality of care were: patient-centred care, access, communication and information, courtesy and emotional support, efficiency of care/effective organization, technical quality, and structure and facilities. These dimensions of care quality comprise new aspects of care quality; however, the component referred to by Donabedian still seems to be relevant.

The terms 'patient's perception of quality of care' and 'patient satisfaction' are often used as equivalent, but the literature distinguishes between the two concepts. Although no common conceptual definition exists, satisfaction is often described as the fulfilment of expectations, needs or desires (Crow et al., 2002) or the difference between patient expectations and experience of care (Sofaer & Firminger, 2005). Larsson and Wilde-Larsson (2010) distinguish between these two terms and viewing patient satisfaction as an emotion. However, Crow et al. (2002) stated that the limitations of assessing quality of care through patient satisfaction are that satisfaction indicates adequate or acceptable care, not excellent care, and that satisfaction is a relative concept, meaning that what satisfies one patient may not satisfy another. Therefore, the trend has moved towards assessing patients' perceptions of their experience of the care quality, related to multidimensional aspects of the care given. To capture patients' perceptions of the care quality, it is important to ask questions about aspects of care important to the patient (Lindblom, 2013). The patient perception of quality of care may be described by what patients perceive as important about their care – their preferences – and how they perceive their experience of the care – their evaluation of the care received (Donabedian, 1980).

Theoretical framework

The theoretical framework on which this thesis is based is the model of quality from the patient perspective developed by Wilde and colleagues (Wilde, 1994; Wilde et al., 1993). The theoretical model was developed by interviews, with patients admitted to hospital, about issues of importance and the care received, using a grounded theory (Wilde et al., 1993). The model is based on the care quality being formed through patient preferences, norms, expectations and experience, and on the encounter with a care structure. From this, care quality can be seen as patients' perceptions of the actual care received (the perceived reality [PR]) and perceptions of how important the various care aspects are to them (the subjective importance of the care aspects [SI]) (Wilde, Larsson, Larsson, & Starrin, 1994).

The model is presented in Figure 1 and comprises two conditions upon which quality of care is built: 'the patients' preferences' and 'the resource structure of the care organizations'. The patients' preferences comprise two aspects: a rational aspect, which refers to the patient's strive for order, predictability and calculability in life, and a human aspect in which patients expect their unique situation to be taken into account. The resource structure of the care organization also consists of two conditions: person-related qualities that refer to the caregivers (nurses, physicians and other healthcare personnel), and physical and administrative environmental qualities that refer to the infrastructural components of the care environment, e.g., organizational rules and technical equipment. Within this theoretical framework, patients' perceptions of quality of care may be considered in the following four dimensions: the medical–technical competence of the caregivers, the physical–technical conditions of the care organization, the identity–oriented approach of the caregivers, and the socio-cultural atmosphere of the care organization (Wilde et al., 1993).

		The resource structure of the care organization	
		Person-related qualities	*Qualities related to the physical and administrative care environment*
The patient's preferences	*Rationality*	Medical–technical competence	Physical–technical conditions
	Humanity	Identity–oriented approach	Socio-cultural atmosphere

Figure 1 Theoretical model of quality of care from the patients' perspective (Wilde, et al., 1993). (Reproduced with permission from John Wiley & Sons.)

The instrument, the Quality from the Patient's Perspective (QPP) (Wilde et al., 1994; Wilde Larsson & Larsson, 2002), was later developed and refined from the theoretical model, reflecting the multidimensional aspects of the care by incorporating the four dimensions of care quality displayed in Figure 1. The QPP measures both the subjective importance (SI) and the perceived reality (PR) of care received.

The model of care quality, describes the patient definition of the quality of care, and shows similar aspects of care as the descriptions of Donabedian (1980) and Sofaer and Firminger (2005). Where the satisfaction definition, described above, includes experiences of care and expectations of care – what patients *expect the care to be* – the model of Wilde et al. differs from satisfaction in that quality comprises both patients' experiences of actual care and what they *want the care to be* in terms of what they consider important (Wilde et al. 1993;Wilde, 1994). In addition, the model of care quality has not been specifically developed in the palliative care setting. Reviewing the palliative care model developed by Ternestedt et al. (2012) and the model of quality of care developed by Wilde et al. (1994; 1993) overall similarities may be found in that both models are based on a person-centred approach to care. At the aspects level, similarities are especially related to, for example: medical–technical competence which includes physical care and symptom relief; identity–oriented approach of the caregiver, which includes aspects with regard to self-determination; and socio-cultural atmosphere, which includes aspects of social relationships.

According to the model of quality of care (Wilde, 1994; Wilde et al., 1993), patients' perceptions of care quality comprises both patients' perceptions of SI and perceptions of PR. Research into patients' perceptions of care quality will be presented according to SI and PR.

Patients' perceptions of subjective importance of quality in palliative care

Earlier reviews on patients' perceptions of quality of care reflects care areas of subjective importance, and their preferences (Petersen, Knudsen, & Vinter, 2015; Sofaer & Firminger, 2005). However, these were not based on perceptions of patients in a palliative care context. There are a few reviews that have investigated care areas of importance to patients in palliative care contexts. Virdun et al. (2015) aimed to find the five most important aspects of care for patients and families. These were: effective communication and shared decision-making; expert care; respectful and compassionate care, and trust and confidence in clinicians; an adequate environment for care; and minimization of the burden to patients. Two reviews, which focused specifically on the environment for older patients in palliative phases and their families in hospitals and hospice-like settings, highlighted patients' preferences for a home-like environment, close to the family and nature, and providing privacy when needed (Brereton et al., 2012; Rigby, Payne, & Froggatt, 2010). Preferences for shared decision-making (Bélanger et al., 2011), a patient-centred approach to care (Bradley, Frizelle, & Johnson, 2011) and dying at home or in hospice inpatient care (Higginson & Sen-Gupta, 2000) have been found to be important for patients in a palliative phase.

Primary studies not included in the reviews have shown patient preferences for palliative care similar to the preferences presented in the review. However, a few new aspect were present and related to: receiving adequate symptom relief, avoiding inappropriate prolongation of dying, achieving a sense of control, strengthening the relationship with loved ones (Singer, Martin, & Kelner, 1999), feeling safe with regards to continuity of care (Werkander Harstäde & Andershed, 2004), being recognized as a person and being

spiritual connected (Strohbuecker, Eisenmann, Galushko, Montag, & Voltz, 2011). In the Norwegian context, a study from the nursing home context (not specifically palliative care), focusing on interpersonal aspects of care, supported the above findings that patients had preferences for an individual approach, in addition to the need for general and specialized care, health promotion and prevention of complications being highlighted (Nakrem, Vinsnes, & Seim, 2011).

To sum up, internationally, several studies have investigated patient preferences and perceptions of subjectively important areas of palliative care. However, studies in the Norwegian context from different palliative settings of care are few. Such studies could inform further development of palliative care. Previous reviews of patient preferences for palliative care have focused on specific areas, including psychosocial support, the care environment, decision-making, place of care and specific settings. There is a need for synthesizing existing research about patient preferences for the combined repertoire of palliative care.

Patients' perceptions of perceived reality of quality in palliative care

Reviews have been found that evaluate patient perceptions of palliative care received. Ventura et al. (2014) investigated unmet needs of patients in home-care settings and found a need for more effective communication from healthcare professionals. Physical care needs were perceived to be met, but spiritual, psychosocial, practical, informational and respite needs, and needs associated with isolation and loss of autonomy, were not met. In addition, Robinson et al. (2013) found that palliative care provided in hospital delivered poor management of symptoms and offered an inappropriate environment, being too busy and noisy. Patients attending palliative day care centres, however, perceived the environment to be restorative and appreciated the support and engagement with others (Stevens, Martin, & White, 2010). With regard to shared decision-making, a review found that most patients did not experience being included according to their preferences (Bélanger et al., 2011).

Several primary studies have investigated patients' perceptions of the care received by patients who are in the palliative phase (Giles & Miyasaki, 2009; Hanratty et al., 2013; Murray et al., 2002; Spichiger, 2010; Strohbuecker et al., 2011). These show similar results and support the findings above. Internationally, a need for more studies from the patient perspective and from a variety of services has been described, especially from hospice settings and studies including patients with diagnoses other than cancer (Addington-Hall & O'Callaghan, 2009; Candy, Holman, Leurent, Davis, & Jones, 2011; Dy et al., 2012; Socialstyrelsen, 2007). In the Norwegian context, a national survey of perceptions of care by patients with cancer has been performed, but patients in the palliative phases have been excluded (Kunnskapssenteret, 2010). Studies have been performed from the perspectives of relatives (Ringdal, Jordhøy, & Kaasa, 2002), nurses, physicians and leaders (Melby, Das, Halvorsen, & Steihaug, 2016). The need for knowledge on patients' perceptions of palliative care has been highlighted (Melby et al., 2016; Norwegian Directorate of Health, 2015b), especially within community care services, including home care and nursing homes (including palliative units in nursing homes) (Norwegian Directorate of Health, 2015b).

To conclude, studies about patients' perceptions of palliative care received are needed, especially from the hospice setting, from community care services and including patients with diagnoses other than cancer.

Patients' perceptions of subjective importance and perceived reality
Studies comparing patients' perceptions of important aspects of care, with the care actually received are sparse. Such studies can identify areas of strength and improvement, and thereby guide further development of specific settings. Three papers (Heyland et al., 2010a; Rocker et al., 2008; Strachan, Ross, Rocker, Dodek, & Heyland, 2009), all from Canada, have highlighted areas for improvement in palliative care including: symptom relief, psychological and spiritual support, enhanced relationships with physicians, participation in decision-making, honest communication, planning, cooperation and continuity of care, reduced family burden, and not being kept alive when there is little hope of a meaningful recovery.

In summary, previous research has commonly compared patients' views about important aspects of care and the care received (Heyland et al., 2010a; Rocker et al., 2008; Strachan et al., 2009), but not within different contexts of care; or investigating care quality within specific settings (Hopkinson & Hallett, 2001; Spichiger, 2009; Strohbuecker et al., 2011), and not including comparison of patients' perceptions of subjective importance and actual care received.

Conditions related to patients' perceptions of care quality
Conditions that may be related to patients' perceptions of care quality can be classified into two areas: person- and organization-related conditions. It may not be possible to alter person-related conditions, but it is important to investigate them to target patients at risk of negative experiences of care quality, and to individualize care. Second, it is useful to adjust for person-related conditions that influence care quality when comparing patients' perceptions of care quality across settings. Investigation of influencing organization-related conditions is relevant and important for healthcare providers to use the knowledge in quality work, by, for example, targeting conditions that influence patients' perceptions negatively, and to develop further and implement the conditions with a positive influence. Based on the theoretical framework (Wilde, 1994; Wilde et al., 1993), previous research is presented according to SI and PR which constitute the quality of care – first, for person-related conditions, then for organization-related conditions, and last for a combination of these conditions.

Person-related conditions
Person-related conditions comprise patient characteristics related to sociodemographic information (e.g., age, education, living conditions) and health information (e.g., diagnosis, quality of life). One study from the palliative care context found that the *subjective importance (SI)* differed according to diagnosis, where patients with COPD preferred a lower level of advanced care than cancer patients (Rocker et al., 2008). From settings that are not specifically palliative contexts, the subjective importance tends to be rated higher by women than by men (Henoch et al., 2011; Wilde Larsson, Larsson, Chantereau, & von Holstein, 2005). However, the association between person-related conditions and SI

seems to be conflicting or uncertain due to the small number of studies available with regard to age (Henoch et al., 2011; Wilde-Larsson, Larsson, Kvist, & Sandin-Bojö, 2010; Wilde Larsson, 1999), patients' health condition (including psychological wellbeing and physical health) (Henoch et al., 2011; Wilde Larsson et al., 2005) and patients' sense of coherence (SOC) (Wilde Larsson & Larsson, 1999) as shown in the following studies:
How patient age is related to SI seems to vary, as some studies found no relationships (Henoch et al., 2011; Wilde Larsson, 1999), whereas in other studies and care contexts the results show that younger patients rated the importance higher (Wilde-Larsson et al., 2010) and yet another found that elderly patients scored more areas higher (Wilde Larsson et al., 2005). Patients' health condition, including both physical health and mental health, has been found to have no statistically significant relationships with patients' perceptions of SI (Henoch et al., 2011). However, another study found that patients' psychological wellbeing showed positive correlations with SI (Wilde Larsson et al., 2005). Patients' SOC has previously been shown to be weakly related to the SI (Wilde Larsson & Larsson, 1999).

Although living conditions (e.g., living alone) (Ek et al., 2011; Hanratty et al., 2013), contact with family and friends (Singer et al., 1999; Strohbuecker et al., 2011), quality of life (WHO, 2002), and existential or religious issues (Miccinesi, Bianchi, Brunelli, & Borreani, 2012) have all been found to be important for patients in palliative care, the relationship between patients' perceptions of SI of these aspects has not been established. This is also the case for conditions of education and multiple medical conditions.

To sum up, relatively few studies have investigated the association between patients' perceptions of SI and person-related conditions, especially in the palliative care context, and the relationships are uncertain.

Several studies have investigated the relationship between person-related conditions and patients' *perceptions of care received (PR)*. Studies specifically from the palliative care context have shown that low levels of education (Hannon et al., 2013), a cancer diagnosis (compared with non-malignant illnesses) (Brännström et al., 2011; Murray et al., 2002; Rocker et al., 2008) and multiple medical conditions (multiple diagnosis)(Higashi et al., 2007; Min et al., 2005) are associated with higher scores of perceived actual care. Although some studies have found conflicting results (Min et al., 2005; Miyashita et al., 2014), this is in line with studies from other care contexts and patients who are not specifically in a palliative phase (Crow et al., 2002; Danielsen, Garratt, Bjertnæs, & Pettersen, 2007; Findik, Unsar, & Sut, 2010; Grøndahl, Karlsson, Hall-Lord, Appelgren, & Wilde-Larsson, 2011; Sofaer & Firminger, 2005; Wilde Larsson, 1999; Wilde Larsson et al., 2005).

Studies including participants not specifically in a palliative care context found that patients who were older (Danielsen et al., 2007; Grøndahl et al., 2011; Henoch et al., 2011; Péfoyo & Wodchis, 2013; Thi, Briancon, Empereur, & Guillemin, 2002; Wilde Larsson, 1999), and had a high level of psychological wellbeing (Henoch et al., 2011), a high SOC (Wilde Larsson & Larsson, 1999) and a religious affiliation, seemed to be associated with higher scores on care quality received (Benjamins, 2006).

The association between person-related conditions and actual care received seems to be conflicting in the areas of gender (Crow et al., 2002; Findik et al., 2010; Grøndahl et al., 2011; Henoch et al., 2011; Wilde Larsson et al., 2005), quality of life (Hannon et al., 2013; Miyashita et al., 2014), physical health (Danielsen et al., 2007; Henoch et al., 2011; Törnkvist, Gardulf, & Strender, 2000) and time in care (Findik et al., 2010; Péfoyo & Wodchis, 2013). For example, studies have found that gender had no influence on patients' perceptions of care (Henoch et al., 2011; Thi et al., 2002), whereas other studies showed that women rated care received higher than men for certain parts of the care (Grøndahl et al., 2011; Wilde Larsson et al., 2005), although yet another study found that men rated the care higher than women (Findik et al., 2010). Better quality of life has, in studies from palliative care contexts, been associated with higher perceptions of care received (Hannon et al., 2013), in contrast to no correlation in another study (Miyashita et al., 2014). The physical health of the patients has been shown to have a significant positive association with experiences of care received (Danielsen et al., 2007; Törnkvist et al., 2000), although another study found no statistically significant relationships for the perceived reality (Henoch et al., 2011). With regard to patients' experiences with time in care, one study showed that patients who had been hospitalized for long periods of time rated the care received higher (Findik et al., 2010), in contrast to another study in which there was a decreased perception of care received with each additional day in hospital (Péfoyo & Wodchis, 2013).

It is known that patients with life-threatening illnesses who live alone may experience the care differently from those living with someone (Ek et al., 2011; Hanratty et al., 2013), however, little is known about whether and how living alone are associated with patients' perceptions of care received. In addition, contact with family or friends have been found to be important to patients in the late palliative phase of their illness (Singer et al., 1999; Strohbuecker et al., 2011). Further research seems to be needed with regard to how the amount of contact with families and friends and how is associated with perceptions of care received.

To conclude, relatively few studies have been found within the palliative care context with regard to how patients' perceptions of PR are related to person-related conditions.

Organization-related conditions

Organization-related conditions relevant to palliative care comprise characteristics of the settings, such as type of setting, number of staff, staff competence, models of nursing care and medical care, availability of multiprofessional staff, systematic assessment and documentation of patient information, and use of theoretical frameworks for the delivery of palliative care. Studies investigating the relationship between organization-related conditions and *subjective importance* have not been found.

Patients' perceptions of *perceived reality* have previously been shown to be associated with ward characteristics such as number of nurses or staff (Aiken, Clarke, & Sloane, 2002; Grøndahl et al., 2011; Kirkevold & Engedal, 2006) and are associated with actual care from the patient and healthcare personnel perspectives. However, the results about the number of staff in the different studies are conflicting. The number of staff had positive relationships with the care quality in two of the studies (Aiken et al., 2002; Kirkevold &

Engedal, 2006), whereas Grøndahl et al. (2011) found that the care received with regard to the sociocultural atmosphere was rated more negatively when the number of nurses on the wards was higher and over-occupancy of the wards more frequent. These studies were from hospital and nursing home settings and did not specifically include patients in palliative phase.

Different models of organization of nursing care and actual care received have been investigated in two studies from a general hospital setting. The results showed that nursing care organized as team nursing or primary nursing did not affect the perception of care received (Sjetne, Veenstra, Ellefsen, & Stavem, 2009; Wu, Courtney, & Berger, 2000). In the palliative care context continuity of care is of the utmost importance to patients (Waibel, Henao, Aller, Vargas, & Vázquez, 2011). Further knowledge of how the organization of nursing care and physicians' medical care affects patients' perceptions of care received, e.g., perceptions of continuity of care, is needed in a palliative care context.

