Quality improvement in palliative care – the role of a national quality register and perceptions of information during palliative chemotherapy

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Hold the question in your mind, but lightly, like it was something alive.

— Philip Pullman (from Northern lights)

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ABSTRACT

INTRODUCTION

There is a need in palliative care for development of structured methods to assess quality and support improvement. This need is present both within and outside specialised palliative care.

Honest information from physicians is regarded as an important part of palliative care. Information about the transition to end-of-life care (ITEOL), conveyed by physicians to patients, has also been described as a 'breakpoint conversation'.

Quality registers enable monitoring and improvement of quality of care, and clinical research. The Swedish Register of Palliative Care (SRPC) is a Swedish national quality register that collects data from hospitals, hospices, nursing homes and home care, with an end-of-life questionnaire (ELQ) about palliative care content focusing on the last week of life.

AIMS

Study I – The aim was to examine the validity of the ELQ from the SRPC.

Study II – The aim was to examine whether participation in the SRPC increases the quality of palliative care over a three-year period regarding eight items in the ELQ.

Study III – The aim was to examine whether an educational intervention for physicians and nurses in nursing homes and hospitals increases the proportion of patients who receive ITEOL.

Study IV – The aim was to describe how patients with cancer perceive the information they receive from physicians during palliative chemotherapy.

METHODS

Study I – Data from 100 medical records and data from the paper versions of the ELQ filled in at a specialised palliative unit were compared with data reported to the SRPC.

Study II – Data from eight items in the ELQ reported to the SRPC from all healthcare units that had reported patients continuously during a three-year period were compared year-by-year with logistic regression.

Study III – Two municipalities (in charge of nursing homes) and two hospitals were randomised to receive an interactive half-day course about ITEOL for physicians and nurses. Four hospitals and four municipalities were assigned matched controls. The proportion of patients who received ITEOL before and after the intervention was measured with the ELQ. The effect of the intervention was analysed with a multivariable logistic regression model.

Study IV – Fifteen semi-structured interviews with patients with incurable cancer were conducted, transcribed verbatim and analysed with qualitative content analysis.

RESULTS

Study I – The questions in the ELQ showed a congruity of 22% to 100% when comparing data from medical records with data reported to the SRPC. Eight questions fell below 80%. The paper versions filled in at the unit and the data reported to the SRPC showed a congruity of between 91% and 100%.

Study II – The prevalence of six symptoms decreased. The prescription of PRN (pro re nata – 'as needed') medications for pain, nausea, anxiety and death rattle increased. A higher proportion of patients died in their place of preference. The patient's next of kin was more often offered a follow-up appointment after the patient's death. There was no change in the proportion of patients or next of kin who received ITEOL.

Study III – The proportion of patients in the intervention group who received ITEOL increased from 35.1% (during a six-month period before the intervention) to 42.0% (during a six-month period after the intervention). The proportion in the control group increased from 30.4% to 33.7%. The effect of the intervention was significant ($p=0.005$) in the multivariable model.

Study IV – Three categories were disclosed during the analytical process: 'living with a death sentence', 'depending on chemotherapy', and 'living with uncertainty'.

CONCLUSIONS

A national quality register has the potential of contributing to quality improvement in palliative care. Study I showed varied validity in the ELQ, implying a need to modify the questionnaire. Study II showed that participation in the SRPC was covariant with quality improvements in end-of-life care over time. Study III showed that more patients received ITEOL after an educative half-day intervention directed to physicians and nurses. Study IV showed that patients undergoing palliative chemotherapy perceived that their disease was incurable and deadly, and that conditions for future treatment and survival were uncertain.

KEY WORDS

Cancer, chemotherapy, communication, end-of-life care, oncology, palliative care, palliative medicine, quality in healthcare, quality register

ABBREVIATIONS

AIDS – Acquired immunodeficiency syndrome

ALS – Amyotrophic lateral sclerosis

BGS – British Geriatrics Society

COPD – Chronic obstructive pulmonary disease

DPD – Danish Palliative Care Database

ECOG – Eastern Cooperative Oncology Group

ELQ – End-of-life questionnaire

EPUAP – European Pressure Ulcer Advisory Panel

ESAS – Edmonton Symptom Assessment System

ITEOL – Information about the transition to end-of-life care

LCP – Liverpool Care Pathway for the Dying Patient

NBHW – National Board of Health and Welfare

NRS – Numeric rating scale

PCOC – Palliative Care Outcomes Collaboration

PRN – pro re nata ('as needed')

RUG-ADL – Resource Utilisation Groups – Activities of Daily Living

SALAR – Swedish Association of Local Authorities and Regions

SRPC – Swedish Register of Palliative Care

VAS – Visual analogue scale

WHO – World Health Organization

SWEDISH AUTHORITIES AND REGISTERS

Name in English	**Name in Swedish**
National Board of Health and Welfare (NBHW)	Socialstyrelsen
National Patient Register	Patientregistret
National Prostate Cancer Register	Nationella prostatacancerregistret
Statistics Sweden	Statistiska centralbyrån (SCB)
Swedish Association of Local Authorities and Regions (SALAR)	Sveriges kommuner och landsting (SKL)
Swedish Cancer Register	Cancerregistret
Swedish Knee Arthroplasty Register	Svenska knäartroplastikregistret
Swedish Tax Agency	Skatteverket

SAMMANFATTNING PÅ SVENSKA

KVALITETSFÖRBÄTTRINGSARBETE INOM PALLIATIV VÅRD – ROLLEN FÖR ETT NATIONELLT KVALITETSREGISTER OCH UPPFATTNINGAR OM INFORMATION GIVEN I SAMBAND MED PALLIATIV CYTOSTATIKA

INTRODUKTION

Det finns ett behov av att utveckla strukturerade metoder för att mäta och förbättra vårdkvalitet inom palliativ vård. Behovet finns såväl inom som utanför den specialiserade palliativa vården.