The competence of nurses and physicians (Aiken et al., 2014; Engelberg et al., 2010) seems to have an impact on patients' perceptions of care quality received. Engelberg et al. (2010) found that physicians' knowledge of palliative care was associated with better patient perceptions of the care received. Aiken et al. (2014) found that a higher number of nurses with a bachelor degree and a lower workload were associated with a decreased mortality among patients in hospital. Additionally, in palliative care, competent healthcare personnel from multiple professions should be available, e.g., nurses, physicians, physiotherapists, occupational therapists, nursing assistants, priests, social workers, nutritional physiologists (WHO, 2002; Norwegian Directorate of Health, 2015a). Patients' perceptions of importance of multiprofessional palliative care has been established (Virdun et al., 2015), but how their availability relates to patients' perceptions of care quality received is not known.

A lower symptom burden has been found to be associated with higher care quality for patients with advanced incurable illness (Engelberg et al., 2010). The use of systematic symptom assessment and documentation may be seen as an important component for managing high-quality symptom control (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). Systematic documentation of patient information, in general (e.g., individual care plan, patient care records), and assessment tools for systematic assessment and documentation of specific areas, e.g., symptoms (Edmonton Symptom Assessment Scale [ESAS]), are necessary to guide care of high quality (Institute of Medicine, 2001; Norwegian Directorate of Health, 2015a). Studies have found that documentation and communication of patient information seem to affect care quality (Chaudhry et al., 2006; Kripalani et al., 2007), but these studies were not specifically from the palliative care context.

Person-centred care (PCC) has been established as an important part of quality of care (Institute of Medicine, 2001). In the palliative care context, a person-centred model of palliative nursing care (Ternestedt et al., 2002) was developed based on the hospice philosophy of care by enhancing care quality. Based on this, it is interesting to investigate whether the use of frameworks, such as PCC or hospice philosophy of care, is associated with patients' perceptions of care quality. The effect of PCC in relation to perceived

quality of care has been explored in two reviews: one concerning PCC for chronically ill patients (McMillan et al., 2013) and one about the consultation process in different settings, not exclusively palliative care (Dwamena et al., 2012). PCC seemed to be beneficially related to perceived quality of care received, but the results were equivocal, and more studies are needed to support or reject the findings (Dwamena et al., 2012).
In summary, even if the organization-related conditions are relevant in palliative care, the studies found are rarely in a palliative care context. More studies seem to be needed for both SI and PR, so that the results can be used further in quality improvement work.

*Patients' perceptions of care quality according to settings of palliative care***.** Patients in the late palliative phase may be admitted to different kinds of care settings, specialized or non-specialized, i.e. hospital wards, nursing home or home care. In addition, patients may receive care from multiple services at the same time, i.e. patients receiving home care might also receive care from physicians (GP), hospital services and day-care services. Whether and how the settings influence patients' perceptions of quality of care are not clear.

Some review studies have been conducted to investigate the effect of various palliative care programmes provided in different settings, often compared with non-specialized care for patients in the palliative phase. Zimmermann, Riechelmann, Krzyzanowska, Rodin, and Tannock (2008) investigated the effect of specialized palliative care and found that the evidence was sparse; however, it seemed that family perception of quality of care improved with specialized palliative care. This was supported by Dy et al. (2012) who found that the quality of care was rated more favourably by patients and caregivers receiving specialized palliative care interventions with regard to continuity, coordination and transitions. However, the study concluded that few studies have been conducted in the hospice setting (Dy et al., 2012). Candy et al. (2011) aimed to investigate hospice care in several settings and found that hospice care (specialized palliative care) at home and hospice inpatient care increased patient and family perceptions of care quality, whereas more studies are needed from nursing homes that provide specialized palliative care. Primary studies investigating day care found that palliative day care settings were associated with patients who were perceived to have positive psychosocial experiences (Bradley et al., 2011).

There are two studies that compare family perceptions of quality of care between hospice and hospital care (Addington-Hall & O'Callaghan, 2009), and across home care, long-term care, hospital and hospital-based palliative care units (Burge et al., 2014). The results of the two studies differed. Addington-Hall and O'Callaghan (2009) found that hospices gained favourable results with regard to, for example, pain control, communication, personal care and dignity, whereas Burge et al. (2014) found that none of the included contexts differed exceptionally. In the Norwegian context, a cluster randomized study has been conducted to assess the effect of a palliative care inpatient and outpatient programme; it found favourable results with regard to home deaths for the palliative care intervention compared with usual care (Jordhøy et al., 2000). Perceptions of care received were not included as an outcome in this study.

To sum up, it seems that more studies are needed to investigate the association between patient perceptions of quality of care and settings, especially for the hospice setting and the specialized nursing home setting, and from the patient perspective. In the Norwegian context, studies seem to be needed from all palliative care settings (Norwegian Directorate of Health, 2015b).

Combination of person- and organization-related conditions

Investigation of the relationship between the combination of person- and organization-related factors and patients' perceptions of SI and PR can contribute to knowledge reflecting the complexity of clinical practice, and enhance individualized care. None of the studies found has investigated the relationship between the combination of person- and organization-related conditions and patients' perceptions of *subjective importance*, in either palliative care or other care settings.

Previous studies found that the combination of person- and organization-related conditions related to *perceived reality* with regard to person-related conditions (e.g., age, gender, time in care and health condition) was the strongest predictor of quality of care received from the patient perspective, and to a smaller degree organization-related conditions (e.g., choice of hospital, size of hospital, lengths of stay) were associated with the quality of care received (Péfoyo & Wodchis, 2013; Thi et al., 2002). Grøndahl et al. (2011) found that the person-related conditions, age, gender and psychological wellbeing, and the organization-related conditions, frequency of over-occupancy and RN headcount were predictors of patients' perceptions of care received in Norwegian hospitals. From the nursing home context, the person-related condition associated with mental capacity, activities of daily living and aggressive behaviour, and the organization-related conditions with regard to type of ward, size of ward and staff to beds ratio influenced the care quality measured from the perspective of the nursing staff (Kirkevold & Engedal, 2006). These studies were not performed explicitly in palliative care settings or with patients in the late palliative phase. More studies seem to be needed that combine person- and organisation-related conditions when investigating their relationship with the patient perspective of palliative care quality.

In summary, studies that have previously investigated the relationship between perceptions of care quality and person- and organisation-related conditions are often conducted in settings other than palliative care and have investigated perceptions of care received. Relatively few studies have explored the relationship between conditions and patients' perceptions of the subjective importance of care aspects.

Instruments to measure quality of care from the patient perspective

The inclusion of patients' perceptions of their care in service evaluations has been prominent for the last four decades. And the importance of patients' opinions has been connected to the person-centred approach, including patients' own experiences, preferences, needs and values being the primary focus of care and the base on which high-quality care is built and is therefore meaningful, and patients' perceptions being a powerful motivator for healthcare outcomes and treatment evaluations (Crow et al., 2002; Institute of Medicine, 2001; Sofaer & Firminger, 2005). However, the criticism has been raised whether to trust patients' evaluations of their own care. Such criticism has been, for example, whether patients have sufficient knowledge to evaluate a physician's level of competence, the subjective nature of patients' perceptions, and whether the instrument used to measure patients' perceptions of their care yields a valid result (Crow et al., 2002; Sitzia, 1999; Sofaer & Firminger, 2005). Even if patients lack knowledge in certain care areas, knowledge of what is important to them and whether this has been achieved are comprehensible to most patients. But this also promotes the importance of patient education to enhance the evaluation of the care quality. Patients' perceptions of quality of care merely reflect patients' perceptions of actual care, not necessarily what has actually happened (Wilde, 1994), and this is important to consider when interpreting the results of patients' evaluations. Last, the criticism raised about instruments used promotes the use of valid instruments when measuring patients' perceptions of the care quality.

In palliative care research, inclusion of the patient perspective on the care quality is still rare due to methodological and ethical challenges, e.g., the vulnerability of the patients and difficulties in obtaining informed consent (Casarett & Karlawish, 2000). Healthcare personnel or family members have therefore often been used as proxies to investigate patients' perceptions of care quality. This enhances the opportunity to include the views of patients who cannot communicate their perceptions of care quality due to advanced illness. However, uncertainties may arise about congruence between patient and proxy perceptions. Studies have shown that the perceptions by relatives or healthcare professionals of patients' experience of care may differ from patients' perceptions (Sofaer & Firminger, 2005), and similarly in palliative care (Heyland et al., 2006; Virdun et al., 2015; Wilde Larsson et al., 2004). Nurses tend to overestimate the importance of psychological aspects and their competence, and underestimate the importance of their skills, provision of equipment and access to care. Physicians seem to underestimate the importance of information and provision of care, whereas performance with regard to access by phone and waiting times was overestimated (Sofaer & Firminger, 2005). Previous studies have shown that relatives and patients have mainly congruent views about their care. However, subjective aspects of patients' experience may differ, such as pain, anxiety, depression and perceptions of the importance of care aspects (Henoch et al., 2011; McPherson & Addington-Hall, 2003; Wilde Larsson et al., 2004), especially when patients and relatives do not have daily contact (Wilde Larsson et al., 2004). Relatives tended to rate the SI of socio-cultural aspects (Henoch et al., 2011; Virdun et al., 2015) and medical–technical competence higher than the patients (Wilde Larsson et al., 2004)

Patients are experts in their opinions about the care they receive. The differences across the opinions of patients, relatives and professionals highlight the importance of including the patient being in the palliative phase of illness, to gain first-hand information of the palliative care experience. Measures of quality of care from the patient perspective can be classified within the terms 'Patient Reported Outcome Measure' (PROM), which includes measures of patient experience of care results – the outcome, in terms of changes in, for example, health status or health-related quality of life due to the delivery of healthcare. 'Patient Reported Experience Measure' (PREM), includes assessment of patients' experiences and perceptions of care in terms of structure, process, and the outcome (Lindblom, 2013). Measures within the PREM and PROM classification have been developed to systematically evaluate health care in general and have recently been introduced into palliative care (Bausewein et al., 2016; Black, 2013; Departement of Health, 2008a; Lindblom, 2013). The definitions of PROM and PREM are not clear and overlap (Lindblom, 2013). In this thesis, instruments related to both PREM (QPP) and PROM (EQ-5D-3L) have been used, but the PROM measures have been included for the purpose of investigating the influence of conditions on patients' perceptions of care quality.

Validated instruments for measuring patients' experiences of quality of care are available. The Patient Experiences Questionnaire (PEQ) (Pettersen, Veenstra, Guldvog, & Kolstad, 2004) comprises 35 items developed to measure patient experiences of hospital care, based on a literature review of relevant items and dimensions, and involvement of the patients. The instrument is frequently used in the Norwegian context at a national level. The eight-item NORPEQ patient experiences questionnaire (Oltedal et al., 2007) was later developed to compare patient experiences of hospital care within the Nordic countries. These instruments were based on a questionnaire commonly used in the Nordic countries.

Previously validated instruments used to measure patients' experience of quality in palliative care have often been developed to measure the perspectives of the relatives, e.g., FAMCARE (Kristjanson, 1993), Views of Informal Carers – Evaluation of Services (VOICES) (Addington-Hall, Walker, Jones, Karlsen, & McCarthy, 1998) and Care Evaluation Scale (CES) (Morita et al., 2004). Some of these instruments have been modified to measure the patient perspective of care (Lo, Burman, Hales, et al., 2009; Lo, Burman, Rodin, & Zimmermann, 2009; Miyashita et al., 2014). However, instruments developed to measure the patient perspective are available, e.g., the Canadian Health Care Evaluation Project (CANHELP), which measures quality related to patients' experience and the importance of various aspects of palliative care (Heyland et al., 2010b), the Quality of end-of-life care (QEOLC) (Engelberg et al., 2010), and the Quality of end-of-life care and satisfaction with treatment quality-of-care scale (QUEST) (Sulmasy, McIlvane, Pasley, & Rahn, 2002). The last two measure specific areas of palliative care received: physicians' skills and interaction with healthcare personnel.

The importance of instruments with a foundation on a theoretical model of care quality, based on the patient perspective and conceptions of the area, can be found in the literature (Campen, Sixma, Friele, Kerssens, & Peters, 1995), and it ensures the measurement of all important aspects of care quality from the patient perspective. The advantage of using existing instruments developed within either the Norwegian context and/or a palliative care context is that the questions asked could be considered relevant to patients in the late palliative phase in Norway. However, none of these instruments included was explicitly founded on either a theoretical model of care quality or the patient perspective of quality, or comprised questions about patients' subjective importance.

The Quality from the Patient's Perspective (QPP) instrument is based on the theoretical model of care quality from the patient's perspective (Wilde et al., 1994; Wilde et al., 1993). A short version of the QPP has also been developed (Wilde Larsson & Larsson, 2002) and frequently used in several care contexts (Fritzell, Eriksson, Björk, Sprangers, & Wettergren, 2012; Holter et al., 2014; Muntlin, Gunningberg, & Carlsson, 2006; Wilde-Larsson et al., 2010), including hospitals in Norway (Grøndahl et al., 2011). In addition, a modified version of the short version has been developed and used in advanced home care (Wilde Larsson et al., 2004). The QPP consists of questions related to patients' perceptions of actual care received (PR) and the SI of the care received. Recently, QPP instruments have been evaluated and recommended in two systematic reviews assessing instruments to measure patients' perceptions of care quality (Beattie, Lauder, Atherton, & Murphy, 2014; Sawyer et al., 2013).

To sum up, the review of instruments showed that the QPP could be considered suitable to use in this thesis because the instrument is based on a theoretical model derived from the patient perspective; it consists of patients' evaluations of both PR and SI of the care received and has previously been used in Norway, and it has been modified and used in palliative home care. However, it has not been developed and undergone a psychometric evaluation in palliative care context. Further development and psychometric evaluation of the QPP for a palliative care context are needed.

Rationale

Palliative care is faced with multiple challenges, and further development and improvement initiatives are needed to ensure high-quality care for patients in need of palliative care. Patients' perceptions of care quality are important in such work. However, knowledge about patients being in the late palliative phase and their perceptions of the care quality is limited.

There seems to be a need to synthesize existing research about patient preferences for palliative care. However, to accurately describe preferences, it is important to include studies with patients who have experienced palliative care services and studies that have been conducted in various settings.

Few studies have combined patients' perceptions of care quality from the perspective of both subjective importance (SI) and the perceived reality (PR) *within* the different settings of palliative care, especially from hospices, palliative units in nursing homes and non-specialized home-care settings. Investigation from both these angles could provide specific knowledge of areas of strength and areas for improvement for further use in quality work.

Previous studies have shown that patients' perceptions of quality may vary according to person-related and organization-related conditions. However, most studies are conducted in settings other than palliative care. There is limited knowledge about the relationship between patients' perceptions of SI and person- and organization-related conditions. Little is also known about the combination of person- and organization-related conditions and their relationship with the patient perspective of care quality, which would reflect the complexity of clinical practice and enhance individualized care.

Earlier studies have shown varied results with regard to whether patients' perceptions of quality vary *across* the settings. These are based on relatives' perspectives. More studies are needed to investigate patients' perceptions of care quality across settings of palliative care to gain knowledge of whether and how the care context influences patient perceptions of quality of care.

Validated instruments, which comprise a theoretical framework based on patients' perceptions of care quality, developed for the palliative care context, are limited. The QPP was considered to hold several of these criteria. However, the QPP has not been psychometrically evaluated in the palliative care context, and must be adapted to adequately address aspects identified as important to patients receiving palliative care.

The use of multiple methods may lead to comprehensive knowledge of quality of care from the patient perspective.

Overall and specific aims

The overall aim was to investigate the quality of palliative care from the patient perspective, to adapt and psychometrically evaluate the Quality from Patients' Perspective instrument specific to palliative care (QPP-PC) and investigate the relationship between the combination of person- and organization-related conditions and patients' perceptions of care quality.

The four papers in the dissertation are based on each other and their specific aims were:

I. Identify preferences for palliative care among patients in the palliative phase of their illness, by synthesizing existing research.

II. (1) Adapt the QPP for use in palliative care contexts, and (2) describe patients' perceptions of the care quality in terms of the subjective importance of the care aspects and the perceptions of the care received.

III. Investigate (1) patients' perceptions of palliative care quality *within* settings (hospice inpatient care, hospice day care, palliative units in nursing homes and home care), including perceptions of care received and their subjective importance, and (2) contrast patients' perceptions of palliative care quality *across* settings.

IV. Investigate the relationships between the combination of person- and organization-related conditions and patients' perceptions of palliative care quality.

Methods

Design (Papers I-IV)

This thesis consists of four papers (I–IV). To address the overall aim, the combination of one systematic mixed studies review, which combined findings from studies using qualitative or quantitative methods by a thematic analysis (I), and three that used quantitative methods by a cross-sectional design and statistical analysis (II, III, IV) was used. The design and methods in the systematic review and the quantitative papers differ with regard to the research paradigm from which they traditionally originate. According to Polit and Beck (2014) qualitative research is related most to a constructivist research paradigm, the research methods for which comprise an inductive approach seeking in-depth understanding of participants' experiences of a phenomenon. Quantitative research methods originating from the positivist paradigm are associated with research methods using a deductive process to measure a pre-specified phenomenon, and make generalizations about the phenomenon. Mixed methods research combines qualitative and quantitative approaches. In nursing, knowledge emerging from methods within different paradigms is needed (Polit & Beck, 2014). Use of several methods strengthens the design of the thesis by gaining comprehensive knowledge of quality of care from the patient perspective. Also, multiple methods may enhance the validity of the results through the findings from one study informing the development of the next (Polit & Beck, 2014).