Ärlig information från läkare anses vara en viktig del av palliativ vård. Information från läkare till patienter om övergången till livets slutskede har beskrivits som ett ”brytpunktssamtal” eller kommunikation om övergången till livets slutskede (eng. ITEOL).

Kvalitetsregister möjliggör monitorering och förbättring av vårdkvalitet samt klinisk forskning. Svenska Palliativregistret (eng. SRPC) är ett svenskt nationellt kvalitetsregister som samlar in data från sjukhus, hospice, särskilda boenden/korttidsboenden och hemsjukvård med en dödsfallsenkät (eng. ELQ) om innehållet av den palliativa vården, fokuserat på den sista veckan i livet.

SYFTEN

Studie I – Syftet var att undersöka validiteten för dödsfallsenkäten från Svenska Palliativregistret.

Studie II – Syftet var att undersöka om deltagande i Svenska palliativregistret under en treårsperiod ökar den palliativa vårdkvaliteten angående åtta frågeområden i dödsfallsenkäten.

Studie III – Syftet var att undersöka om en utbildningsintervention riktat till läkare och sjuksköterskor inom kommunala boendeformer och sjukhus ökar andelen patienter som erhåller brytpunktssamtal.

Studie IV – Syftet var att beskriva hur patienter upplever den information de får från läkare under tiden de behandlas med palliativ cytostatika.

METODER

Studie I – Uppgifter från 100 patienters journaler och de ifyllda pappersversionerna av dödsfallsenkäten insamlade från en palliativ enhet jämfördes med data som rapporterats in till Svenska palliativregistret.

Studie II – Data från åtta frågor i dödsfallsenkäten som rapporterats in till Svenska palliativregistret från alla sjukvårdsenheter som deltagit i registret under en treårsperiod jämfördes år för år med logistisk regression.

Studie III – Två kommuner och två sjukhus valdes slumpmässigt ut till att erhålla en interaktiv halvdagsutbildning i brytpunktssamtal för läkare och sjuksköterskor. Andelen patienter som erhöll brytpunktssamtal före och efter interventionen mättes med dödsfallsenkäten. Fyra kommuner och fyra sjukhus matchades till kontroller. Effekten av interventionen analyserades med en multivariabel logistisk regressionsmodell.

Studie IV – Femton semistrukturerade intervjuer med patienter med obotlig cancer genomfördes, skrevs ut ordagrant och analyserades med kvalitativ innehållsanalys.

RESULTAT

Studie I – Frågorna i dödsfallsenkäten uppvisade en samstämmighet på 22 – 100 % när uppgifter från patientjournalerna jämfördes med data inrapporterat till Svenska palliativregistret. Åtta frågor uppvisade under 80 % samstämmighet. Pappersversionerna av dödsfallsenkäten som fyllts i på den palliativa enheten och data rapporterad till Svenska palliativregistret uppvisade en samstämmighet på 91 – 100 %.

Studie II – Prevalensen av sex symptom minskade. Förskrivningen ökade av vid behovs-medicin i injektionsform för smärta, illamående, oro/ångest och rosslighet. En högre andel patienter dog på den önskade platsen. Patienternas närstående blev oftare erbjudna ett efterlevandesamtal. Andelen patienter och närstående som erhöll brytpunktssamtal förändrades inte.

Studie III – Andelen patienter i interventionsgruppen som erhöll brytpunktssamtal ökade från 35,1 % (under halvåret före interventionen) till 42,0 % (under halvåret efter interventionen). Andelen i kontrollgruppen ökade från 30,4 % till 33,7 %. Effekten av interventionen var signifikant (p=0,005) i multivariabelmodellen.

Studie IV – Tre kategorier framkom under analysprocessen: ”leva med en dödsdom”, ”vara avhängig av cytostatika” och ”leva med osäkerhet”.

SLUTSATSER

Ett nationellt kvalitetsregister har potential att bidra till kvalitetsförbättring inom palliativ vård. Studie I visade att frågorna i dödsfallsenkäten hade varierande validitet, vilket visade på ett behov av att modifiera enkäten. Studie II visade att deltagande i Svenska Palliativregistret samvarierade med kvalitetsförbättring av vård i livets slutskede. Studie III visade att fler patienter i livets slutskede erhöll brytpunktssamtal efter en halvdags utbildningsintervention riktad till läkare och sjuksköterskor. Studie IV visade att patienter som behandlades med palliativ cytostatika upplevde att de blivit informerade att deras sjukdom var obotlig och dödlig, och att villkoren för deras framtida behandling och överlevnad var osäkra.

NYCKELORD

Cancer, cytostatika, kommunikation, kvalitetsregister, onkologi, palliativ medicin, palliativ vård, vård i livets slutskede, vårdkvalitet

ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their roman numerals, I–IV:

I. Martinsson L, Heedman PA, Lundström S, Fransson G, Axelsson B. Validation study of an end-of-life questionnaire from the Swedish Register of Palliative Care. Acta Oncol. 2011 Jun;50(5):642-7.

II. Martinsson L, Fürst CJ, Lundström S, Nathanaelsson L, Axelsson B. Registration in a quality register: a method to improve end-of-life care: a cross-sectional study. BMJ Open. 2012 Aug 30;2(4).

III. Martinsson L, Heedman PA, Eriksson M, Tavelin B, Axelsson B. Increasing the number of patients receiving information about transition to end-of-life care: the effect of a half-day physician and nurse training. BMJ Support Palliat Care. 2015;0:1–7.

IV. Martinsson L, Axelsson B, Melin-Johansson C. Patients' perception of information from physicians during palliative chemotherapy: a qualitative study. Submitted.

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INTRODUCTION

TERMINOLOGY IN PALLIATIVE CARE

PALLIATIVE CARE

The word 'palliative' is derived from the Latin word *pallium*, which means cloak (1). Palliative care has an alleviating and holistic perspective, which could be seen as a mantle for the patient (2). Palliative care is described as an active philosophy of total care where quality of life is in focus; where physical, psychological, social and existential/spiritual needs are addressed; and where the patients' next of kin and their needs also are in focus (1, 3, 4). In Sweden, palliative care is often described as having four cornerstones: symptom control, teamwork, communication/relationships and family support (5, 6), but it has also been suggested that this metaphorical description does not cover all the important aspects of palliative care (5).