A systematic mixed studies review (Higgins & Green, 2011; Moher, Liberati, Tetzlaff, & Altman, 2009; Polit & Beck, 2012; Sandelowski, Voils, & Barroso, 2006) was conducted to integrate and synthesize findings from qualitative and quantitative studies addressing the same phenomenon (patients' preferences for palliative care) (I). The design was chosen to gain broader knowledge as a result of including studies investigating patients' preferences for palliative care from different angles. A quantitative approach with a cross-sectional design was used to further develop the QPP questionnaire, to investigate patients' perceptions of the quality of palliative care and to investigate how person- and organization-related conditions are related with patients' perceptions of care quality (II-IV). The papers were sequentially built on each other's findings. The findings in Paper I were used to adapt QPP to the palliative care context (II). The QPP instrument specific to palliative care (QPP-PC) (II), was used further in analysis in Papers III and IV. See Table 1 for an overview of the papers and designs.

Table 1 Overview of the papers in the thesis.

Paper	Method/Design	Data collection	Methods of analysis
I	Systematic mixed studies review Integrated	Literature retrieval	Qualitative thematic analysis
II	Quantitative Cross-sectional	Questionnaire	Descriptive, inferential and psychometric statistics
III	Quantitative Cross-sectional	Questionnaire	Descriptive and inferential statistics
IV	Quantitative Cross-sectional	Questionnaire	Descriptive and inferential statistics

The systematic mixed studies review (Paper I)

Fundamental principles established by the Cochrane Collaboration (Higgins & Green, 2011) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009) guided the methods used to identify and select relevant papers, assessment of the study quality and extraction of the data.

Identification and selection of relevant literature

Eligible criteria. The eligible criteria reflected the aim of the review and guided the search method and assessment of relevance when identifying and selecting relevant studies.

Type of studies. Peer-reviewed research articles using qualitative, quantitative or mixed methods, both primary research studies and systematic reviews, in English, Norwegian, Swedish or Danish should be included.

Type of participants/settings. Studies were included in which participants were aged ≥18 years, with no cognitive impairments, diagnosed with an advanced, life-threatening, progressive, incurable illness (EAPC, 2009; Van Mechelen et al., 2013; WHO, 2002) or admitted to specialized palliative care services and with experience of such services (specialized or non-specialized) (Van Mechelen et al., 2013). Patients' preferences of care should be clearly presented if studies that showed a family perspective were included. Similarly, studies targeting a mix of patients were included if preferences of patients being in a palliative phase were presented separately.

Type of outcome. Studies were included if they had a clear focus on preferences for overall palliative care from the patient perspective. Studies focusing on specific areas of care, e.g., preferences with regard to pain alleviation were excluded.

Search method. The literature was first retrieved by searching six electronic databases selected to cover a multidisciplinary healthcare area, with no limits on date of publication beyond the coverage of the databases themselves. Searches were performed in May 2012 and updated in June 2014. The databases, search terms and their combinations are displayed in Table 2. A specialist librarian was consulted when developing the search strategy to ensure rigour in the search process. References were handled using the EndNote X4 software. The literature was also retrieved using a snowballing technique to hand search references in the studies selected from the electronic search.

Table 2 Search terms.

The searches were structured according to PICO **(Higgins & Green, 2011)** and primarily conducted in Medline using both MeSH terms (when available) and free text words, and then modified appropriately for other databases.

Databases: Cochrane Library (Cochrane reviews and other reviews), Medline (from 1946), CINAHL (from 1982), PsycINFO, Scopus (from 1963) and Sociological abstracts (from 1952).	
Participants	(Patient OR client OR consumer)
	AND
Intervention/setting	('terminally ill' OR 'palliative care' OR 'terminal care' OR 'hospice care' OR 'end of life care')
	AND
Outcome	(preference OR perspective OR expectation OR perception OR priority OR experience OR needs assessment OR 'quality of care' OR 'patient satisfaction' OR 'consumer satisfaction')
Limitations	Title and abstract, subject heading word and/or text word, adult, research article, peer reviewed, language: English, Norwegian, Swedish or Danish

Selection of literature. The electronic database searches and searches in reference lists identified a total of 3038 records (databases; 2945, reference lists; 93). The identification and selection process is displayed in Appendix 1. Relevance assessment was first conducted by screening the title and abstract (n = 2606) and then by assessing full-text articles (n = 165), using a form developed to reflect the eligibility criteria and aim of the study. This left a total of 23 studies to be included in this review. Two additional publications from one study that was already included were also retrieved because they provided further information and findings relevant to the aim of this review.

Appraisal and data extraction

Quality assessment was performed for each study included using the Critical Appraisal Skills Programme Tools (CASP) for qualitative and quantitative studies (Public Health Resources Unit England, 2006), modified by Nordström and Wilde-Larsson (Nordström & Wilde- Larsson, 2006a, 2006b). Further modification was made by the research team to suit this paper. A simple scoring system rated the studies as high, medium or low quality (Nordström & Wilde- Larsson, 2006a, 2006b). Data were extracted on study methods, participant characteristics, settings and findings, using a data extraction form that was developed by the research team.

Analysis

The extracted findings were synthesized and analysed according to the analysis stages specified by Whittermore and Knafl (Whittemore & Knafl, 2005), allowing grouping of findings that addressed the same phenomenon (Sandelowski et al., 2006), rather than by method. The analysis stages consist of data reduction, data display, data comparison, and conclusion and verification. Data about patients' preferences were extracted (data reduction) and summarized (data display – see Table 2 in Paper I). Furthermore, the findings were analysed (data comparison), first, by being coded and condensed according to preferences for aspects of palliative care. Then, preferences were grouped according to patterns and themes while contrasts and comparisons between and within groups of preferences were constantly evaluated, revealing both commonalities and differences. Finally, themes and subthemes were identified and their internal relationships described (conclusion and verification). Throughout the analysis, preferences were verified using primary sources to ensure accuracy and reliability. In addition, Excel was used to ensure rigour in the analysis steps.

Descriptions of studies included

The studies represent research from 1982 to 2013, with most being published during the last decade 16 (70%). No systematic reviews were identified. A total of 1583 patients participated in the 23 studies. Studies reported on patients with cancer (13 [57%]) and studies with combined results for patients with cancer or other life-threatening illnesses and elderly patients who were frail (8 [35%]). One study presented findings separately for patients with diagnoses other than cancer.

Table 3 Descriptions of studies included (n = 23 studies, 1583 participants).

			***n* (%)**
Studies	Study design	Qualitative methods	13 (57)
		Quantitative methods	10 (43)
	Geographical data	North America	7 (31)
		European countries	11 (48)
		Australasia	4 (17)
		Middle East	1 (4)
	Settings	Hospitals	5 (22)
		Long-term care services	2 (9)
		Hospice inpatient service	2 (9)
		Hospice or palliative day care	3 (14)
		Home care	3 (14)
		Palliative outpatient clinic	1 (5)
		General practice	1 (5)
		Multiple services	5 (22)
Participants	Age (range in years) (reported in 23 studies)		23–101
	Gender (%) (reported in 18 studies)	Male	52
		Female	48
	Social status (%) (reported in 12 studies)	Married/partner	62
		Single	38

Validity and reliability

Validity and reliability in systematic mixed studies reviews refer to how well each step in the review has been performed and described. This involves whether a systematic review: (1) addresses a clear and relevant research question and has an appropriate study design; (2) clearly describes inclusion and exclusion criteria; (3) provides a well-described search strategy, comprehensively performed literature search and a clear description of the selection process (duplicate assessment of relevance and provision of a flow chart); (4) makes use of a respected quality assessment scale and duplicates quality appraisal; (5) provides a clear description of data extraction method and data extracted (including duplicate data extraction and display of study characteristics); (6) has an appropriate analysis method and thorough description of the analysis; and (7) discusses limitations of the study and that reasonable conclusions have been drawn (including implication for practice and further research) (Higgins & Green, 2011; Moher et al., 2009; Polit & Beck, 2012; Shea et al., 2007; Whittemore & Knafl, 2005).

Validity and reliability were achieved by a thorough and transparent performance and description of all steps described under Methods above, and guided by acknowledged and fundamental principles (Higgins & Green, 2011; Moher et al., 2009). As this review aimed to include studies using both qualitative and quantitative methods, a mixed studies review was appropriate (Polit & Beck, 2012). The aim and eligible criteria of the study were developed according to PICO as recommended by Higgins and Green (Higgins & Green, 2011). The eligible criteria reflected the aim and guided the identification and selection of relevant studies, and were determined before the literature search. The search strategy included both database and reference list searches. Comprehensive electronic searches were conducted and guided by a specialist librarian. Due to time limitations, experts in the field were not contacted, nor were searches for 'grey literature' conducted. Two

researchers (TS and IR or RH or SH or BWL) independently selected (duplicate assessment) studies for inclusion, quality assessment and data extraction, as recommended by Higgins and Green (Higgins & Green, 2011). The selection process was presented in a flow chart in Figure 2. The forms used for assessment of relevance and quality were developed or modified from well-known sources such as CASP (Public Health Resources Unit England, 2006). Pilot testing of the assessment of relevance, quality assessment tools and the data extraction form was conducted by evaluation of the inter-rater agreement. Ten of the full-text papers (with various methods) were assessed for relevance and quality, and data were extracted independently by TS (all papers) and all the other researchers in the team (two to three paper each). As the forms were developed by the research team, the inter-rater agreement was high. Only minor revisions were performed for further clarification of the forms. Uncertainties and disagreements about the selection of studies, the quality assessment and data extracted were discussed by the research team until agreement was reached. All papers included were scored as medium or high quality. Data extracted (study characteristics), including the results of the quality assessment, were presented in a table. The analyses followed the steps described by Whittemore and Knafl (2005), and each step in the synthesis of the findings was discussed by the research team.

The quantitative studies (Paper II-IV)

Participants and settings

Patients were recruited from hospice inpatient care, hospice day care, palliative units in nursing homes and home-care districts, representing densely and sparsely populated locations in the eastern part of Norway (II-IV). The settings are described in Table 4.

Table 4 Descriptions of the settings in Papers II–IV

Type of setting	Number of wards	Organization within the healthcare system	Specialized in palliative care	Number of patients in palliative phase
Hospice inpatient care	2	One ward – specialist healthcare services One ward – community care services	Specialized in palliative care	23 beds
Hospice day care	2	Specialist healthcare services	Specialized in palliative care	65 patients per week
Palliative units in nursing homes	2	Community care services	Specialized in palliative care	12 beds
Home care	2	Community care services	Non-specialized in palliative care	Patients in palliative phase not registered.

The hospice inpatient and day-care wards, and the palliative care units in the nursing homes, can be characterized as specialized in palliative care, in that they care exclusively for patients in palliative phases (EAPC, 2009). The home-care settings could be characterized as non-specialized palliative care services, in which all patients in need of home care receive care and not exclusively patients in palliative phases. Both home-care districts did offer specialized trained personnel, such as palliative care teams and cancer nurses, to patients in the palliative phase.

Patients were included if they were in a late palliative phase (Grov, 2014; Jarlbæk et al., 2014), defined as being in an advanced phase of their illness, with a 1-year life expectancy

(Thomas et al., 2011) and experience of palliative care services (Van Mechelen et al., 2013) (specialized or non-specialized) (II-IV). Patients were consecutively recruited by the registered nurse selected as responsible for recruiting patients in each site (recruiting registered nurse [RRN]) and invited to participate in the study when they met the following inclusion criteria: (1) adult (≥18 years), (2) no cognitive impairment (judged by the RRN), (3) understand Norwegian, (4) has received assistance from the services for at least 3 days and (5) has an advanced, life-threatening illness in a late palliative phase (malignant or non-malignant) (judged by the RRN), guided by the nurse's negative response to the question: 'Would you be surprised if this patient were to die within the next year?' (Thomas et al., 2011). For patients admitted to non-specialized palliative care services, documentation in the patient journal was searched by the RRN, for an indication that the patient was in a palliative phase, to guide the decision whether to include the patient. In addition patients should be aware that they are in a palliative phase and receiving palliative care (judged by the RRN). The patients' physicians and one of the researchers (TS) were consulted when uncertainties arose about the inclusion criteria. The RRN in each site had comprehensive experience with the patient group and most had formal education specializing in palliative or cancer care.

Of the 262 patients asked to participate, 191 returned the questionnaire (response rate = 73%). In Paper II, seven patients were excluded from the statistical analysis due to the proportion of items answered 'not applicable' (or missed observations), leaving 184 patients for statistical analysis. Descriptions of the participants are presented in Table 5.

*Table 5 Description of the participants in Papers II–IV (*n *= 191/184).*

	Paper II	Papers III–IV
	n = 184	*n* = 191
Age (years) (mean score [SD], range)	66.51 (11.71), 41–94	66.80 (11.62), 41–94
Missing	7	7
Gender *n* (%)		
Female	101 (56)	108 (57)
Male	80 (44)	80 (43)
Missing	3	3
Education *n* (%)		
Primary school or equivalent	44 (25)	47 (25)
High school or equivalent	69 (38)	72 (39)
University/university college	66 (37)	67 (36)
Missing	5	5
Type of diagnosis *n* (%)		
Malignant illness (cancer)/Mixed malignant and non-malignant illnesses	154 (84)	159 (84)
Non-malignant illness (e.g., COPD, HF, MS, ALS, Parkinson's disease)	29 (16)	31 (16)
Missing	1	1
Setting (*n* (%))		
Hospice inpatient care	69 (37)	72 (37)
Hospice day care	51 (28)	51 (27)
Palliative care units in nursing homes	29 (16)	30 (16)
Home care	35 (19)	38 (20)

ALS, amyotrophic lateral sclerosis; COPD, chronic obstructive pulmonary disease; HF, heart failure; MS, multiple sclerosis.

Data collection – the questionnaire

A questionnaire based on the QPP, which is developed within the theoretical framework of quality of care from a patient perspective (Wilde et al., 1994; Wilde et al., 1993), was used, together with data about patient characteristics (person-related conditions) and data from the settings concerning organization-related conditions.

The questionnaire to the patients included four instruments. Below, the four instruments are described within the following terms – 'quality of care' and 'person-related conditions' – followed by descriptions of the validity and reliability of the instruments. This is followed by the questions, to the included settings, about the organization-related conditions. The selection of the QPP items and instruments/questions to measure person- and organization-related conditions were based on previously developed QPP instruments (Wilde et al., 1994; Wilde Larsson & Larsson, 2002; Wilde Larsson et al., 2004), the findings of Paper I and the researchers' knowledge of the field. The description of the questionnaire and the organization-related conditions, and the respective three papers, is given in Table 6.

Table 6 Description of the questionnaire and organization-related conditions and their use in the respective three papers.

		Paper II	Paper III	Paper IV
Quality of care	QPP – modified version	x		
	QPP-PC		x	x
Person-related conditions	**Health-related quality of life**			
	Five dimensions			
	EQ-VAS		x	x
	Psychological well-being		x	x
	SOC		x	x
	ESRQ			
	Patient characteristics	x	x	x
Organization-related conditions	Organizational model for physicians			x
	Organizational model for nurses			x
	Settings with physicians who have trained in palliative medicine as a subspecialty			x
	Systematic assessment of symptoms			x

EQ-VAS, EuroQol-visual analogue scale; ESRQ, Emotional Stress Reaction Questionnaire; SOC, sense of coherence.

Descriptions of instruments, validity and reliability

The included instruments are described below according to quality of care, person-related conditions and organization-related conditions. Each instrument is followed by descriptions of its validity and reliability. Validity refers to whether an instrument measures what it is intended to measure; this is assessed by the instrument's face, content, criterion and construct validity (including convergent and discriminant validity) (Polit & Beck, 2012; Sitzia, 1999). Face validity refers to whether the instrument appears to measure the intended construct/phenomenon. Content validity assesses whether the instrument contains items that are adequate for measuring the construct. The instrument's ability to correlate with external criteria is known as criterion validity. Construct validity is a key criterion for assessing the validity of an instrument and concerns the degree to which the instrument measures the intended construct. The reliability of an instrument concerns the degree of consistency with which an instrument measures a certain attribute

(Polit & Beck, 2012; Sitzia, 1999). This includes both stability (similar scores given on separate occasions) and internal consistency (the degree to which all parts of an instrument measure the same attribute/phenomenon).

Quality of care

Patients' perceptions of quality of care were measured using a modified version of the QPP adapted to measure quality of care from the perspectives of patients with different life-threatening illnesses in diverse palliative care settings (69 items). The theoretical model on which QPP is based was developed by interviews with patients using a grounded theory approach (Wilde et al., 1993), and further developed into the QPP instrument consisting of the following four dimensions: medical–technical competence of the caregiver (MT), physical–technical conditions of the care organization (PT), identity–oriented approach (ID) and socio-cultural atmosphere (SC) (56 items full version) (Wilde et al., 1994). Later, a short version consisting of 24 items (Wilde Larsson & Larsson, 2002) and modified versions for different care context were developed, e.g., for advanced home care (Wilde Larsson et al., 2004). The QPP full version has been psychometrically validated using factor analysis (Wilde et al., 1994), and further validated by a dimensional analysis using structural equation modelling (Larsson, Wilde Larsson, & Munck, 1998). The short version of the QPP has been validated (Wilde Larsson & Larsson, 2002). The full and short versions have been evaluated in a recent systematic review (Beattie et al., 2014), which found the content validity and reliability to be excellent, the construct validity good, and the criterion validity excellent for the short version and poor for the full version (due to the study design).

Each item of the QPP-PC was answered in two ways: perceptions of the actual care received (perceived reality – PR scale) and importance of each aspect of care (subjective importance – SI scale). The subjective importance describes the patients' preferences – what is considered important. The PR scale was measured by items starting with: 'This is what I experience …' (e.g., the best possible help for my pain). The items measured on the SI scale started with: 'This is how important this is to me …' (e.g., the best possible help for my pain). A 4-point Likert-type scale, ranging from 1 (do not agree at all) to 4 (fully agree), was used for the PR and SI scales: 1 (of little or no importance) to 4 (of the very highest importance). A non-applicable response was available for both scales. For the QPP-PC dimensions and factors, a mean value was calculated based on the individual participant's response to the items in the respective dimension or factor (single items excluded). In addition, two open-ended questions – 'What is important for you in your situation?' and 'What is important to you about the care you receive?' – were also in the questionnaire, but were not used in this thesis.

The adaptation and validation of the QPP to palliative care

The modified version of the QPP adapted to measure quality of care from the perspectives of patients in palliative care (69 items) consisted of items from the full and short versions and from the modified version for advanced home care. In addition, new items were developed. Modifications of the QPP items and development of new items were mainly based on a systematic review of the literature (I), of symptoms presented in the revised version of the Edmonton Symptom Assessment System (ESAS-r) (Bruera et

al., 1991; Watanabe et al., 2011) and the research team's expert knowledge of the field, based on experience working with patients in the palliative phase and by conducting research in the context of palliative care. The adaptation process is shown in Appendix 2. The QPP instrument was adapted for palliative care in four steps:

1) *Selecting items from the QPP*: items were selected from the full and short versions and from the modified version for advanced home care.

2) *Modifying items:* of the 35 original QPP items, 10 were modified to suit the palliative care context better by altering wording, e.g., the item 'Feeling that the nurses showed interest in my outlook on life [my spiritual needs]' was modified to 'The nurses support me in tending to my spiritual and existential needs'. In addition, QPP items about nurses and physicians were modified by adding items to cover multiprofessional staff (labelled 'other personnel'). This comprised 8 additional items, with a total of 43 items.

3) *Constructing new items for the palliative care setting*: 34 new items were then developed to cover palliative-specific aspects of care that were not or were only partly covered by the QPP. These new items included: symptom management of tiredness and depression (two items); preservation of dignity (three items); financial concerns (one item); information about diagnosis and prognosis (two items); choosing place of care (one item); practical support (one item); sufficiency of multiprofessional care (ten items); support, information and participation of the family (four items); a secure atmosphere (one item); support from fellow patients (one item); and continuity, planning and cooperation (eight items). The total number of items at this stage was 77.

4) *A pilot evaluation*: a pilot evaluation of the *face validity, content validity* and comprehensibility of the items, and clarity of instructions, was conducted by one researcher (TS). This involved interviews with eight patients in late palliative phases after completion of the questionnaire. Patients in the pilot study were recruited from two hospice inpatient units (n = 4) and two hospice day-care units (n = 4). Four men and four women, with ages ranging from 45 years to 70 years, participated. The interview consisted of the following topics: relevance of items to quality of palliative care, perceptions about completing the questionnaire, length of the questionnaire, comprehensibility of the items and instructions for filling out the questionnaire, and suggestions for improving items. The results from the pilot evaluation showed good face and content validity in that items encompassed quality of palliative care, and that items and instructions were comprehensible, but the number of items was perceived as too high. Based on these results, the research group conducted a critical assessment of the items, resulting in a reduction in the wording of 31 items. In addition, a conflation of items was performed which resulted in the removal of eight items which were considered to be covered by other items. For example, the two items measuring a secure atmosphere and a pleasant atmosphere were reduced to 'There is a pleasant and secure atmosphere at the ward'. This step resulted in a total of 69 items.

Construct validity. To ensure a stable factor solution, further reductions of items were needed before doing the principal component analysis (PCA). A critical assessment of items was carried out, guided by the results of the descriptive analysis of the response alternative 'not applicable' (and missed observations). Of the 69 items, 17 were excluded because a high proportion (>35%) of patients scored them as 'not applicable'/missed observations and these items were also assessed as covered by existing items. This left 52 items. Further validation related to the construct validity of the QPP-PC is described under Results.

Internal consistency (reliability). In previous studies using the QPP in similar populations internal consistency (reliability) has ranged between 0.65 and 0.95 for the four dimensions on the PR and the SI scales (Henoch et al., 2011; Wilde Larsson et al., 2004). The corresponding Cronbach's α in this thesis using the QPP-PC is presented in the 'Results'. The QPP-PC was validated in Paper II and further used for statistical analyses in Papers III and IV.

Person-related conditions

Data about *participants' characteristics* comprised age, gender, diagnosis, time in care, education, language/ethnicity, living conditions, contact with family and friends and religious affiliations (10 items).

Data on *health-related quality of life* were collected, using the EQ-5D-3L (including the EuroQol-visual analogue scale: EQ-VAS) questionnaire from the EuroQol Group (Brooks, 1996; EuroQol Group, 1990) (6 items). This questionnaire is a standardized generic measure of health-related quality of life, designed for self-completion by respondents (Hurst, Kind, Ruta, Hunter, & Stubbings, 1997; Rabin & Charro, 2001). The EQ-5D-3L consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems, some problems, extreme problems. In addition, an overall measure of health-related quality of life is measured, the EQ-VAS, which measures the respondent's self-rated health on a vertical, visual analogue scale ranging from 0 to 100. The endpoints are labelled 'best imaginable health state' (100) and 'worst imaginable health state' (0). The score shows how patients perceive their health-related quality of life. A mean value was calculated to describe the health-related quality of life in the sample of patients.

Validity/reliability. The EQ-5D has been validated (Brooks, 1996; Hurst et al., 1997) and used by patients in various countries and settings, and also found to be suitable for use in palliative care (Färkkilä et al., 2014). The EQ-5D has been found to have a reasonable degree of content validity and construct validity (Lang, Chuang, Shun, Hsieh, & Lan, 2010). The reliability has proved to be good and shown good stability through test–retest methods(Brooks, 1996). Only EQ-VAS was used in this thesis, but it is planned to use the data from the EQ-5D dimensions for further studies.

Physiological well-being was measured by one item from the QPP questionnaire, related to the sentence: 'I feel that my physiological well-being is…', using a 5-point Likert-type scale ranging from 1 ('very poor') to 5 ('very good') (Wilde et al., 1994).

The sense of coherence (SOC) scale is developed to measure a patient's life orientation (Antonovsky, 1993; Eriksson & Lindström, 2005), and is an operationalization of the construct, the sense of coherence, in the theoretical salutogenic model developed to explain how people manage stressful situations and stay well. The scale comprises questions about comprehensibility, manageability and meaningfulness (Antonovsky, 1993; Eriksson & Lindström, 2005). The SOC scale originally consisted of 29 items (Antonovsky, 1987). Later a 13-item version was also developed. In this thesis the Norwegian 13-item version was used (Eide, 1991). Each item, e.g., 'Do you have the feeling that you're being treated unfairly?', is scored on a 7-point response scale ranging from 1 ('very often') to 7 ('very seldom or never'). The SOC index was calculated by adding the score from each item, ranging from 13 to 91. High scores represent a strong SOC.

Validity/reliability. High levels of face, content and construct validity have been shown in studies, and SOC also seems to be cross-culturally applicable (Antonovsky, 1993; Eriksson & Lindström, 2005). Criterion validity has been examined by determining the correlations between the SOC and the standardized instrument for measuring health, perceived self, stressors, quality of life, well-being, attitudes and behaviours used in different studies (Antonovsky, 1993; Eriksson & Lindström, 2005). Most measures showed a statistically significant correlation. Reliability has been tested, and the instrument shown to be relatively stable over time (one year, three years, four years, five years and 10 years) (Eriksson & Lindström, 2005). Internal consistency measured by Cronbach's α has in previous studies (127 studies) ranged from 0.80 to 0.92 (Eriksson & Lindström, 2005), and was 0.78 in this thesis.

Emotional Stress Reaction Questionnaire (ESRQ) was used to measure patient satisfaction as an emotion (Larsson, 1987; Larsson & Wilde-Larsson, 2010). The instrument is based on a theoretical framework (Larsson, 1987) which was further developed and adapted to a care context version and translated into Norwegian (Grøndahl, Hall-Lord, Karlsson, Appelgren, & Wilde-Larsson, 2013).

Validity/reliability. The construct validity, criterion validity and reliability have previously been assessed and described (Larsson & Wilde-Larsson, 2010). The ESRQ was not used in the studies presented in this thesis but there are plans to use it in further studies.

Organization-related conditions

Organization-related conditions included questions related to: *setting characteristics* (e.g., number of patients a year, number of patients in palliative phase a year, type of diagnosis in the ward), *organizational models for nurses and physicians*, *availability and number of staff* (including nurses, cancer nurses, physicians, nursing assistants, physiotherapists, occupational therapists, priests, social workers, nutritional physiologists) and *personnel's competence in palliative care* (formal education for all available personnel). Additionally, questions were included about; the *use of a theoretical framework* (hospice philosophy and person-centred care) and of *assessment tools* (e.g., ESAS, individual care plan), and *documentation* (e.g., documentation systems used, frequency of documenting that patients were in the late palliative phase).

A selection of variables for the final analysis was made based on an evaluation of the following: whether the data from the four settings (eight wards) could be compared and the importance of the variable because there was a limitation of numbers of variables in relation to the number of wards (eight wards/groups minus two degrees of freedom). In addition, data were evaluated according to whether data were complete and whether the variable was uniquely distributed (not correlated in the model) across the categories/settings in relation to the other variables. The selection process resulted in four included variables: organizational model for physicians, organizational model for nurses, settings with physicians who have specialized in palliative medicine as a subspecialty and systematic assessment of symptoms (ESAS). The variable about the use of ESAS with the response alternatives (1) all patients, (2) most patients, (3) some patients and (4) no patients were recoded to: (1) all or most patients and (2) some (few) or no patients to distinguish between regular use and occasional use of the ESAS.

Procedure

Procedure for collecting data from patients

Before the data collection, the author informed the senior charge nurse and the registered nurses responsible for recruiting patients (RRNs) about the study, both in writing and verbally. The written information contained the following: the author's contact information, inclusion criteria, a guide of how to proceed when recruiting patients, a list to note all patients asked to participate (age, gender, declined or included), and the questionnaire and patient information. The author went through all the documents with the RRN and educated her or him on how to recruit patients, encouraging any questions. Each ward also received a folder containing documents that presented information about the study, for all the staff to read. This was to inform the staff and enable them to know how to proceed if patients had any questions. During the data collection period, the author contacted the RRNs in the eight wards every second week by phone, and conducted meetings approximately once a month in the wards. The purpose of these meetings was to support the RRNs in the recruitment of patients by, for example, discussion of any patients they were not sure whether to recruit. These meetings were also important for the author to learn whether there were any problems or uncertainties that should be clarified.

Data were collected using the instruments described above from November 2013 to December 2014. In each eight-ward or home-care district, the RRNs screened patients and asked them to participate in the study. In addition, they provided information about the study, instructed the patients how to fill out the questionnaire, informed them that participation was voluntary, the answers would be treated de-identified and none of the staff would know the individual patient responses, and whom to contact if any questions arose. The participants were told that they could use the time needed to fill out the questionnaire. They were also informed of the possibility of filling out just parts of the questionnaire, but were asked to try to complete the parts they did choose to fill out. If patients were willing to participate, they were instructed to return the completed questionnaire and a consent form for participation in a sealed envelope. These sealed envelopes were stored in the RRN's office until the researcher collected them on a ward visit.

Patients who needed help filling out the questionnaire were offered to be interviewed by the author. The interviews were carried out by the author reading each question in the questionnaire aloud to the respondents. The response scales were enlarged on separate sheets of paper to enable patients to point at the appropriate response category or answer verbally. The researcher then wrote their responses on the scales after each question. The interviews were conducted in either a private room in the ward or in their homes. Of the 191 (184 in paper II) participating patients, 54 (50) received help filling out the questionnaire. Of these, 7 (5) were from hospice inpatient care, 8 (8) from hospice day care, 22 (21) from palliative units in nursing homes and 17 (16) from home care.

Procedure for collecting data on organization-related conditions

Data were collected from February to March 2015, and focused on the organization of care for the year 2014, which was the time period of the patient data collection. Data were obtained from the senior charge nurse in the wards and from leaders of home-care services. In addition, data from the home-care settings were collected from people responsible for or with expert knowledge of the field or professions, e.g., the district medical officer who had comprehensive knowledge about community general practitioners (GPs). The senior charge nurse and the leaders of home-care settings received the questions by email. The author collected the data by personal contact, either by visiting the wards/home-care districts in person or receiving the data through a combination of phone and email.

Statistical analyses

IBM SPSS Statistics Data Editor Software (Field, 2013), version 23, was used to analyse the data. The statistical significance was assumed at $p < 0.05$ (II and IV), and was reduced to $p < 0.025$ in Paper III to avoid any type 1 errors. The analyses used in the three quantitative papers are displayed in Table 7.

Table 7 Presentation of the analyses used in the three quantitative papers

Paper II	Paper III	Paper IV
Descriptive statistics Frequencies Percentages Mean Standard deviation Range	**Descriptive statistics** Frequencies Percentages Mean Standard deviation Range	**Descriptive statistics** Frequencies Percentages Mean Standard deviation Range
Reliability Cronbach's α	**Reliability** Cronbach's α	**Reliability** Cronbach's α
Psychometric evaluation Exploratory factor analysis (EFA) using principal component analysis (PCA) with Varimax rotation	**Investigate differences in patient characteristics across settings** Pearson's χ^2 test for independence; ANOVA with Tukey's post-hoc test	**Investigate the combination of person- and organisation-related conditions and their relationship with patients' perceptions of the palliative care quality** ANCOVA[1] (strength and direction of relationship)
Investigate patient perceptions of care quality (SI and PR) Paired sample *t*-tests	**Investigate patient perceptions of quality *within* each setting (SI and PR)** Paired samples *t*-tests	
	Investigate patient perceptions of quality *across* settings ANCOVA[1]	
Statistical significance assumed at $p < 0.05$ level	Statistical significance assumed at $p < 0.025$ level	Statistical significance assumed at $p < 0.05$ level

[1]ANCOVA, analysis of covariance.

Descriptive statistics with frequencies and percentages (categorical/nominal data) and mean, standard deviation and range (continuing/interval data) were used to describe the study sample (Field, 2013). Mean and standard deviation were also used to describe patients' perceptions of perceived reality and subjective importance (II–IV). *Differences in patient characteristics* in the four settings were examined using Pearson's χ^2 test for independence and analysis of variance (ANOVA), followed by Tukey's honest significant difference test for post-hoc comparison, as appropriate (Field, 2013).

For the *psychometric evaluation* (II), initially analyses were conducted using Bartlett's test of sphericity to assess the data's suitability for exploratory factor analysis (EFA), which tests the overall significant differences in the correlation matrix. In addition, the Kaiser–Meyer–Olkin (KMO) test was performed to check that the sample adequacy was appropriate (Field, 2013; Hair, Black, Babin, & Anderson, 2014). EFA using principal component analysis (PCA) was used to psychometric evaluate the underlying structure among the items (Field, 2013). This analysis was chosen because the QPP instrument was modified for use in a new context with no assumption of a known hypothesis about the dimensionality of a set of items (Field, 2013; Hair et al., 2014). Kaiser's criterion was used to guide the extraction of factors and factors with an eigenvalue ≥1.0 were obtained for

further analysis (Field, 2013). To give further support to the extraction of factors, Varimax rotation methods with Kaiser normalization were used (Field, 2013). Varimax was chosen to ascertain how the items correlate with the different components of the quality-of-care construct (Field, 2013). Items loading at ≥0.4 were considered acceptable as loadings to the factor (Hair et al., 2014). Items were included in the factor where they loaded the highest. Labelling of the factors was based on the content of the items correlating with them (Hair et al., 2014). PCA was performed for both the SI and the PR scales, at the item level, to investigate the underlying structure among the items, and then for each factor and each dimension to control whether the same pattern appears. *Reliability* was assessed by Cronbach's α to determine the internal consistency of the QPP-PC (dimensions and factor levels) and SOC (Hair et al., 2014) (II–IV).

Paired sample *t*-tests were used to *investigate patients' perceptions of the care quality* for the whole patient group (II) and *within each setting* (III) in terms of differences in SI and PR (Field, 2013).

To *investigate patient perceptions of quality across settings* (III), ANCOVA was performed to compare means of patients' perceptions of the care quality (QPP-PC dimension and single items) across the four settings while controlling for statistically significant differences in age, levels of education and number of diagnoses (main effect) (Field, 2013; Tabachnick & Fidell, 2014). Furthermore, two-way interactions between these variables were assessed, and statistically significant interactions were included in the analysis. Significant *F* levels of ANCOVA were followed by Bonferroni's test for post-hoc comparison to analyse differences in the adjusted means. Analyses were conducted to ensure no violation of the assumptions made as a result of using ANCOVA (III) (homogeneity of variance, linearity and homogeneity of regression) (Tabachnick & Fidell, 2014). Analyses of homogeneity of variance tested by Levene's test were significant for several dimensions and single items. This could influence the interpretation of *p*-value and increase the risk of a type 1 error. A type 1 error is referred to as rejecting the null hypothesis, which is in fact true (false-positive conclusion), as opposite to type 2 error that is accepts the null hypothesis when it is in fact false (false-negative conclusion) (Field, 2013). The risk of a type 1 error can be controlled for by selecting a stricter level of significance and the risk of a type 2 error may be reduced by, for example, increasing the sample size (Polit & Beck, 2012). However, the two types of error influence each other by decreasing the risk, e.g., a type 1 error increases the risk of a type 2 error (Field, 2013). Based on the increased risk of a type 1 error, the statistically significant level for all the analyses (III) was reduced to $p < 0.025$; in addition, conservative post-hoc tests for the ANCOVA analysis were chosen, as recommended by Tabachnick and Fidell (2014).

ANCOVA was also used to *investigation of the combination of person- and organisation-related conditions and their relationships with patients' perceptions of the palliative care quality* (IV). This analysis was performed at the dimension and single item level, to explore the amount of the variance in the dependent variables that could be explained by a combination of the independent variables: – both person- and organization-related conditions – while controlling for differences in covariate variables (Field, 2013; Tabachnick & Fidell, 2014). Univariate analyses were performed because no correlations between the depended

variables had been established. ANCOVA analysis methods were also considered appropriate because most of the independent variables were categorical. Analyses were conducted to ensure no violation of the assumptions made through use of ANCOVA (Tabachnick & Fidell, 2014) (IV), and were considered not to have been violated for the four dimensions on the PR and SI scales. For the single items, the linearity was unclear, indicating that results involving single items must be interpreted with caution (IV).

Additional analysis
The influence of data collection methods (interview vs self-completion) was measured by an independent Student's *t*-test. Grouping the participating services into settings of hospice inpatient care was controlled by comparing patient characteristics across the wards (hospice inpatient wards and palliative care units in nursing homes), using Student's *t*-test for independence or Pearson's χ^2 test as appropriate.