Modern palliative care has its roots in England, where the first hospice (St Christopher's Hospice) was started in 1967 by Dame Cicely Saunders (1). The word hospice is derived from the Latin word *hospitium*, which means hospitality. Before the first modern hospices started, during the middle of the 1900s, dying persons were mostly taken care of at hospitals. Care for dying patients had gradually shifted from their own homes to hospitals during the last half of the 1800s and the first decades of the 1900s. This is often explained by increased medical knowledge and the ability to treat and cure diseases that had been major causes of death. Unfortunately, this also resulted in the healthcare service regarding death as a defeat and not as a natural part of life (4, 7). High quality care for dying patients was not in focus at the hospitals. There are stories of physicians not visiting these patients, because 'nothing could be done', leaving them without adequate support and symptom relief, despite being at a hospital. Drugs for symptom alleviation, such as morphine against pain, were used sparsely (4, 8). The hospice movement started as a reaction against these shortcomings (4).

During the last decades, palliative care has been gradually separated from hospice care. Palliative care is described in the literature as a broader term, including not exclusively care for dying patients, but also for patients in earlier stages of incurable diseases. Palliative care is now seen as care that can and should be integrated early into the progress of incurable diseases, and it does not exclude other forms of therapy, for example, chemotherapy (7, 9, 10). There has also been a transition from palliative care being a form of care exclusively for patients with cancer to being a form of care for patients with all forms of progressive incurable diseases, for example, heart diseases, respiratory deficiency and neurological diseases, such as amyotrophic lateral sclerosis (ALS) (1, 4, 10).

Table 1. WHO definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The World Health Organization (WHO) published the first version of their definition of 'palliative care' in 1990, and the current version in 2002 (Table 1) (9, 10). Their first definition focused on the dying phase, whereas the current definition has a broader perspective. The newer definition also widens the focus on patients with cancer to one in which palliative care is not narrowed to specific diagnoses (10). The possibility of integrating other therapies along with palliative care has also been emphasised (9, 10). The current definition from the WHO has been criticised for toning down the holistic view derived from hospice care. The increased focus on active treatments has also been argued to be a risk for medicalisation and objectification of the patients (7).

Official Swedish definitions of terms used in palliative care were published in a term bank by the Swedish National Board of Health and Welfare (NBHW) in 2011. In the term bank, palliative care is defined as healthcare which aims to relieve suffering and promote quality of life of patients with progressive and incurable diseases or injuries, regarding physical, psychological, social and existential needs, and organised support to next of kin (11). This Swedish definition does not limit palliative care to specific diagnoses. Unlike the WHO definition of palliative care, it is not stated that the disease or injury has to be life threatening. Neither the WHO definition nor that of the NBHW limits palliative care to a specific time frame before death.

EARLY AND LATE PHASES OF PALLIATIVE CARE

A commonly used illustration of palliative care is a division between an early and a late palliative phase (1, 12-15). In the early palliative phase, the disease is incurable, progressive and deadly, but treatment to prolong life (e.g., antitumoral therapy) is possible. The focus during the early palliative phase is

both to prolong life and to give the patient a high quality of life, for example, by alleviating symptoms (1, 15). The early palliative phase can have a duration of up to several years, and the late palliative phase is typically a couple of weeks (1, 15, 16), but this differs much between different diseases and individuals (15).

In the late palliative phase, treatment of the incurable disease is not likely to prolong life, and the goal of care shifts towards providing the best possible quality of life and support of next of kin (1, 15, 16). The start of the late palliative phase is also sometimes described as when the patient no longer responds to antitumoral treatment (15), but in reality some patients enter the late palliative phase even at the diagnosis (17). The late palliative phase in oncology typically is weeks or a month (15).

The division of palliative care into early and late palliative phases is not always used to illustrate palliative care in texts about palliative care. For example, in the latest Swedish national guidelines for palliative care, early and late palliative phases are not defined and are only briefly mentioned (4). Instead, the disease trajectory is sometimes described as a chronic phase and the end of life (4, 17).

The change from early to late palliative phase can be difficult to assess for patients with incurable diseases other than cancer, such as congestive heart failure, chronic obstructive pulmonary disease (COPD), diabetes and dementia (1, 4, 17). The palliative trajectory of cancer is often described as a rapidly progressing deterioration that ends with death of the patient, while the palliative trajectory of diagnoses with less predictable prognosis is sometimes described as a slow deterioration interrupted by several acute phases, where each one may end with death but also may be partly reversible (4, 17). If no acute incidents occur, the patient can live for a long time with poor general health. For example, it has been stated that for patients with Alzheimer's disease, the most common form of dementia, both the early and late palliative phases can have durations of up to several years (1).

END OF LIFE AND END-OF-LIFE CARE

End of life and end-of-life care are terms that are widely used but not clearly defined. The terms 'end-of-life care' and 'palliative care' have often been used synonymously in the scientific literature, and have thus not acknowledged the possibility of using disease-specific treatment, such as chemotherapy, in palliative care (3). End of life and the late phase of palliative care are sometimes described in similar ways or as two terms describing the same phenomenon (6, 18). For example, in a thesis by Näppä, end-of-life care in oncology was described as palliative care when life prolongation by further treatment of the cancer disease itself is no longer realistic (3).

The term ‘end of life’ has also sometimes been used to describe the last year, half-year or three months in a person’s life, sometimes the last week, and sometimes the point when death will occur within days (16, 19, 20). The problem with defining end of life as a time period before death is that it can only be defined afterwards. The NBHW defines ‘palliative care in the end of life’ as palliative care during the patient’s last period in life when the goal of the care is the relief of suffering and promotion of quality of life (11). Neither ‘end of life’ nor ‘end-of-life care’ is defined by the WHO.