Drop-out analysis and handling of non-applicable and missed responses
Non-response analysis was performed using an independent Student's *t*-test and χ^2 test for independence, as appropriate (Field, 2013). Patients who chose not to participate (n = 71) did not differ significantly from patients who participated with regard to age (p = 0.569) or gender (p = 0.117).

An instrument developed to measure perceptions of care quality of patients with different life-threatening illnesses receiving care in various settings has many advantages, for example when comparing groups of patients or services. However, the disadvantage may be that not all items are relevant to all patients. A non-applicable response alternative was therefore available for each item. In order to recognize the remaining items when analysing the data at the dimension and factor level, a mean value was calculated based on the individual participant's response to the remaining items in the respective dimension or factor. As the non-applicable responses and missed responses were coded together, this applied to missed responses as well. The missed responses in the data-set were judged to be random.

For the PCA (II), a mean of the remaining responses in the respective variable was substituted for the 'not applicable' response. This option was chosen to allow patients to be included in the analysis even when some items were recorded as 'not applicable', and thereby recognize 'not applicable' as a valid response alternative. However, this could imply a risk for correlations with the substituted mean rather than with the remaining patients' responses to the respective items in the PCA (Tabachnick & Fidell, 2014). To reduce this risk, seven patients with particularly high proportions of 'not applicable' or missing responses, making it possible to calculate fewer than six out of 12 factors (SI and PR) or one out of four dimensions (SI and PR), were excluded from the analysis, leaving 184 patients for statistical analysis.

Ethical approval and considerations

Ethical approval was not needed for Paper I, because this was a review article. However, in the quality assessment of each included paper, the ethical considerations described were assessed by the following: whether ethical considerations were adequately addressed, the study had been ethically approved and details of how participants were informed and handled were provided and if a description was provided of whether patients' participation was voluntary.

The quantitative study (II–IV) was reported to the Regional Committee for Medical and Health Research Ethics in South East Norway (REC), which considered the study to be conducted without any further approval from the REC (REC no. 2013/865). The study was therefore reported to and approved by the Norwegian Social Science Data Services (NSD, no. 34770). Approval for conducting the study was obtained by the head administrators of all the wards included.

The ethical challenges of including patients with life-threatening illnesses in the context of palliative care research have focused on the following: vulnerability of the patients, difficulty obtaining informed consent, difficulty balancing research clinical roles, and difficulty assessing risks and benefits (Casarett & Karlawish, 2000). To ensure that the studies dealt with these challenges and complied with ethical principles, the Ethical guidelines for nursing research in the Nordic countries (Sykepleiernes Samarbeid i Norden (SSN) [Northern Nurses´ Federation], 2003) and the International Council of Nurses' (ICN's) code of ethics for nurses (International Council of Nurses (ICN), 2012) have guided the considerations and decisions when conducting and reporting the studies. The principals proposed for nursing research by the SSN and ICN are as follows: autonomy, beneficence (doing good), non-maleficence (not causing harm) and justice.

Autonomy includes voluntariness, informed consent, confidentiality, the right to withdraw from a research project, and respect for patients' dignity, integrity and vulnerability (SSN, 2003). As patients depended on the care that they were asked to evaluate, it was especially important to ensure voluntary participation. This was achieved by each patient being informed, both verbally and in writing, about the study and ensured that participation was voluntary. Only patients with no cognitive impairment were recruited, as judged by the RRN in each site. Patients were offered the opportunity to withdraw from the study. Patients and personnel were also informed that, whether or not patients decided to participate, this would have no consequences for the patient's care. Patients who chose to participate provided verbal and written consent. Confidentially was ensured by patients returning the questionnaire (which included no patient names) and the consent form in a sealed envelope, which was opened only by the author. This indicated that only the author knew the patient's answers to the questions. The questionnaires were coded by the author and a list was made with names corresponding to the number coded on the questionnaire. The code list and the written consent were safely locked away and kept separately from the questionnaires. The written consent had the purpose of offering patients the opportunity to withdraw from the study; it was voluntary to fill in this paper. Returning the questionnaire was also regarded as written consent to participate, as stated in the

patient information sheet. The individual patient's responses could not be identified in the findings.

Beneficence concerns the potential benefit of the research for the patient or the group of patients (SSN, 2003). The results would probably not benefit the participants in this study because their life expectancies were limited. However, many patients spontaneously commented on being grateful for the opportunity to contribute to knowledge that could improve the care for others, and many of those interviewed appreciated the conversation and time spent during the interview. It was intended that the benefits of the findings of the studies would be communicated in respected international journals and at several conferences covering a multiprofessional care area. In addition, the results from each participating ward have been presented for six of the eight wards.

Non-maleficience concerns the research having no harmful effect on the patients (SSN, 2003). This was regarded as being of the utmost importance, because the patients involved could be characterized as vulnerable (Casarett & Karlawish, 2000). Patients were offered the chance to talk to the author and/or the RRN about the questionnaire if any emotional aspects emerged after filling out the questionnaire. None of the patients expressed this need. In meetings with the RRNs the right time to approach the patients was often discussed with the author. The RRNs made their decisions based on ethical judgement and knowledge of the patient's situation.

The research group was especially concerned about the length of the questionnaire, and the burden that this could cause the patients. An attempt was made to reduce this potential burden by the following: the lay-out of the questionnaire split the questionnaire into five parts. Patients were told to fill out as many parts as they could or wished to, and thereby if patients felt that they were not strong enough they did not need to complete the questionnaire. They could also use as much time as they needed to complete the questionnaire, e.g., over a few days. We registered the time spent to complete. Finally we asked for feedback at the regular meetings with the RRNs on reactions from patients filling out the questionnaire. We experienced patients saying that the questionnaire was long, although often completed in a shorter time than expected. Most patients completed the questionnaire in between one and two hours, often including breaks. Some patients chose not to participate (n = 71), and we did not register the reasons, but the feedback from the RRNs was that some perceived there being too many questions. Some patients chose not to complete all parts of the questionnaire, e.g., the last part (SOC instrument) was not completed by 44 patients. Of those interviewed, many patients spontaneously stated the appreciation of the opportunity to participate and to contribute their experiences.

Justice. This implies protecting the weak, against being exploited, and providing knowledge that may potentially reach all patient groups (SSN, 2003). Studies of patient perspective on care are still rare because this often creates methodological and ethical challenges due to, for example, the vulnerability of the patients. By including these patients in this thesis, they were given an opportunity to express their views and thereby have been given a voice. When patients spent their valuable time contributing to this study, it became

important that their contribution should be included in the results. This guided the choice of how the answers 'not applicable' and 'missing' were handled in the studies. Furthermore, it has been important to inform patients, relatives, healthcare personnel, leaders, researchers and policy-makers about the knowledge gained from the papers in this thesis, both nationally and internationally.

Permission was obtained to use the QPP, the SOC scale, the EQ-5D-3L questionnaire and the ESRQ scale, and to reproduce the published article in the paper version of the thesis. The doctoral study was partly funded by external partners in the palliative care field. The author and supervisors were free to plan and conduct studies without any further regulations, except that hospice care should be included in the research.

Main findings

The main findings from the four papers in this thesis are presented in seven sections. First, the results from the systematic mixed studies review are presented under the heading 'Patients' preferences for palliative care' (I), because these results were used further in the development of the QPP-PC. Patients' preferences for care reflect the subjective importance of the care aspects – what is considered important with regard to care. Then, the psychometric evaluation and description of the QPP-PC are presented as 'Quality from the Patient's Perspective instrument for use in palliative care (QPP-PC)' (II). Further, the findings are presented according to the results measured by the QPP-PC in 'Patients' perceptions of subjective importance of palliative care' (II, III, IV), 'Patients' perceptions of perceived reality of palliative care (care received)' (II, III, IV) and 'Areas of strength and areas for improvement' (II, III) within and across the settings. Last, the findings about the 'Relationships between the combination of person- and organization-related conditions and patients' perceptions of subjective importance' (IV), and 'Relationships between the combination of person- and organization-related conditions and patients' perceptions of perceived reality' (IV) are described.

Patients' preferences for palliative care (I)

The literature revealed four themes that made up patients' preferences for palliative care: 'Living a meaningful life', 'Responsive healthcare personnel', 'Responsive care environment' and 'Responsiveness in the organization of palliative care'. The relationship between these themes was that the theme 'Living a meaningful life' illustrated what patients strived for and their preference for a healthcare system that focused on this. The opportunity to focus on living required the presence of a healthcare system around the patients being responsive to their preferences, including healthcare personnel, environment and organization of palliative care. Responsiveness in this thesis includes both recognition of, and performance according to, patients' preferences for care.

Living a meaningful life

This contributed to preferences for healthcare personnel and services that conveyed a focus on living, not necessarily for as long as possible, but as meaningfully as possible. Living a meaningful life included patients wanting to 'Be who I am', bringing meaning to sustain their identity, retain their self-worth, and live as normal and as meaningful a life as possible. This led to preferences for individualized care and help from healthcare personnel to retain normal activities. The focus on living also involved 'Being with people I love' and included being with family and friends, because they were the main source of support and strength. Patients therefore preferred care that facilitated companionship and opportunities to maintain and strengthen important relationships. 'Doing the things I like' involved doing meaningful activities, things that patients liked doing, doing something useful like contributing something to others, being able to finish things and prepare for life's end. Being engaged in activities made patients feel like they had escaped their sick roles. Patients had preferences for healthcare personnel and services that provide an individual approach when assisting patients with meaningful activities, finding new activities when illness deteriorates and helping them prepare for life's end. Patients

expressed preferences for their care to focus on 'Hope for the future'. This included, for example, hope for comfort, peace and future treatment.

Responsive healthcare personnel

This theme comprised patients' preferences for healthcare personnel who were responsive to the needs of patients and their families for care, a good relationship with the healthcare personnel and the opportunity to participate in their own care. 'Receiving support for me and my family' included care from competent healthcare personnel with regard to symptom control, psychosocial support, practical help (e.g., personal hygiene, food and medical equipment), financial and legal assistance, and having personal beliefs and religion respected and facilitated. A clear family focus was emphasized, including support for family and friends, and respite care. 'Having a good relationship with healthcare personnel' included preferences for a relationship built on respect, trust, dignity, friendliness, patience and compassion. Such relationships were shown by how the personnel communicated with the patients, e.g., by listening to their concerns, using an interactive dialogue, providing a caring touch and showing they understood. Patients additionally had preferences to receive information, in particular about their illness, treatment and prognosis, with honesty, that was easy to understand and expressed in a sensitive manner. A good relationship with healthcare personnel seemed to be especially important for patients with no family or difficult relationships with their friends and families. Patients' preferences 'to participate in the care' comprised being recognized and included in the care team, but also helping to make difficult decisions. Different levels of preferences for participation and decision-making appeared, from being empowered to make their own decisions to wanting a shared approach, or to leave difficult decisions to their families or physicians. Variations were also present with regard to participation in the planning of future care and treatment level: some wanted a peaceful death with no prolongation of life, whereas others wanted to continue treatment and prolong life. Hence, the level of participation in care and treatment needs to be adapted according to patients' preferences. Patients wanted family to participate in the care, treatment decisions and planning of care, and even to be included in the healthcare team. This included the family being provided with information and helped to understand.

Responsive care environment

This theme comprised patients' preferences for a care environment that was responsive to their preferences about atmosphere, fellow patients and place of care. Patients had preferences for 'Being cared for in a safe, comfortable and relaxed atmosphere', including an atmosphere that was friendly, warm and intimate. A responsive care environment also included 'Being with fellow patients and having privacy'. Interaction with fellow patients in a similar situation, and therefore likely to understand them, was considered to be a resource that provided well-being and independence. Other patients highlighted the need for privacy such as a private room, to allow patients and families to be comfortable and able to discuss matters privately. Patients had preferences for 'Being in the place of care consistent with my choice'. The literature especially highlighted patients' preferences to be cared for at home, for as long as possible, or to be able to die at home. However, there were also patients' preferences for dying or being cared for in institutions. Patients living

alone were particularly concerned about place of care, especially if they were unable to remain in their own homes.

Responsiveness in the organization of palliative care
Patients preferred palliative care services to be organized according to their preferences, including receiving help when needed, and services that were well coordinated, well planned and provided continuity. 'Receiving help when needed' comprised availability of preferred services, help when needed, access to multiprofessional healthcare personnel (e.g., nurses, physicians, physiotherapists, occupational therapists and chaplain services), knowledge about whom to contact and recreation when necessary. 'Continuity and coordination of care received' included preferences for continuity of care in general, and with regard to their physicians and nurses in particular. Knowing who was in charge and preferably knowing that person personally contributed to a feeling of safety and trust. Seeing different healthcare professionals and receiving help from several different services led to preferences for healthcare personnel and services to provide coordinated care and to cooperate and work as a team. The importance of a plan for palliative care that could be used when patients were transferred from one service to another was highlighted. This ensured that adequate information about the patient was transferred and facilitated provision of the best care.

Quality from the Patient's Perspective instrument specific to palliative care (QPP-PC) (II)

Further validation of the instrument was performed by examining the *construct validity*. EFA using PCA with Varimax rotation showed a stable 12-factor solution for the SI scale, with most items correlating strongly with the factors. After the adaptation process and psychometric evaluation, the QPP-PC consisted of 12 factors (49 items) with an eigenvalue ≥1.0, and showed a stable factor solution that explained 68.25% of the total variance. Similar results were also shown for the PR scale. Furthermore, PCA analyses at dimension and factor levels (SI and PR scales) confirmed the patterns found at the item level, and that the factors and items made up the four dimensions of quality of care: 'medical–technical competence of the caregiver' (MT; two factors and 10 items), 'physical–technical conditions of the care organization' (PT; one factor and three items), 'Identity–oriented approach' (ID; four factors and 20 items), 'socio-cultural atmosphere' (SC; five factors and 16 items), and three single items about medical care, personal hygiene and atmosphere, representing quality of care. A description of the QPP-PC at dimension, factor and single item levels is presented in Table 8 and a full text version of all items is displayed in Appendix 3.

Table 8 OPP-PC: dimensions, factors and single items.

Dimensions	Medical–technical competence	Physical–technical conditions	Identity–oriented approach	Socio-cultural atmosphere
Factors and single items	Symptom relief Exhaustion Medical care (single item) Personal hygiene (single item)	Access to help, food and equipment	Information Honesty Respect and empathy Participation	Meaningfulness Spiritual and existential Relatives and friends Continuity Planning and cooperation Atmosphere (single item)

Internal consistency was assessed by Cronbach's α and the reliability coefficients for the dimensions on the PR scale were: 0.91 for MT, 0.44 for PT, 0.88 for ID and 0.90 for SC. At factor levels the α values range between 0.55 and 0.96. For the dimensions on the SI scale, α was: 0.91 for MT, 0.65 for PT, 0.94 for ID and 0.92 for SC. The α values at the factor level ranged between 0.44 and 0.97.

Patients' perceptions of subjective importance of palliative care (II–IV)

Mean scores of patients' perceptions of SI ranged between 3.16 and 3.51 at the dimension level, 2.98 and 3.70 at the factor level and 3.47 and 3.79 at the single item level (II, IV). Aspects of care that received the highest scores (≥3.55) on the SI scale were the factors respect and empathy and honesty (II) in the ID dimension, care for relatives and friends, planning and cooperation in the SC dimension (II) and the single items about medical care and atmosphere in the ward (II, IV). The lowest level (≤3.00) on the SI scale was reported for the factor 'Spiritual and existential' in the SC dimension (II). None of the dimensions received scores >3.55 or <3.0. Patients' perceptions of SI contrasted across the four settings: hospice inpatient care, hospice day care, palliative units in nursing homes and home care showed no significant differences between the settings (III).

Patients' perceptions of perceived reality of palliative care (II–IV)

Mean scores of patients' perceptions of PR ranged between 3.05 and 3.51 at the dimension level, 2.88 and 3.74 at the factor level and 3.49 and 3.89 at the single item level (II, IV). Patients in the late palliative phase scored the highest PR (≥3.55) for the factors 'Respect and empathy' and 'Honesty' in the ID dimension (II), 'Relatives and friends' in the SC dimension (II), and for the single items about medical care, the atmosphere (II, IV) and personal hygiene (IV). The lowest levels (≤3.00) for PR were reported for the MT dimension and the factors 'Exhaustion' and 'Spiritual and existential' in the SC dimension (II). None of the dimensions received scores >3.55 or <3.0.

Patients' perceptions of the care received differed according to the setting to which they were admitted (III). Patients in hospice inpatient care scored the care received significantly higher than those in palliative care units in nursing homes for the ID dimension and higher than home care in the SC dimension and the single item about medical care. Patients in hospice day care scored the care higher than home care for the SC and higher than hospice inpatient care for the single item about the atmosphere. Patients in palliative units in nursing homes scored statistically higher than home care on the single item about medical care (III).

Table 9 Statistical significant differences in patients' perceptions of care received across the four settings, by dimensions and single items.

Dimensions/single item	Hospice inpatient care (HIC)	Hospice day care (HDC)	Palliative units in nursing homes (PUNH)	Home care (HC)		
	n = 72	*n* = 51	*n* = 30	*n* = 38		
	Adjusted mean	Adjusted mean	Adjusted mean	Adjusted mean	p^1	p^2
Medical-technical competence Medical care (single item)	3.72	3.53	3.68	3.04	0.001	HIC > HC: 0.001 PUNH > HC: 0.018
Identity-oriented approach	3.46	3.39	3.11	3.16	0.004	HIC > PUNH: 0.013
Socio-cultural atmosphere	3.45	3.34	3.25	2.95	<0.001	HIC > HC: <0.001 HDC > HC: 0.008
Pleasant and safe atmosphere (single item)	3.79	4.00	3.95	–	0.011	HDC > HIC: 0.009

[1]*p* values refer to differences in adjusted mean, after control for differences among the groups with regard to age, education levels and number of illnesses, measured by ANCOVA analysis.
[2]*p* values refer to Bonferroni's test for post-hoc comparison.
The statistical level was assumed at the $p < 0.025$ level.