DYING

‘Dying’ or ‘actively dying’ has been described as a process of hours or days (12, 19). The start of the dying phase is hard to define (12). ‘Dying’ has been defined by the NBHW as ‘a period with failure in the individual’s vital functions and symptoms showing that death is close’ (11). The WHO does not define dying. The following physical signs have been associated with dying among patients with cancer: pulselessness of radial artery, decreased urine output, Cheyne-Stokes breathing, respiration with mandibular movement, death rattle, a decreased response to visual stimuli, an inability to close eyelids, drooping of the nasolabial fold, hyperextension of the neck, grunting of vocal cords and upper gastrointestinal bleeding (21, 22). Signs of dying according to the Liverpool Care Pathway for the Dying Patient (LCP) include being bedbound, having reduced consciousness, being only able to drink small amounts of water, and being unable to swallow pills (23), but it has been proposed that this definition should be reviewed, because patients with dementia or neurodegenerative disorders can fulfil these criteria long before death (24).

TERMINAL CARE

Terminal care is an earlier, frequently used term for palliative care or end-of-life care, but is now rarely used (1, 15). The recommendation from the NBHW is not to use the term ‘terminal care’ (11).

TRANSITIONS

TRANSITION FROM CURATIVE TO PALLIATIVE TREATMENT

The change from curative to palliative treatment is often referred to in oncology as a transition, and has been described as occurring when there is no longer any chance to cure the patient’s disease (25, 26). Neither the WHO nor the NBHW define the transition from curative to palliative treatment.

TRANSITION TO END-OF-LIFE CARE

The shift from early to late palliative phase, or to end-of-life care, is also commonly referred to as a transition, or ‘breakpoint’, mostly in Swedish but also in international literature (11, 13, 16, 17). This transition from early to late

palliative phase is the transition that is mainly referred to in the palliative medicine literature. The NBHW defines the 'transition to palliative care in the end of life' as the stage when the main purpose of the care changes from prolonging life to optimising quality of life (11). The WHO does not define this transition.

INFORMATION ABOUT TRANSITION TO END-OF-LIFE CARE

In Sweden, terminology has been developed to describe the occasion when patients receive information about the transition to end-of-life care (ITEOL). This discussion has been described as a 'breakpoint conversation' (*brytpunktssamtal*) or communication about the transition to end-of-life care (4, 11, 13, 27, 28). The NBHW defines 'breakpoint communication at the transition to palliative care in the end of life' as 'communication between the physician in charge and a patient about the decision to initiate palliative care in the end of life, where the content of care is discussed in relation to the patient's condition, needs and wishes' (11). The WHO does not define ITEOL.

SPECIALISED PALLIATIVE CARE

Specialised palliative care is defined by the NBHW as 'palliative care provided for patients with complex symptoms or a life situation with special needs, and delivered by a multiprofessional team with specific knowledge and competence about palliative care' (11). Specialised palliative care has also been known as 'advanced palliative care', but the NBHW recommends that this term not be used (11). The WHO does not define specialised palliative care.

It has been estimated that about 1/3 of dying patients have modest symptoms and needs that are mostly related to daily life, while 1/3 have some need of hospital care, and 1/3 have symptoms that demand more specialised palliative medicine and care (29). The availability of specialised palliative care varies worldwide. In Sweden, around 15% of all dying patients receive specialised palliative care to some extent (30).

PALLIATIVE CHEMOTHERAPY

The aim of therapy against cancer can be divided into curative and palliative. Curative treatment aims to cure the patient of cancer, but cure is not always achieved. The chance to successfully cure a patient differs greatly between different cancer diagnoses. For example, the chance of cure is high for thyroid cancer, testis cancer and some lymphomas, but low for pancreatic cancer. Also, other factors, such as old age, can affect the chances of cure. Even if a curative treatment does not succeed, the treatment often has benefits for the patient, in that it may prolong life and/or diminish symptoms (26).

There is no consensus on how large the required chances for cure should be to initiate treatments with curative intention, and patients and physicians do not necessarily weigh the risks and potential chances for cure in the same way. According to a study by Slevin et al., patients with cancer accept a treatment with a much smaller chance of cure compared to physicians, nurses and healthy controls (31). Patients' preferences for palliative chemotherapy based on likely survival time benefits were shown by Silvestri et al. (32) to vary considerably. Patients sometimes demand active treatment in situations where there are no or very low chances of cure (26).

Whereas 'palliative' usually refers to a measure that aims to increase quality of life of the patient, palliative chemotherapy often aims to prolong the patient's life (33). The purpose of palliative chemotherapy is often described as prolonging life and/or alleviating symptoms by reducing the tumour load and/or slowing tumour growth (33, 34). The term palliative chemotherapy was previously not clearly defined (15), but the current version of the WHO definition of palliative care has made it clear that palliative chemotherapy does not exclude other forms of palliative care (7, 9, 10). Cooperation between oncology and palliative care is now considered necessary for patients with incurable cancer (15).

Survival benefit is often the primary outcome measure in clinical research examining palliative chemotherapy (33). Fewer studies have examined the effect of chemotherapy on quality of life and alleviation of symptoms (26). While the survival benefit of palliative chemotherapy varies considarably between different cancer diagnoses and different types of chemotherapy, the survival gain tends to be months rather than years (33). Examples of cancer diagnoses where antitumoral therapy can prolong life by months or years are colorectal cancer, malignant lymphomas, leukaemia, ovarian cancer, breast cancer and urine bladder cancer (26).

While great risks are sometimes accepted for the chance to achieve cure, much caution should be taken with palliative treatment, so that risks and side effects do not exceed the benefits of treatment. It is important to continuously balance these factors (26). Palliative chemotherapy often has considerable toxicity and modest survival benefits, which can make decisions about initiating or ceasing treatment difficult (33). A good treatment choice in the early palliative phase can become a bad choice later in the disease trajectory. The potential side effects should be carefully balanced with the potential benefits for the patient when making a treatment choice in the early palliative phase (34). To accept a very low chance of beneficial effects of chemotherapy can lead to many patients being exposed to chemotherapy with heavy side effects that has no positive effect on the patients' survival time or quality of life (26).

DEATH AND DYING IN SWEDEN

Palliative care has developed considerably in Sweden during the last years. The first national guidelines for palliative care were launched in Sweden in 2012 (4). During 2010–2014, there was a government programme called 'Better Life for Most Sick Elderly', which promoted palliative care, among other areas (28, 35). The first modern Swedish palliative home care started in 1976 in Motala (7). The first Swedish hospices started in the 1980s (13). The first professor in palliative medicine in Sweden was appointed in 1997 (1). Palliative medicine became a medical speciality in 2015 (36). In recent years, it has become increasingly more common to have palliative teams that can be consulted, for example, by primary care (29).

Around 90 000 people die every year in Sweden. This corresponds to approximately 1% of the Swedish population. There were 90 505 deaths in Sweden (46 777 women and 43 728 men) during 2013 (37). The most common cause of death was cardiovascular disease (38% of all deaths in women and 37% in men), followed by cancer (24% women and 27% men). The most common cancers resulting in death were lung cancer in women (followed by breast cancer) and prostate cancer in men (37). Dementia is an increasing cause of death (37). During 2013, life expectancy in Sweden was 83.7 years for women and 80.1 years for men (38). A common approximation is that about 80% of all deaths in Sweden are slow, which means that the death is predictable, and there is time to provide end-of-life care (12).

There are no updated Swedish national statistics on where the deaths occur. Data from the Swedish Register of Palliative Care (SRPC) shows that out of all patients registered to the SRPC in 2014 35.5% died in nursing homes, 34.7% in hospitals, 10.2% in hospices/specialised palliative hospital wards, 7.6% in short-term care homes, 5.5% in regular home care, 5.2% in specialised palliative home care and 1.3% in other places (39). According to data from the National Patient Register, 34 000 died in Swedish hospitals during 2013 (28). During 1996, 42% died in hospital, 31% died in nursing homes and other types of municipal care, 20% died in their homes and 7% had an unknown place of death. There were big geographical differences (12).

Because of decentralisation of the decision-making in healthcare to the 290 municipalities and 20 counties in Sweden, healthcare services are diversely organised. The municipalities are responsible for care of the elderly, and the counties in Sweden are responsible for hospital care. There are also an increasing number of private caregivers that mostly perform licensed work for municipalities and counties, and a small number of private caregivers that are strictly private. Around 500 000 people work in healthcare and social care in Sweden (40). Overall, end-of-life care is provided, to some extent, by over 6000

healthcare units, such as hospital wards, nursing homes, hospices and home care teams (28).

Eldercare takes place in nursing homes or in the patient's own home with support from home care. General physicians are responsible for the elderly in nursing homes. The approximately 80 hospitals in Sweden can be divided into small hospitals with a selection of the most common forms of care, county hospitals with most forms of specialised care, and university hospitals with subspecialised care (41). In most places, one general physician is responsible for several nursing home wards. In hospitals, usually several physicians are responsible for each ward. There are very seldom volunteers present in Swedish healthcare.

There is a lack of documentation of end-of-life care outside the specialised palliative care in Sweden (42), and different systems for medical records have been shown to sometimes hinder the exchange of necessary medical information about a patient's palliative care plan between nurses and other staff involved in the care of the patient (43).

SPECIALISED PALLIATIVE CARE IN SWEDEN

Specialised palliative care in Sweden is diversely organised. There is no cohesive national structure, and the division between specialised and nonspecialised palliative healthcare units is not clear. As an example of this, the survey from 2006 by the NBHW divided palliative care in Sweden into palliative healthcare units in hospitals, healthcare units in primary care, hospices, palliative home care or palliative advisory teams from hospitals, palliative home care from primary care and palliative day care (44). The survey also showed that specialised palliative care in Sweden was unevenly distributed (43, 44). Specialised palliative home care was sometimes available only during office hours and was not available at all in some municipalities (44). In some places there was a lack of physicians (43). Another conclusion in the survey was that there was a need for professional development for staff working in palliative care (44), which was also underlined in a Swedish governmental report from 2001 (12).

Brännström et al. showed that there is unequal palliative care in Sweden when comparing patients with cardiovascular diseases with patients with cancer (45). Older patients with COPD, severe chronic heart diseases and dementia do not have access to specialised palliative care equal to that of younger patients with cancer (43), which can be exemplified by the fact that over 80% of patients cared for in specialised palliative care in Sweden have cancer (28). It has been argued that taboo of death contributes to this inequality in palliative care (43).

LEGAL ASPECTS OF PALLIATIVE CARE IN SWEDEN

The Swedish Health Care Law requires that the person with the greatest need for healthcare should be given priority (46). The political ambition is to offer all citizens dignified, well-operating healthcare at the end of life, regardless of where the palliative care is given (12). According to a governmental investigation of priorities, a dignified farewell from life should be one of the mostly highly prioritised rights in healthcare, and that end-of-life care should be prioritised on an equal basis with care for acute life-threatening diseases/injuries and severe chronic diseases (47). In Sweden, a patient is allowed to decline the care offered but does not have the right to demand a treatment that is not medically motivated (26). Euthanasia is not legal. The practice usually is to inform patients about their health status, which is also mandated by the law (48).

QUALITY IN PALLIATIVE CARE

GOOD END-OF-LIFE CARE

The British Geriatrics Society (BGS) has proposed a list of high quality end-of-life care characteristics for older people (Table 2) (49), which are widely used as a basis for defining good end-of-life care, for example, by the SRPC.