Areas of strength and areas for improvement (II, III)

Care areas of strength refer to the combination of the highest scores on PR and SI scales and care areas for improvement refer to significant differences between PR and SI scores, where SI is scored higher than PR (See Table 10). Strengths were related to treating patients with honesty, providing a pleasant and safe atmosphere (III), respect and empathy, providing care for relatives and friends and medical care (II).

Areas for improvement were related to symptom relief, information, participation, continuity, and planning and cooperation (II). When contrasting the settings, areas for improvement were: participation in the decision about place of care in the hospice inpatient care, information (especially about diagnosis and prognosis) in hospice day care, palliative units in nursing homes and home care, and symptom relief, medical care, meaningfulness, continuity and planning and cooperation in the home-care setting (III).

Table 10 Care areas of strength and care areas for improvement within each setting (factors and single items).

	Hospice inpatient care	**Hospice day care**	**Palliative units in nursing homes**	**Home care**
Care areas of strength	*MT dimension:* Medical care (single item) *ID dimension:* Honesty Respect and empathy *SC dimension:* Planning and cooperation Pleasant and safe atmosphere (single item)	*MT dimension:* Medical care (single item) *ID dimension:* Honesty Respect and empathy *SC dimension:* Pleasant and safe atmosphere (single item)	*MT dimension:* Personal hygiene (single item) *PT dimension:* Access to help, food and equipment *ID dimension:* Honesty *SC dimension:* Relatives and friends Pleasant and safe atmosphere (single item)	*ID dimension:* Honesty
Care areas for improvement	*ID dimension:* Participation (regarding decisions about place of care)	*MT dimension:* Medical care (single item) *ID dimension:* Information (about diagnosis and symptoms, prognosis, medication and self-care) *SC dimension:* Planning and cooperation	*ID dimension:* Information (about diagnosis and symptoms and prognosis)	*MT dimension:* Symptom relief Medical care (single item) *ID dimension:* Information (about diagnosis and symptoms, prognosis and the nurse in charge of their care) *SC dimension:* Meaningfulness Continuity Planning and cooperation

Relationships between the combination of person- and organization-related conditions and patients' perceptions of subjective importance (IV)

The association between patients' perceptions of SI and the combination of person- and organization-related conditions was that gender, daily contact with family and friends, and health-related quality of life have a statistically significant association with how important patients perceive the care to be (IV). Women scored the subjective importance significantly higher than men for three out of the four quality dimensions (MT, PT, ID) and two single items – hygiene and atmosphere. The SI was also rated higher for patients with daily contact with their families and friends for the dependent variables MT, ID and SC dimensions, and for the single item about medical care. The 'health-related quality of life' was negatively related to the dependent variable ID dimension. This combination of independent variables (person- and organization-related conditions) explained the variance in the dependent variables by: 18% for MT dimension, 18% for PT dimension, 30% for the ID dimension, 24% for the SC dimension, and for the single items: 19% for medical care (R^2 value: 0.187), 24% for personal hygiene (R^2 value: 0.238) and 32% for atmosphere (R^2 value: 0.317) (IV). None of the organization-related conditions was associated with SI (IV).

Relationships between the combination of person- and organization-related conditions and patients' perceptions of perceived reality (IV)

Patients' perceptions of actual care received (PR scale) had a statistically significant relationship to the person-related conditions SOC and age (IV). There was a positive relationship between SOC and all of the quality dimensions (MT, PT, ID and SC dimensions), and the single items about medical care and atmosphere. The condition 'age' was negatively related to the ID dimension. With regard to the organization-related conditions, patients who received care from settings where physicians were available in the wards rated the PR higher for the single item about medical care than patients receiving medical care from GPs (IV). The combination of independent variables (person and organization related) explained the variance in the dependent variables by: 24% for MT dimension, 22% for PT dimension, 30% for the ID dimension, 28% for the SC dimension, and for single items: 26% for medical care (R^2 value: 0.257) and 29% for atmosphere (R^2 value: 0.285).

Summary of findings

The summary of findings is presented according to the overall aim.

Quality of palliative care from the patient perspective

- The literature review revealed four themes comprising patients' preferences for palliative care. The theme 'living a meaningful life' illustrated what patients strived for and showed preferences for the healthcare system to focus on. The opportunity to focus on living required a healthcare system serving the patients to be responsive to their preferences, including 'Responsive healthcare personnel', a 'Responsive care environment' and 'Responsiveness in the organization of palliative care' (I).
- Subjective importance scored highest for the factors and single items related to: medical care (MT), respect and empathy, honesty (ID), care for relatives and friends, planning and cooperation and the atmosphere in the ward (SC) (II, IV). Subjective importance scored lowest for the factor related to the SC dimension; 'Spiritual and existential' (II).
- Patients' perceptions of the subjective importance did not differ across settings (III).
- Perceived reality scored highest for the factors and single items related to: medical care and personal hygiene (MT) (II, IV), 'Respect and empathy' and 'Honesty' (ID) (II), 'Relatives and friends' and the atmosphere (SC) (II, IV). The lowest levels for PR were reported for the MT dimension and the factors 'Exhaustion' and one factor related to the SC dimension; 'Spiritual and existential' (SC) (II).
- Patients' perceptions of the care received differed according to the setting to which they were admitted (III). Patients in hospice inpatient care scored the PR significantly higher for most areas compared with patients in other settings. These areas were within the MT dimension the single item about medical care, the ID and the SC dimension (III).
- Areas of strength were related to the factors and single items within the MT, ID and SC dimensions: medical care (MT) (II), treating patients with honesty (III), respect and empathy (ID) (II), providing care for relatives and friends (II) and a pleasant and safe atmosphere (SC) (III).
- Areas for improvement were related to factors and single items: symptom relief (MT), information about diagnosis and prognosis, participation regarding place of care (ID), continuity, and planning and coordination of care (SC) (II).
- When contrasting patients' perceptions across the settings, the patients in the home-care setting scored significantly lower than patients in the other settings, and most areas for improvement were present in the home-care setting. These were related to the MT, ID and SC dimensions: symptom relief, medical care (MT), information (ID), meaningfulness, continuity, and planning and cooperation (SC) (III).

Adaptation and psychometric evaluation of QPP-PC

- The QPP-PC was adapted and psychometrically evaluated resulting in a stable 12-factor solution (including 49 items) and 3 single items, for the SI and PR scales which made up the four dimensions (MT, PT, ID and SC) of quality of care based on the theoretical model described by Wilde et al. (1993) and Paper I. Internal consistency was assessed by Cronbach's α and the reliability coefficients were acceptable for most factors and dimensions (II).

Relationships between the combination of person- and organization-related conditions and perceptions of care quality

- The person-related conditions – women, daily contact with family and friends and lower health-related quality of life – were significantly associated with higher scores on the SI scale. None of the measured organization-related conditions was associated with SI (IV) and no significant differences were shown across the four settings with regard to SI (III).
- Person-related conditions (higher SOC scores and lower age) and organization-related conditions (physician available in the ward) had a statistically significant relationship with higher scores on the PR scale (IV).

Discussion

Discussion of the results

Quality of palliative care from the patient perspective is discussed according to the aim of the thesis, starting with a discussion of 'Quality of palliative care from the patient perspective, including patients' preferences and perceptions of subjective importance (SI), patients' perceptions of perceived reality (PR), and areas of strength and importance within and across settings. Then follows the adaptation and evaluation of the QPP-PC. Finally, the relationship between the combination of person- and organization-related conditions and perceptions of SI and PR are discussed.

Quality of palliative care from the patient perspective

Patients' preferences and perceptions of the subjective importance of palliative care (SI) (I–IV)

Most care aspects were considered as being important to patients (II–IV), in line with a Canadian study including seriously ill patients admitted to hospital (Heyland et al., 2006; Virdun et al., 2015) and a systematic review including cancer patients in hospital (not palliative care) (Petersen et al., 2015). However, the scores in this thesis are slightly lower at the dimension level than two studies in a Swedish care context, one of which included cancer patients (Henoch et al., 2011) and the other patients receiving specialized palliative home care (Wilde Larsson et al., 2004).

The subjective importance scored lowest for the factor related to the socio-cultural atmosphere (SC) dimension 'Spiritual and existential' (II). This is not in line with the findings in Paper I, the 6' S nursing model (Ternestedt et al., 2012), and with definitions of palliative care (EAPC, 2009; WHO, 2002), in which existential support by healthcare personnel is highlighted as important. This may be explained by the way in which this aspect was measured or that patients in this study did not find this aspect to be of greatest importance. Within the different settings, however, low scores for this factor were present only in the palliative care unit setting (mean 2.51) (III). At the factor level, no statistical comparison of patients' perceptions across settings was performed, therefore no conclusion could be made. However, further studies should investigate whether the subjective importance of the care aspect 'Spiritual and existential' varies across settings and, if this is true, investigate the reason why.

At the dimension level, significant differences across the four settings with regard to SI were not present (III), indicating that patients' perceptions of SI are not influenced by the care context. This is in line with the results in Paper I in which preferences seemed to have more similarities than differences across cultures of care. In contrast, a study comparing hospital care found that patients in the wards had higher SI scores than patients admitted to day surgery units (Wilde Larsson et al., 2005). One explanation could be the differences in the patients included. However, studies investigating SI across settings are few and more studies are needed to draw a conclusion.

Patients' preferences for palliative care included living a meaningful life and responsive healthcare personnel, care environment and organization of care (I), line with patients'

scores of SI (II-IV). The findings show that it is important for patients that palliative care is responsive. For healthcare personnel to provide high-quality care, it is therefore important for the care to be in line with what is considered important by the patients and to be person centred. The person-centred nursing model of palliative care (Hermansson & Ternestedt, 2000; Ternestedt et al., 2002; Ternestedt et al., 2012) is in line with many of the care areas found to be important for patients in this thesis. Also it appears that the theme 'Living a meaningful life' (I) is in line with the '6'S' model. In addition, the '6'S' model provides useful guidance for achieving this theme in clinical practice.

Nurses hold unique competence and responsibilities for communication and collaboration in team work, coordination of nursing and creating an environment that is safe and based on respect for the individual patient (AACN, 2012; ICN, 2012). The multiprofessional nature of palliative care (WHO, 2002) requires nursing competencies with regard to team work. In addition, patients' preferences related to the environment of palliative care, and organization, planning and coordination of care, challenge the nurses to hold such competencies and take responsibility according to these aspects of care. When providing palliative care, nurses must be aware of patients' perceptions of importance and of their own unique responsibility related to these aspects of care.

Patients' preferences may serve as a definition of what constitutes high-quality palliative care (Sofaer & Firminger, 2005). The findings in this thesis about patients' preferences are congruent with many of the aspects in the WHO and EAPC definitions of palliative care (EAPC, 2009; WHO, 2002), and the national guidelines developed for palliative care (Norwegian Directorate of Health, 2015a), aimed at improving the quality of life. However, the content of the concept 'quality of life' has been criticized for being mainly related to symptoms, functioning and psychological wellbeing, and not targeting patients' goals related to meaning, purpose, spirituality and grief (Kaasa & Loge, 2003). Patients' preferences for help in living a meaningful life is connected to the aim of palliative care – to improve quality of life- including the patient perspective of what is considered meaningful and important.

Patients' perceptions of quality of perceived reality (PR) (II-IV)

The quality of care received by patients receiving palliative care in the included settings could be interpreted as being moderate to high for most dimensions, factors and single items (II, IV). The mean scores in this thesis are less favourable than scores from a previous study, which included patients in palliative care in Sweden (Wilde Larsson et al., 2004) and from a study in Norwegian hospitals (not specifically palliative care) (Grøndahl et al., 2011), but are in line with scores obtained from patients with lung cancer in a Swedish care context (Henoch et al., 2011), all using the QPP instrument. A recent report evaluating palliative care in the Norwegian context found that the leaders evaluated the overall quality of palliative care as 'high' in the hospitals and as 'good enough' in community care (Melby et al., 2016). However, this evaluation of quality of care was at an overall level. Perceptions of care quality in relation to different aspects of care could be experienced differently from the different perspectives (Donabedian, 1980; Larsson & Wilde-Larsson, 2012) of, for example, leaders and patients. In addition, the report stated that patients' perceptions barely were collected in these care contexts (Melby et al., 2016), so the is a need for frequent evaluation of the patient perspective.

Patients' perceptions of PR differed according to the *setting* to which they were admitted (III). Patients in specialized palliative care scored the PR significantly higher than patients in non-specialized settings of care. In particular, patients in hospice inpatient care scored favourably for most care areas (ID, SC and single item about medical care), compared with the other settings. Previous research, mostly from the relatives' perspectives, similarly found specialized palliative care in dedicated hospice inpatient care and nursing homes to be beneficial compared with settings not specializing in palliative care, especially with regard to pain control, communication, and medical and nursing care (Addington-Hall & O'Callaghan, 2009; Candy et al., 2011; Lammi, Kosunen, & Kellokumpu-Lehtinen, 2001). However, Burge et al. (2014) investigated relatives' perceptions of care quality in both specialized (hospital-based palliative care unit) and non-specialized (home care, long-term care and hospital ward) settings, and found that none of the settings was exceptional. The lack of studies from the patient perspective makes it difficult to reach any conclusions.

According to the principles of evidence-based nursing, nursing care incorporates: knowledge of patients' experiences, values and preferences; the nurses' knowledge, experiences and attitudes; relevant research/evidence; and available resources (Willman, Stolz, & Bahtsevani, 2016). These findings of this thesis about patients' experiences of care and their preferences, may inform nurses and healthcare personnel about taking evidence-based decisions for the welfare of their patients.

Areas of strength and areas for improvement (II-IV)

In this thesis, care *areas of strength* refer to high scores on SI and PR scales. Areas of strength were related to the MT, ID and SC dimensions (II, III), the single item concerning medical care (MT), the factors concerning giving honest answers to patients, providing respect and empathy (ID), care for relatives and friends, and the single items concerning a pleasant and safe atmosphere in the ward (SC). In particular, areas of strength were related to hospice in patient care, hospice day care and palliative care units in nursing homes (III).

Studies from settings of hospice day care and hospice inpatient care (relatives' perspectives) support the medical–technical competence, identity–oriented approach and socio-cultural atmosphere being well provided for (Addington-Hall & O'Callaghan, 2009; Bradley et al., 2011; Stevens et al., 2010). However, the environment of care in hospital settings not specialized in palliative care has been found inappropriate, being too busy and noisy (Brereton et al., 2012; Rigby et al., 2010; Robinson et al., 2013). Hence, this emphasizes the importance of developing the care environment according to patients' preferences (I) and to ensuring high-quality care at home or in nursing homes, to enable patients who are especially sensitive to environmental change to receive care in familiar surroundings for as long as possible.

The care area of honest answers from healthcare personnel was an area of strength in all the included settings. A study including patients from palliative hospital-based home care units showed that all patients want to know the truth, although they define it differently (absolute truth, partial truth and desirable truth), and elicited coping strategies according to these definitions (Friedrichsen, Lindholm, & Milberg, 2011). This highlights the

importance of gaining knowledge about patients and their preferences when providing honest answers.

To keep up the good work, it is important to build on areas of strength. The care environment, healthcare personnel, provision of care and patients' perceptions of care have mutual influences (Arnetz, 2012). Hence, knowledge of strengths may serve as an important motivator for nurses, and other healthcare personnel, to continue providing high-quality care.

Care *areas for improvement* refer to significant differences between low PR and high SI scores. Areas for improvement were related to the MT, ID and SC dimensions (II, III): symptom relief (MT), information about diagnosis and prognosis, participation over place of care (ID), continuity, and planning and coordination of care (SC). Previous studies from the different palliative care context confirm that improvement in these care areas is needed (Bélanger et al., 2011; Robinson et al., 2013; Ventura et al., 2014).

Most areas for improvement were present within the home-care setting and related to symptom relief, medical care (MT), information (ID), meaningfulness, continuity, and planning and cooperation (SC) (III). A review from the home-care setting supported these findings, and found that patients and relatives needed more information about the illness and how to manage their lives, experienced insufficient communication with physicians, including lack of interest and time for patients' concerns, and lack of communication between healthcare personnel resulting in poor coordination of care. Last, unmet needs were present related to spiritual, psychosocial, practical, respite care, isolation and increased dependence on help (Ventura et al., 2014).

In the Norwegian context, challenges in providing palliative care in the community have been related to, for example, the healthcare personnel's competence in palliative care (Ministry of Health and Care Services, 2015), availability and follow-up from physicians, insufficient resources e.g., staff and problems coordinating care (Melby et al., 2016). Continuity, planning and coordination of palliative care across settings have been pointed out as an area in need of special attention (WHO, 2004). For the home care services this seems to be particularly relevant. A study from the Norwegian home care context (Gjevjon, Eika, Romøren, & Landmark, 2014) showed a low degree of interpersonal continuity for older patients receiving high-frequency home care (patients with life-threatening illness excluded), in which patients received an average of 17 different carers during a period of four weeks. Home care services are facing existing and future challenges related to more patients with complex needs requires palliative care in their homes, and the facilitation of home deaths (Ministry of Health and Care Services, 2013). For patients to be confident that they will receive care of high quality in their homes, the need for improvement is apparent and related to several specific care areas presented in this thesis and previous studies. These areas for improvement can inform nurses and other healthcare personnel, leaders and policy-makers on the daily performance of high-quality care, and help when planning and developing improvement initiatives. Settings that excel should be consulted about quality work to use in settings that need improvement. Also further interventions studies should focus on palliative care interventions, including the hospice philosophy, in homecare.

Adaptation and psychometric evaluation of the QPP-PC

The psychometric evaluation of the QPP-PC showed a stable 12-factor solution (explained variance: 68.25%) (including 49 items) and 3 single items, making up the 4 dimensions of quality in palliative care, for the SI and PR scales (II). To our knowledge, previous instruments measuring patients' perceptions of palliative care do not cover all these aspects of care in one single instrument, including measurements of PR and SI.

Compared with the QPP, differences appeared according to (1) divergent correlations of items including the presence of single items and (2) new factors and items. Three single items are present in the QPP-PC. The item about the ward's atmosphere was not applicable to patients in the home-care setting, and personal hygiene was not applicable for many in the day-care settings. The item about medical care showed a pattern different to the other items in the 12-factor solution and the QPP. For a previous adaptation and psychometric evaluation of the QPP-PC in in vitro fertilization (IVF) care (QPP-IVF) (Holter et al., 2014), results were similar, and 'medical care' was kept as a single item – an explanation being its overall nature. In this thesis, the two items (medical care and hygiene) were conceptually related to the MT dimension, and atmosphere to the SC dimension when describing the instrument. However, they should be analysed as single items.

New items and factors in the QPP-PC compared with the QPP (Wilde et al., 1994; Wilde Larsson & Larsson, 2002; Wilde Larsson et al., 2004) were as follows: extended items about symptom relief relevant to palliative care and the factor 'exhaustion'(MT); the item about waiting times (previously in the MT dimension) which correlated with the items about food and equipment and formed the new factor 'Access to help, food and equipment, (PT); new items about information on illness, symptoms and prognosis, and participation (in nursing and medical care, individual care plan and place of care) (ID); the factors 'meaningfulness' and 'spiritual and existential' which have been modified according to content and factor names; new items about care and participation of family and friends; the item about care being determined at one's own request (individual care) which correlated with a new factor called 'continuity'; and the new factors and items about continuity and planning and cooperation. Compared to the QPP items about nursing and physician care, the QPP-PC includes more professions.

The main differences between the QPP and the QPP-PC are related to the adaptation to the palliative care context, e.g., symptom relief, broader multiprofessional approach, individual plan for care, care for family, continuity and planning and cooperation. These aspects of care are in line with regulatory documents in palliative care (WHO, Ministry of Health and Care Services; 2002, 2004) and findings in Paper I. Continuity and planning and cooperation within and between services can be considered important regardless of the setting (Sofaer & Firminger, 2005), however these aspects were absent in the theoretical model of quality of care (Wilde, 1994; Wilde et al., 1994; Wilde et al., 1993). One explanation could be that the model was developed based on interviews with patients admitted to hospital wards. Further studies should include these aspects to confirm the findings of this thesis.

The single item regarding pleasant and secure atmosphere in the ward was not included in the QPP-PC when used in the home care setting because patients were receiving care in their homes and not in an institution. However, one could argue that the care provided also influences the care atmosphere in the patients' homes. Further use of QPP-PC could therefore also include the single item regarding pleasant and secure atmosphere for patients in home care.

The QPP-PC was adapted to the palliative care context, and new aspects of care were found compared with the QPP. Further discussion of the construct validity and reliability of the QPP-PC is presented under the methodological considerations.

Relationships between the combination of person- and organization-related conditions and perceptions of care quality

The relationships between the combination of person- and organization-related conditions and perceptions of subjective importance

The conditions that were shown to have statistically significant relationships to patients' perceptions of SI were the person-related conditions: gender, contact with family and friends, and health-related quality of life (IV). Previous studies, including the combination of person- and organization-related conditions and their relationship to SI, have not been identified. However, a few studies have investigated the relationships between person-related factors with SI and these will be included in further discussion of the results.

Women rated the SI higher than men for the MT, PT and ID dimensions and two single items: hygiene and atmosphere (IV). Previous studies investigating person-related conditions have shown conflicting results. A study from hospital wards in five European countries found that women scored the SI higher than men for all items (Wilde Larsson et al., 2005), whereas another study that included patients with lung cancer found no differences in SI (Henoch et al., 2011). Patients with *daily contact with family and friends* rated the SI higher than those with less contact for the MT, ID and SC dimensions and the single item about medical care (IV). This is in line with a previous study from the palliative home-care setting in which family members with daily contact with patients rated the SI higher for aspects of care related to the MT and ID dimensions than family members who seldom met the patients (Wilde Larsson et al., 2004). One explanation could be that patients having daily contact value frequent contact with relatives and healthcare personnel, especially when experiencing life-threatening illnesses. On the other hand, for those who live alone or do not have frequent or close contact with family and friends, the relationship with healthcare personnel could be particularly important (Dzul-Church, Cimino, Adler, Wong, & Anderson, 2010; Hanratty et al., 2013) compared with patients living with someone (Hanratty et al., 2013). Further knowledge is needed, especially related to the differences in MT scores. Patients with lower *health-related quality of life* rated the SI higher than patients with higher health-related quality of life in the ID dimension (IV). In contrast, Henoch et al. (2011) found no statistically significant relationships between self-rated physical health and SI of care aspects. However, from the primary health care context, patients with low health status placed greater emphasis on personal care and enough time to talk about their problems (Jung, Baerveldt, Olesen, Grol, & Wensing, 2003), which is in line with the findings in this thesis.

The results of the combination of person- and organization related conditions indicated that patients' perceptions of SI were related to person-related conditions. This can help healthcare personnel to identify patients for whom certain care aspects are particularly important, thereby enhancing provision of person-centred care. None of the measured organization-related conditions was associated with SI (IV). More studies are needed investigating whether, and if so, which organization-related conditions are related to SI, as well as the relationship between the combination of person- and organization-related conditions and perceptions of SI.

The relationships between the combination of person- and organization-related conditions and perceptions of perceived reality

The significant relationship between the combination of person- and organization-related conditions and perceptions of PR was related to the person-related conditions – age and SOC – and the organization-related conditions – organizational model for physicians (IV). With regard to *Age*, older patients rated the care received lower than younger patients for one (ID) of the four dimensions (IV). This could indicate that older patients received care of lower quality. However, findings from studies performed in settings other than palliative care more commonly found that elderly patients rated the quality of care received higher than younger patients (Crow et al., 2002; Grøndahl et al., 2011; Sofaer & Firminger, 2005; Wilde Larsson, 1999). Further studies from the palliative care context are needed to confirm or refute this finding. Patients with a higher *SOC* scored the PR higher for all the dimensions (MT, PT, ID and SC), and the single items about medical care and atmosphere (IV). The high degree of association between SOC and several dimensions of PR is in line with a previous study investigating the association between SOC and quality of care received in hospital wards (Wilde Larsson & Larsson, 1999). A high SOC means that patients have a positive life orientation, including high comprehensibility, manageability and meaningfulness, which enable patients to manage stressful situations and stay well (Antonovsky, 1987; Eriksson & Lindström, 2005). Possibly one explanation for why patients with higher SOC scores on the PR scale could be that these patients to a greater extent cope with their situation, and are more content with their life situation in general. *Organizational model for physicians* was significantly related to PR (IV). Patients who received care in settings where physicians were available on the wards rated the care received for the single item about medical care higher than patients receiving medical care from GPs. In home-care, patients' GPs are responsible for medical care. However, the follow-up and engagement by GPs with patients in the late palliative phases have been found to vary in a recent report evaluating palliative care (Melby et al., 2016). This could explain why patients' perceptions of quality of medical care received were scored lower for patients in settings where GPs were responsible for their medical care.

The results indicated that the combination of person- and organization-related conditions was related to PR. Nurses are obliged to have competencies for provision of high-quality nursing care, to be involved in quality work (ICN, 2012) and to apply quality improvement (AACN, 2012; Cronenwett et al., 2007). The knowledge of the variation in patients' perceptions of care received, according to person- and organization-related conditions, can help nurses and other healthcare personnel to identify subgroups of patients needing special attention.

Methodological considerations

Design

This doctoral thesis has been conducted with studies using different methods, including a systematic literature review exploring preferences for palliative care, quantitative studies investigating patients' perceptions for palliative care quality and psychometric testing of an instrument that measures patients' preferences.

One could argue whether a mixed methods study design would have been appropriate to use when combining findings from a systematic mixed studies review and quantitative methods addressing the overall aim. There are different ways of describing mixed methods designs (Creswell & Plano Clark, 2007; Polit & Beck, 2014). Commonly, mixed methods studies are described in terms of quantitative and qualitative data and do not explicitly include systematic reviews. However, one could argue that mixed methods using sequential design could have been used, and the papers with different, but equally dominant, methods were conducted at different time points and sequentially built on each other's findings (Polit & Beck, 2014).

Using methods within different paradigms is necessary in nursing research to gain comprehensive knowledge of complex phenomena (Polit & Beck, 2014). Multiple methods could thereby strengthen the design of the thesis and enhance the validity of the results, in that the findings from one paper inform the development of the next (Polit & Beck, 2014), and gain comprehensive knowledge of quality of care from patient perspective.

The systematic mixed studies review (I)

Validity and reliability

Validity and reliability in systematic mixed studies reviews refer to how well each step in the review has been performed and described, and these steps were presented in the methods section. Hence, in this section more overall issues are discussed in terms of strengths and limitations.

The synthesis of findings from studies using quantitative and qualitative methods is methodologically challenging, and this highlights the importance of a transparent process (Sandelowski, Voils, & Barroso, 2007). However, the strength of combining such findings is the comprehensive nature of the knowledge gained (Whittemore & Knafl, 2005). Validity and reliability were achieved via a thorough and transparent performance and description of all steps in the methods section, guided by acknowledged and fundamental principles (Higgins & Green, 2011; Moher et al., 2009). In addition, the fact that the researchers worked closely together and in pairs, when performing duplicate selection of studies for inclusion, quality assessment and data extraction, ensured rigour at all stages.

Although comprehensive electronic searches were conducted and reference lists were screened, limitations were related to the fact that experts in the field were not contacted and no searches for 'grey literature' were conducted. The choice to include studies that more comprehensively investigate patients' preferences for palliative care from the patient perspective, and exclude studies focusing on specific areas of care, e.g., advanced care planning, may have led to the exclusion of many relevant studies. However, the inclusion

of studies focusing on specific areas of palliative care could have biased the results because studies on aspects subjected to a high level of research could wrongly be interpreted as particularly important to patients. Reliable quality assessment tools were used, although there may be weaknesses in these rating systems, which could have rated the quality of studies too high or too low.

Generalization
This paper comprises studies including adult patients with both malignant and non-malignant diagnoses who receive palliative care in several specialized and non-specialized settings. This makes the findings relevant to nurses and other healthcare personnel, leaders, policy-makers and researchers in palliative care. Each theme from the thematic findings is represented by all the studies included, suggesting that preferences for care seem to have more similarities than differences, even if the studies were conducted within different cultures and over a time span of 31 years. The themes represent what is regarded as important for patients in palliative care, and thereby relevant for inclusion in measurements of patients' perceptions of quality of palliative care (II–IV).

The quantitative study (II–IV)
Validity concerns to what degree the inferences are accurate and well-founded (Polit & Beck, 2014). It also included the degree to which an instrument measures what it is intended to measure. The validity with regard to the included instruments was described in the methods section. Further validity is discussed within the following four aspects of research design: statistical conclusion validity, internal validity, construct validity and external validity (Polit & Beck, 2014). In addition, comments about the reliability, with regard to the accuracy and consistency of the information obtained (Polit & Beck, 2014), are discussed.

According to Polit and Beck (2014), *Statistical conclusion validity* concerns the statistical analysis, whether the inferences about relationships and differences are accurate, and the statistical power of the study. The decision to use parametric analyses for this thesis was based on the research aims and the data level (most analyses were performed at the factor and dimension level) (Field, 2013).

The power evaluation for estimating the necessary sample size was based on previous studies using the QPP in related samples (Henoch et al., 2011; Lövgren, Wilde-Larsson, Hök, Leveälahti, & Tishelman, 2011; Wilde Larsson et al., 2004), and an expected medium effect size was estimated, resulting in inclusion of a minimum of 300 participants to achieve a minimum 80% power. Of the 262 patients asked to participate, 191 returned the questionnaire (response rate = 73%) (Polit & Beck, 2012). The recruitment of large samples of patients in the late palliative phase of their illnesses is difficult. To enhance the number of patients included, the data collection period was extended by six months, but the estimated sample size was not achieved due to, for example, many patients having cognitive impairment and patients dying before the scheduled interviews. The number of participants was most critical for obtaining a stable factor solution in the PCA analyses (II), often relying on the participant to variable ratio. To enhance a stable factor solution, the number of items was reduced, based on critical assessments by the research group.

The Kaiser–Meyer–Olkin (KMO) test was >0.8 for the whole instrument and >0.6 for all individual factors, and a stable pattern of factors was achieved. Consequently, the sample size appeared to have been sufficient (II). The number of participants and the response rate are considered to be sufficient and the risk of bias relatively small for the other analyses (III, IV) (Polit & Beck, 2012).

Internal validity concerns inference that the outcome was caused by independent variables rather than other conditions (Polit & Beck, 2014). A threat to the internal validity concerns the selection biases. A consecutive sample means that everyone who met the inclusion criteria should be invited to participate (Polit & Beck, 2014). Even if the registered nurses recruiting patients (RRNs) were taught how to include participants, there is a risk that not all eligible patients were recruited. Other tasks sometimes took priority due to the hectic nature of the RRNs' daily work. In some cases, they perceived that the identification of patients in their last year of life was difficult, especially in the home-care setting. Another reason could be that RRNs hesitated to ask patients, e.g., because patients were considered to be too ill, or they did not want to burden the patients. The frequent contact with the author served as a reminder to screen patients for inclusion and to discuss patients whom the RRNs hesitated to include. Patients who did not respond did not differ from patients included with regard to age and gender. However, there was a concern that patients who had not responded were those with poor physical and psychological health, hence creating a difference between those who were included and those who did not respond. The participants had varying levels of self-reported physical and physiological health (III, IV).

Data collection methods could influence perceptions of care quality (Addington-Hall et al., 1998; Wilde Larsson, 2000). Of the included patients, 54 had help filling out the questionnaire (II–IV). Independent sample t-test was run to control whether patients' perceptions of care quality had been influenced. The analysis indicated that the data collection method used did not bias the majority of the results.

Another threat to the internal validity is related to the instrument used (Polit & Beck, 2014). The questionnaire may have been too comprehensive, possibly resulting in that patients got tired and answered randomly or chose not to complete. To reduce the burden of filling out, and enhance the completion of each instrument, particular attention was paid to the layout, the instructions on how to fill out the questionnaire and the modification of items. The questionnaire was divided into five sections (one for each instrument and one for demographic items), in which patients were told to complete all items in the parts that they chose to fill out, and that they could use all the time needed to complete it. The QPP items were modified by reducing the number of words and merging items, to lessen the amount of text. However, the last sections/instruments (health-related quality of life, psychological wellbeing and SOC) had the highest number of missing items (health-related quality of life: $n = 25$; psychological wellbeing: $n = 21$; and SOC: $n = 44$) (IV), indicated that the number of items could have been perceived as too high.

The participants in the four settings differed by age, education, type of diagnosis, number of diagnoses and time in care (III). However, in the analysis, differences in patient characteristics were taken into consideration and controlled for, except for 'type of diagnosis' (too few with non-malignant diagnosis) and 'time in care' (type of organization). Patients with non-malignant illnesses have been found to be related to perceptions of low quality (Brännström et al., 2011; Murray et al., 2002), and extended time in care has been associated with higher perceptions of care quality (Findik et al., 2010). It is therefore difficult to assess whether differences observed across the settings were influenced by patients' diagnoses or time in care.

Grouping the patients in the two hospice inpatient services (III) could be questionable because they differed in their organization of care – one was delivered through community care and the other through specialist care services. Additional analyses were conducted to check whether patient demography in these two hospices differed significantly, and whether hospice care delivered through community care differed significantly from that of the palliative units in nursing homes in community care. The results justified grouping together the two hospice wards because patients' characteristics in these wards did not differ, but significant differences were found for the palliative units in nursing homes.

The model for each dimension on the SI and PR scales explained about 18-30% and 22-29% respectively, of the variance, leaving about 75% unexplained. Several independent variables about organization-related conditions were collected (see Methods section). However, in the services, data were registered in different ways and this making it difficult to use the data in the analyses. Future research need to find how to measure organization-related conditions in multiple palliative settings.

The patients included were asked to evaluate their palliative care during admission, which presents challenges both methodologically and ethically (Addington-Hall, 2002; Casarett & Karlawish, 2000). On one hand, patients could feel obliged to rate the care more positively. On the other hand it may be considered unethical not to include these patients. Steps were taken to reduce this risk as previously described. Receiving both high and low scores for the care quality, and scores similar or below previous studies, this seems not to have influenced the findings substantially.

Construct validity involves inferences from a study's particulars to a higher-order construct that it intends to represent, and includes the degree to which the instrument measures the intended construct (Polit & Beck, 2014). The strength of the QPP-PC is that it is based on the QPP, which is a frequently used and well-validated instrument derived from a theoretical framework of quality from the patient perspective and patients' preferences for palliative care (I). The QPP-PC is considered to have a strong conceptual foundation (Hair et al., 2014). The construct validity was tested by psychometric evaluation of the QPP-PC and showed a stable 12-factor solution (explained variance: 68.25%), including 49 items and 3 single items, making up the 4 dimensions of quality in palliative care, for the SI and PR scales. The 12 -factor solution was supported by the following: eigenvalue > 1.00 for all factors which explained; 68.25% of the total variance, considered satisfactory (Hair et al., 2014); and the Varimax rotation for which most items loaded

strongly in each factor (Hair et al., 2014). Based on a theoretical foundation and promising results when testing for validity and reliability (Campen et al., 1995; Sitzia, 1999), the QPP-PC can be used to measure patients' perceptions of quality in palliative care.

The QPP-PC was developed to measure quality of palliative care from the perspective of patients with different life-threatening illnesses admitted to different settings. Therefore, items with a 'not applicable' response were present, as expected. This was handled through calculation of a mean, based on individual patient answers to the remaining items within the factor or dimension, and, for the PCA, the mean of the remaining responses in the variable substituted for the 'not applicable' response (Fox-Wasylyshyn & El-Masri, 2005). However, this could imply a risk for correlation with the substituted mean rather than the remaining patients' responses to the respective items in the PCA. Steps were taken to reduce this risk: seven patients were excluded from the statistical analysis because of the high proportion of items answered 'not applicable'. The decision to exclude these participants was not predetermined but made after exploration of the data. In addition, before to the PCA, items with not-applicable or missing responses >35% were eliminated. This decision was based on the pilot study revealing that some patients found the questionnaire too long so that items with high amount of not-applicable or missing data, which were covered by existing items, were removed. As the remaining items were judged to cover the items removed satisfactorily, the impact on the results and the construct was determined to be small. After the adaptation process, the QPP-PC consists of a considerably reduced number of items (n = 52). Most importantly, this reduces the burden on patients to complete the instruments, and also reduces the probability of 'not applicable' and missed responses for future use of the QPP-PC.