Table 2. Principles of a good death according to the British Geriatrics Society

1. To know when death is coming and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and other symptoms
5. To have choice and control over where death occurs (i.e. a home or elsewhere)
6. To have access to any spiritual and emotional support required
7. To have access to hospice care in any location, not only in hospital
8. To have control over who is present and who shares the end
9. To be able to issue advance directives which ensure wishes are respected
10. To have time to say goodbye and control over other aspects of timing
11. To be able to leave when it is time to go and not have life prolonged pointlessly

SYMPTOM CONTROL

Symptom control is central to palliative care and end-of-life care (50) and is included in the definition of palliative care from the WHO (9). A symptom can be described as the organism's answer to stimuli from within or from the outside that is interpreted as a sign of illness by either the organism or the surroundings (51). Common symptoms in the end of life are pain, anxiety, nausea, shortness of breath, fatigue, loss of appetite, depression, drowsiness and delirium (4, 50).

Research about symptom control in the end of life has mostly focused on patients with cancer, while symptom control for patients with other life-threatening diseases has not been as well studied (52). In a literature study, Solano et al. compared the symptom prevalence in very advanced cancer, acquired immunodeficiency syndrome (AIDS), heart disease, COPD and renal disease, and found that pain, breathlessness and fatigue were found among more than half of patients for all five diseases, suggesting that symptom prevalence in end of life is similar for many diseases (52).

Symptom alleviation with subcutaneous injections using a subcutaneous needle is often used for alleviation of pain and other symptoms during the last days of life. Injections are recommended over oral administration because it has a quicker and more reliable effect. Subcutaneous injections have been recommended over intravenous because intravenous injections can cause more discomfort and have a higher risk for infections (16).

A structured assessment of symptoms is essential for symptom control (53). Several tools for assessment of pain and other symptoms are used in palliative care. The visual analogue scale (VAS) is a tool used for assessment of pain and other symptoms that usually consists of a 100 mm line marked with the extremes in symptom intensity, for example, 'no pain' and 'extreme pain'. The respondent places a mark on the line corresponding to the intensity of the symptom experienced (54). The numeric rating scale (NRS) is a tool for assessment of pain and other symptoms in which the patient rates intensity from 0 ('no suffering') to 10 ('unbearable suffering') on a numbered scale instead of on the continuous scale used in VAS (55). The Edmonton Symptom Assessment System (ESAS) (also commonly referred to as the Edmonton Symptom Assessment Scale) is a questionnaire that uses numeric rating scales to measure levels of pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath (55, 56).

A special consideration when collecting patient-rated data from patients in the end of life is that the questionnaires have to be brief to enable the patients to answer. In the last days of life it is common for patients to only manage to answer yes or no; they may be too tired or cognitively impaired to use a VAS (56). Proxy rating (by next of kin or healthcare professionals) is a potential source of symptom assessment if the patient is unable to provide it (54), but symptom rating by proxies has been shown to differ from the patient's own rating (57, 58). For example, Broberger et al. showed that both family caregivers and nurses generally rated symptom occurrence as greater than the patients with lung cancer (59). The Abbey Pain Scale is a tool that was developed to assess the pain of patients with dementia who cannot verbalise. The scale is used by healthcare professionals, who score the patient's signs of pain by assessing vocalisations, facial expressions, changes in body language, behavioural changes, physiological changes and physical changes (53).

PREVENTION OF PRESSURE ULCERS

Pressure ulcers are wounds that occur when skin or underlying tissue suffers injury because of direct pressure or pressure with shear forces (60). Pressure ulcers can be graded from one to four according to the European Pressure Ulcer Advisory Panel (EPUAP) (61). Grade one is an area of persistent skin redness, grade two is partial loss of skin layers, grade three is deep skin craters and grade four includes exposure of bone or muscle (62).

Pressure ulcers can negatively affect patients' well-being and quality of life (62). Few trials have been published about prevention of pressure ulcers in advanced illness, but it has been shown that frequent changes of positions with a tilt of 30 degrees is preventive (4, 60). Prevention of pressure ulcers when the patient has an advanced illness is challenging (60), and it has been stated that not all pressure ulcers are preventable (60). During the dying phase, prevention of pressure ulcers should be weighed against the discomfort the patient may experience if the body position is changed regularly (4).

PRESENCE AT TIME OF DEATH

To allow the patient to have control over who is present at the end is regarded as important in end-of-life care, but how many patients do not want to die alone or who these patients want to be with at the time of their death is not known. Many health professionals argue that a dignified death means not dying alone (12).

PREFERRED PLACE OF CARE IN END OF LIFE

To be able to choose the place of end-of-life care is regarded by the BGS as part of good end-of-life care (49). When asked about their preferred place of end-of-life care, Swedish citizens wished to be cared for at their own home (12). In a study by Tang, 87% of terminally ill patients with cancer wished to die at home (63). Another study including patients with congestive heart failure, COPD and pneumonia found that only 43% preferred to have terminal care at home, while 48% preferred hospitals (64).

QUALITY INDICATORS IN END-OF-LIFE CARE

The NBHW defines quality as 'the degree to which a medical service satisfies the requirements placed on it' (65, 66). A quality indicator is defined as an explicitly defined and agreed upon measurable item that give an indication of the quality of care, referring to clinical outcomes, processes (e.g., following of guidelines) or structures. Quality indicators are usually described with a numerator and a denominator. The numerator is the number of cases that fulfill a predetermined criterium, the denomerator is the total number of cases in the intended population and the quota indicate the performance. The indicators are based on a standards that are derived from scientific evidence or expert panels. Quality indicators are used to monitor and evaluate quality in healthcare (67-70).

There are few randomised controlled trials to support quality indicators for end-of-life care, and the basis for quality indicators is often poorly documented in medical records (69). It can also be problematic to define the target population in end-of-life care because of the diverse patient population (69). Many quality indicators in palliative care are focused on specific populations, such as patients with incurable cancer, and are focused on specific types of treatment (67, 68). Some quality indicators proposed in palliative care are defined retrospectively from the time of death, which limits their use prospectively (69). A review found that most sets of quality indicators in palliative care do not contain all three types of quality indicators (structure, process and outcomes of care) (67). Social and spiritual aspects of palliative care are underrepresented in the quality indicators described in the literature (67, 68, 71).