When interpreting the care quality measured by the QPP-PC, the areas for improvement were based on significantly higher scores on the SI compared with the PR scale. To identify areas of strength, patients' perceptions of care quality were interpreted as high and low, inspired by a previous interpretation of high QPP values (Henoch et al., 2011). Importantly, these interpretations should not be seen as fixed cut-off values. High scores interpreted as ≥3.55 meaning that patients' responses are between 'partly agree' and 'fully agree' (PR) or 'high' to 'very highest' importance (SI). From these values the highest levels of PR and SI were captured, reflecting areas of strength when factors received the highest scores on the PR and SI scales. However, the value ≥3.55 could be considered too high. The interpretation of low scores (≤3.00), could also be considered too high. Future studies could consider reducing this level, for example, to 2.5 or 2 to capture the lowest scores. In this thesis, a lower level would not have influenced the interpretation of the results, because most of the means were above 2.5.

Reliability refers to the degree of accuracy and consistency of the instrument measuring a certain attribute (Polit & Beck, 2014). The internal consistency measured by Cronbach's α, was presented in the Results section with regard to the QPP-PC. The internal consistency of the QPP-PC showed acceptable α values (>0.7) (Hair et al., 2014) for most dimensions and factors for the PR and SI scales, and were in line with previous studies (Henoch et al., 2011; Wilde Larsson et al., 2004). Overall, the internal consistency of the

QPP-PC is considered to be sufficient. However, the exceptions were for the PT dimension on the SI and PR scales (0.65/0.44), which consisted of the factor 'Access to help, food and equipment' only, and the factors 'continuity' (0.55/0.53) and 'relatives and friends' (0.66) on the PR scale, which all showed lower values. The α value for the PT dimension is in line with that of previous studies (Grøndahl et al., 2011; Wilde Larsson & Larsson, 2002), where low values could be explained by the low number of items (Field, 2013). It could be considered whether the PT dimension should be supplied by more items. Further studies are needed to confirm or refute these findings.

The psychometric evaluation showed promising results with regards to validity and reliability, indicating that QPP-PC can be used to measure patients perceptions of palliative care quality in various settings. However, further psychometric evaluation of the QPP-PC should include confirmatory factor analysis to support or refute the items and factors in this thesis. It is also necessary to investigate further the QPP-PC's feasibility (Polit & Beck, 2012), including the number of questions, and development of a short version should be considered.

Validated, reliable and frequently used instruments (SOC, EQ-3D) were used in this thesis. The reason for using the SOC-13 version was related to a reduction in the number of questions for the patients to answer. The EQ-5D-3L (including EQ VAS) questionnaire from the EuroQol group (Brooks, 1996; EuroQol Group, 1990) was chosen to reduce the amount of text for the patients. Validity could have been strengthened if the EQ-5D-5L had been used because the number of response alternatives is increased to reduce ceiling effects (EuroQol Group, 2011). The internal consistency measured by Cronbach's α for the SOC was acceptable (>0.7) and in line with previous studies.

External validity concerns the inference that the findings in a study can be generalized to different patients, conditions and settings (Polit & Beck, 2014). Participants represent a variety of life-threatening diagnoses in the late palliative phase relevant for palliative care, both different malignant and non-malignant diagnoses such as ALS, COPD, heart failure (HF) and MS. Most patients had cancer. This reflects the population who receive specialized palliative care (Norwegian Directorate of Health, 2015a). Most of the patients were older (mean: 66.80, range 41–94 years). Generalization to younger patients and patients with other diagnosis than cancer must therefore be made with caution.

Patients were recruited from both specialized and non-specialized palliative care settings (hospice inpatient care, hospice day care, palliative units in nursing homes and home care), in both sparsely and densely populated locations. However, patients do receive palliative care from contexts other than those included in this thesis, e.g., general hospital wards and community-based, non-specialized wards in nursing homes. Consequently, generalization to patients in other contexts must be made with caution. Similarly, generalization to patients who do not understand Norwegian, are cognitively impaired and/or are in an early palliative phase of their illnesses must be made carefully.

Conclusion and implication for practice

In conclusion, this thesis showed the patient perspective of the quality of palliative care, including subjective importance and the perceived reality of care received. Findings from the adaptation and psychometric evaluation of the QPP-PC have been presented. Relationships between the combination of person- and organization-related conditions and patients' perceptions of care quality were indicated.

- Patients' preferences for palliative care, as revealed in this thesis, need to be included in daily care and quality improvement work.
- Patients' perceptions of quality of palliative care received were mostly moderate and high.
- Patients' perceptions of palliative care received differed across settings, with patients in hospice inpatient care scoring significantly higher and patients in home care scoring significantly lower, for several areas.
- Nurses, other healthcare personnel, leaders and policy makers should build on areas of strength and address areas for improvement in efforts to continually provide and develop palliative care of high quality.
- The QPP-PC can be used to measure patients' perceptions of palliative care in quality work.
- Nurses and other healthcare personnel need to take person- and organization-related conditions into account when providing high quality person-centred palliative care.

Future research

- Further studies are needed to investigate areas of strength and areas for improvement in palliative care from the patient perspective, especially in non-specialized nursing home wards and hospital wards.
- Further psychometric evaluation of the QPP-PC with confirmatory factor analysis is suggested. In addition, development of a short version of the QPP-PC would be beneficial.
- Qualitative as well as quantitative studies are needed to investigating palliative care quality from the perspective of patients with other life-threatening illnesses than cancer.
- The findings of this thesis can be used to plan and conduct interventional studies to improve palliative care, especially in home-care settings.

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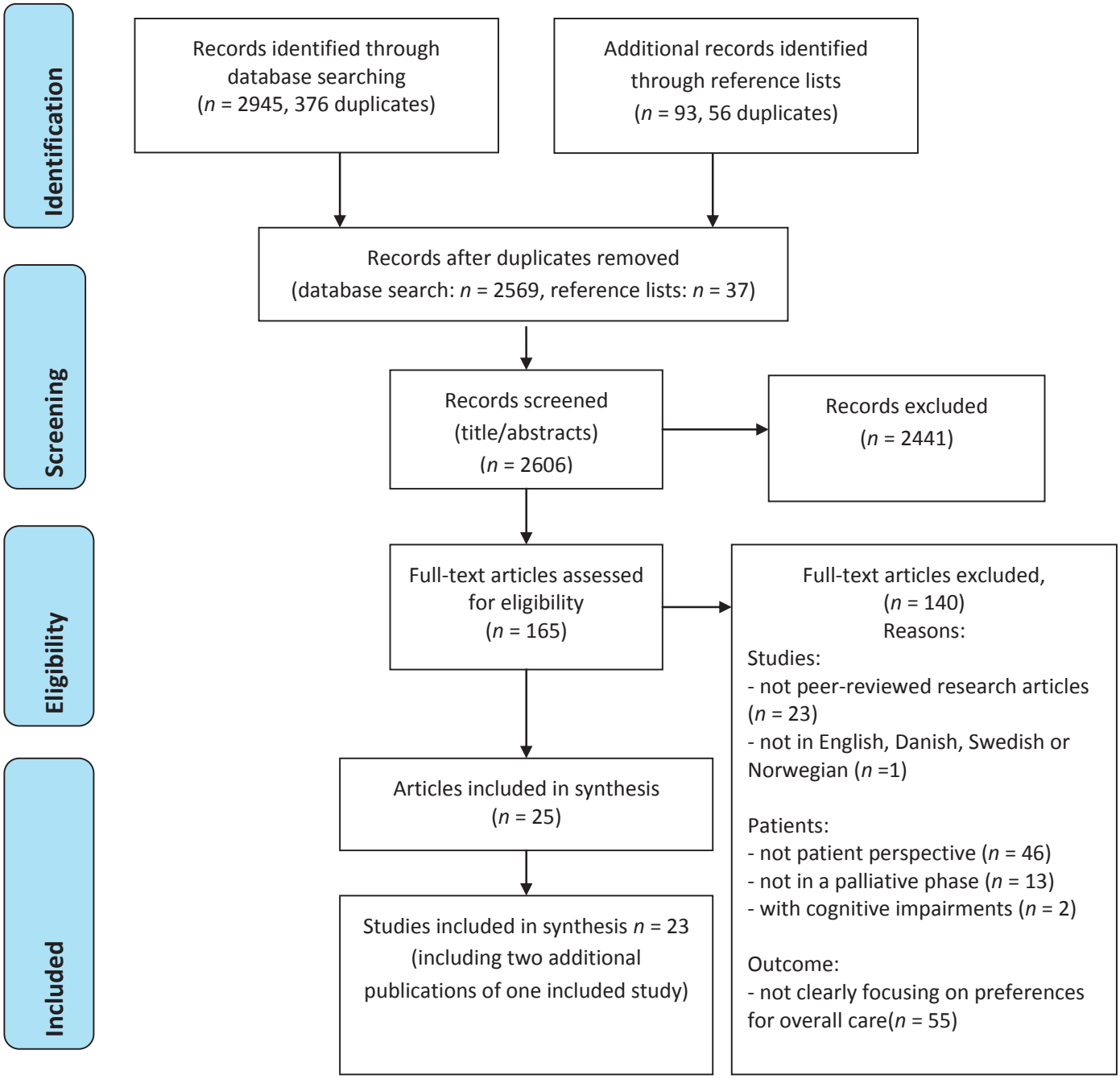
Appendix I

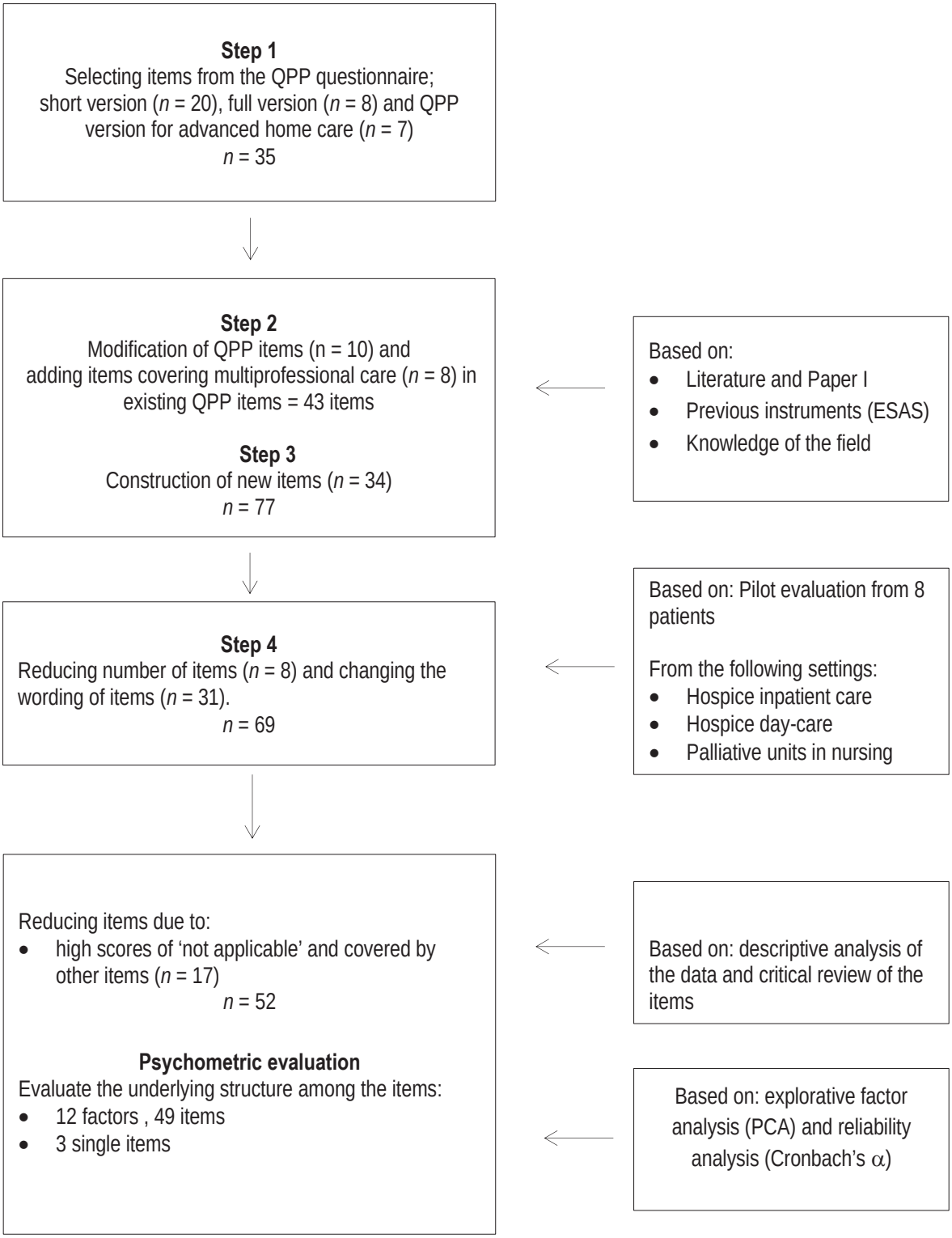
Appendix 1 Flow diagram of the selection process



Source: Modified version of flow diagram in Sandsdalen, T., Hov, R., Høye, S., Rystedt, I., & Wilde-Larsson, B. (2015). Patients' preferences in palliative care: A systematic mixed studies review. Palliative Medicine, 29(5), 399–419. With permission from Sage journals.

Appendix II

Appendix 2 Flow diagram of the adaptation and psychometric evaluation process of QPP-PC



Appendix III

Appendix 3 Full text of all dimensions, factors, single items and items in the QPP-PC

Dimensions	**Factors/**Single items/Items
Medical–technical competence	**Symptom relief**
	I receive the best possible help for pain
	I receive the best possible help for nausea/vomiting
	I receive the best possible help for loss of appetite
	I receive the best possible help for shortness of breath
	I receive the best possible help for depression (feeling sad)
	I receive the best possible help for anxiety (feeling nervous)
	I receive the best possible help for lack of sleep
	I receive the best possible help for constipation/diarrhoea
	Exhaustion
	I receive the best possible help for tiredness (lack of energy)
	I receive the best possible help for drowsiness (feeling sleepy)
	Medical care (single item)
	I receive the best possible help for the best possible medical care
	Personal hygiene (single item)
	I receive the best possible help to take care of my personal hygiene
Physical–technical conditions	**Access to help, food and equipment**
	I receive help within an acceptable waiting time
	I receive food and drink that I like
	I have access to the necessary equipment
Identity–oriented approach	**Information**
	I receive useful information on how care and treatments will take place
	I receive useful information on the effects and use of medicine
	I receive useful information on my illness and my symptoms
	I receive useful information on what I may expect in the near future (development of the illness and symptoms, my health and function)
	I receive useful information on how to take care of myself
	I receive useful information on which doctor is responsible for my medical care
	I receive useful information on which registered nurse is responsible for my nursing care
	Honesty
	The doctors give me honest answers to my questions
	The nurses (RNs) give me honest answers to my questions
	Other personnel[1] give me honest answers to my questions
	Respect and empathy
	The doctors understand how I experience my situation
	The nurses (RNs) understand how I experience my situation
	Other personnel[1] understand how I experience my situation
	The doctors are respectful towards me
	The nurses (RNs) are respectful towards me
	Other personnel[1] are respectful towards me
	Participation
	I have good opportunity to participate in the decisions that apply to medical care
	I have good opportunity to participate in the decisions that apply to nursing care
	I have good opportunity to participate in the decisions that apply to my individual care plan
	I have good opportunity to participate in the decisions that apply to choosing where to receive my care

Socio-cultural atmosphere	**Meaningfulness**
	The doctors support me in living my life in a meaningful way
	The nurses (RN) support me in living my life in a meaningful way
	Other personnel[1] support me in living my life in a meaningful way
	Spiritual and existential
	The doctors support me in tending to my spiritual and existential needs
	The nurses (RN) support me in tending to my spiritual and existential needs
	Other personnel[1] support me in tending to my spiritual and existential needs
	Relatives and friends
	My relatives and friends are treated with respect
	My relatives receive the best possible help, support and care
	My relatives may participate in decisions about my care, according to my preferences
	Continuity
	I usually receive help from the same doctor
	I usually receive help from the same nurse (RN)
	My care is determined by my own requests and needs rather than staff's procedures
	Planning and cooperation
	There is good planning of my medical care
	There is good planning of my nursing care
	The personnel cooperate well
	All the health and welfare services that I receive are well coordinated
	Atmosphere (single item)
	There is a pleasant and secure atmosphere on the ward

[1]Other personnel refers to: assistant nurse, priest, physiotherapist, occupational therapist or social worker.

Quality in palliative care from the patient perspective

Knowledge about patients' perceptions of palliative care is limited and valid instruments are needed. The aim of this thesis was to investigate quality of palliative care from the patient perspective, adapt and evaluate an instrument to measure patients' perceptions of quality in palliative care (QPP-PC), and investigate the relationship between the combination of person- and organization-related conditions and patients' perceptions of care quality. A systematic literature review and quantitative methods were used.

Patients' preferences in palliative care included help living a meaningful life and responsive personnel, care environment and organization of care. The QPP-PC was developed and identified patients' perceptions of areas of strength and for improvement in hospice inpatient and day care, palliative units in nursing homes and home care settings. Perceptions of care quality seemed to be related to person- and organization-related conditions, and differed across settings, although subjective importance did not.

The patient perspective of care quality should be integrated into daily care and quality work, and QPP-PC can be used in such work. Registered nurses and other healthcare personnel need awareness of person- and organization-related conditions to provide high-quality person-centred palliative care.

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