SWEDISH QUALITY INDICATORS IN PALLIATIVE CARE

Lind et al. reviewed Swedish policy documents in 2013 and found seven general quality indicators in palliative care and end-of-life care: proportion of relatives offered counselling for survivors, use of an NRS for pain estimation during the palliative phase, registration in the SRPC, prescription of injectable PRN (pro re nata – 'as needed') opioid to alleviate pain during end-of-life care, documentation of the patient's transition to the palliative phase, guidelines and procedures used for end of life care and nursing that describe how informed counselling can be offered to terminally ill people aged 65 years and older, and proportion of people aged 65 years and older who have died for whom pain was estimated with the aid of a scientifically evaluated instrument the final week of life. There were no indicators relevant for palliative or end-of-life care in the national guidelines for cardiology, pulmonary diseases, stroke, diabetes or dementia (65).

In 2013, the NBHW published a report about good palliative care in end of life (6). In the report, six quality indicators for good palliative care in the end of life were identified: proportion of deceased patients reported to the SRPC (a structure indicator), two or more admissions to in-hospital care in the last 30 days in life, documented individual prescription of injectable PRN medication to alleviate anxiety, documented individual prescription of injectable PRN opioid medication, documented assessment of oral health in the last week of life (process indicators) and presence of pressure ulcers grades 2–4 according to EPUAP (61) (an outcome of care indicator). Three indicators for development were also identified: ITEOL (a process indicator), analysis of pain and regular evaluation of pain intensity (a process indicator) and regular use of tools for symptom assessment (described by the NBHW as a structure indicator) (6).

In the current national guidelines for breast, prostate and colorectal cancer, one quality indicator regarding palliative care (palliative radiotherapy for bone metastases) is defined (72). In the current national guidelines for lung cancer care, two quality indicators regarding palliative care (palliative radiotherapy for lung cancer stages IIIB and IV, and palliative chemotherapy for lung cancer) are identified (73).

STANDARDISED CARE PATHWAYS

Care pathways are widely used to systematically plan and follow up a patient-focused care programme (74), but can sometimes be perceived as too rigid (24). The Liverpool Care Pathway for the Dying Patient is the most widely used standardised care programme in end-of-life care. The aim of the LCP is to translate the model of hospice care for the dying into other healthcare settings. It is meant to be used during the last hours or days in a patient's life (75). There are indications in the literature that quality of the care has increased when the LCP has been used, but the evidence is poor (76, 77). No studies examining end-

of-life care pathways for improving outcomes in caring for the dying have met the inclusion criteria in the Cochrane review (77).

The LCP has been widely used the latest decade, especially in the UK (24). Several reports of misuse of the pathway have been put forward. In the UK, the LCP has been shown to have been inappropriately used as a surrogate for clinical responsibility, and there were performance-related payments to hospitals for the number of patients cared for using the LCP that possibly influenced the hospitals to use the LCP inappropriately. Now the LCP is being phased out in the UK (24, 77). Davis and Tomas have proposed that lack of consensus of terms, including 'palliative', 'end-of-life care' and 'dying', could be a reason for the misuse of the LCP (24).

COMMUNICATION ABOUT THE DIAGNOSIS AND GOAL OF CARE

The practice of disclosing the diagnosis and goal for treatment varies geographically, in different cultures and over time (78, 79). Generally, decision-making in healthcare has shifted from a paternalistic approach to one based on patient autonomy, where patients are informed about their disease and use this information to make informed decisions about their care (79, 80). Open communication with the patient and the next of kin, and the healthcare staff involved in the patient's care, about diagnosis, risks and benefits of palliative chemotherapy and the basis for treatment decisions is considered necessary and important for the patient's autonomy and decision-making (15, 26, 81), and for helping next of kin prepare for their impending loss and their bereavement (82).

The transition from curative to palliative care is not only difficult for the patient and the next of kin, but also for the healthcare staff. Healthcare staff often experience it as a failure, and there is a risk of this affecting the patient's palliative care in a negative way. At this transition, there is a risk that physicians and other healthcare staff may not inform the patient, or that the treatment which previously had a curative intention may continue, despite the changed conditions (26). Mistaking palliative treatments for curative may cause patients to make different treatment decisions than they would make if they fully acknowledged their situation (83).

There are indications in the literature that information can not only improve quality of life in palliative care but also cause it to deteriorate. For example, accurate prognostic knowledge has been associated with anxiety, depression and lower quality of life (84-86); however, it has also been associated with hope, a feeling of control, no increase or a decrease in anxiety, better symptom control and greater satisfaction with the healthcare service (78, 80). If the patient's next of kin has more information than the patient, next of kin can experience a feeling of being isolated from the patient (78).

Although providing information about diagnosis, treatment options and prognosis is essentially thought of as the physician's responsibility, nurses play an important role in identifying the patient's problems and needs, and communicating these to the physician (87). Moreover, it is regarded as important that all healthcare staff share the same knowledge and agenda regarding end-of-life care (87).

THE PATIENT'S WISHES FOR INFORMATION

Many of the studies that have examined patients' preferences on prognostic disclosure have been conducted on patients with cancer. Studies have shown

that most, but not all, patients with cancer want to know whether their disease can be cured and if it is life threatening (80, 87, 88), and some patients also want more detailed statistical information about their disease (80). Patients and their next of kin generally want honest and accurate information from their physicians (89-91).

Patients often express ambivalence to learning the whole truth when given bad news (80, 87, 92). Patients find themselves in a paradox: they want honest, realistic and clear information, but they also want this information to be presented in a way that gives them hope. This was exemplified in a study by Kutner et al., where all study respondents wanted their physicians to be honest, but 91% also wanted their physicians to be optimistic (93). Patients do not always ask their physicians about information they want to receive, for example, information about prognosis (87). It has been shown that sometimes both the patient and the healthcare staff member wait for a starting signal from the other to talk about impending death, resulting in a 'Catch 22' situation where important subjects are not addressed (92).

The patient's needs and wishes for information change during the course of a cancer disease (80, 87, 92). In a study by Schildmann et al., patients with pancreatic cancer described two stages in decision-making about information and treatment: in the first stage there was a feeling of having no choice and a feeling of trust in the physician; in the second stage the patients had a more proactive role in information and decision-making (81). Grunfeld et al. showed that women with advanced breast cancer had greater information needs while being offered first-line chemotherapy compared to second-line chemotherapy (94).

MISUNDERSTANDING OF THE PROGNOSIS AND GOAL OF CARE

There are several contemporary examples in the literature of patients with incurable cancer who received palliative chemotherapy or palliative radiotherapy but who were not aware of their prognosis and the goal of care (83, 84, 95-100). In a study by Elkin et al. from 2007 a majority of elderly patients with metastatic colorectal cancer said that chemotherapy was somewhat likely or very likely to cure them (95), and in a study from 2012 by Mitera et al., 23%–25% of patients with advanced cancer undergoing radiotherapy for symptomatic mestastases believed that their cancer was curable, 15%–17% believed that radiotherapy would cure their cancer and 40%–45% believed that radiotherapy would prolong their life (97).

In a study from 2013 by Lennes et al., 76% of patients newly diagnosed with cancer had the same perception of the goal of care of chemotherapy as their physician's perception, and the most common misperception seen was in patients having palliative chemotherapy who claimed that the treatment was curative (83). In a study from 2006 by Burns et al. it was common for both patients with advanced cancer and their caregivers to misunderstand the goal

of care as cure (98). In a study from 2012, 69% of patients with stage IV lung cancer and 81% of patients with stage IV colorectal cancer did not report understanding that chemotherapy was very unlikely to cure their cancer (99). In a study from 2012, 64% of patients with incurable lung cancer who received radiotherapy did not understand that the radiotherapy was not at all likely to cure their cancer (100).

Even if patients understand the goal of care, they can still misunderstand the survival benefit from palliative chemotherapy. Survival benefit and toxicity from palliative chemotherapy vary considarably between different cancer diagnoses and different types of chemotherapy, which complicates decisions about initiating or ceasing treatment (33). Lux et al. showed that patients tend to expect longer survival benefit from breast cancer treatment than physicians do (101). Mende et al. showed that patients who are treated with palliative chemotherapy tend to overestimate their expected survival, compared with actual survival time (102).

WHY ARE PROGNOSIS AND GOAL OF CARE MISUNDERSTOOD?

Physicians are often reluctant to talk with their patients about prognosis and survival time because of prognostic uncertainty (78, 87) and fear of negative impact on the patients (78). When asked about expected survival time, physicians tend to answer vaguely or too optimistically (87). It is stressful for physicians to break bad news to patients, even for those who regularly do this (87). Many physicians have never received any formal training in breaking bad news (103). Friedrichsen and Millberg showed that physicians experience that there is a risk of losing control when breaking bad news to patients dying from cancer, and doing so can be experienced as a failure (104). One barrier for physicians in communicating about these issues with patients is the worry that they as physicians will not be given enough support from colleagues if needed (105). Time constraints can also be an explaination for giving inadequate information (92).

Patients do not remember everything that is said to them during the patient–physician meeting (104), and physicians tend to overestimate how much information has been given (106). Common oncology terms (107) and common statistical terms (87) can be difficult for patients to understand, for example, the word 'treatment' is sometimes interpreted differently by physicians and patients (108). Patients' choices of treatment options can be influenced by the way statistics are presented, for example, by absolute or relative risk reduction (109). In a study by Audrey et al. from 2008, the survival benefit of palliative chemotherapy was discussed vaguely or not at all, and numerical data of survival benefit was only discussed in a minority of cases (33). Graugaard et al. examined patient–physician meetings regarding prognostic information in haematologic and rheumatologic settings, and showed that one strategy that physicians used for softening bad news was to emphasise that future

development of disease is uncertain (110), which was also shown in a study on patients with small cell lung cancer by The et al. (108).

Patients having an overly optimistic view of their prognosis is not a product only of their physicians' nondisclosure or lack of communication skills (108). Patients' perspectives on palliative chemotherapy and information about the prognosis and goal of care are not completely known (111). In a study by The et al., both patients with small cell lung cancer and their physicians were shown to focus on the treatment plan in the short term rather than on the issue of prognosis (108). Buiting et al. showed that patients with colorectal and breast cancer can use ongoing chemotherapy to deliberately focus on the present and to shift their attention away from the approaching end of life, suggesting that anxiety about the future can be a reason for wanting chemotherapy (111). Jacobsen et al. proposed several reasons that a patient seemingly misunderstands information, including healthy coping strategies, language barriers, impaired cognitive functions and receiving conflicting information because of prognostication difficulties or wanting to bring hope to the patient (112).

Even if a patient clearly is informed about and understands a palliative prognosis, it does not necessarily mean that the patient expresses this verbally (113) or thinks about it all the time. Salander has described how patients who have been informed about their progressive and life-threatening diseases sometimes express things that lead the healthcare team to believe that they have not understood the information given, for example, talking about plans for the future. This can be explained by a 'creative illusion', a way to find meaningfulness in life despite severe illness (114). Lindqvist et al. showed that it is possible to experience wellness despite advanced cancer (115, 116).

HONEST INFORMATION AND HOPE

Hope is often described as important when talking about prognosis and goal of care, and when breaking bad news (80). Hope has been described as a 'confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant', but there is no research consensus of the definition of hope (91). There are concerns and indications that honest prognostication hinders patients from feeling hope (78, 80, 87, 91), but hope can also be diminished if the physician avoids informing or gives information that is too veiled (80, 91, 117).

The way the information is given is important for the patient's feeling of hope (91). If the physician uses phrases such as 'nothing more can be done', it can cause the patient to experience feelings of frustration and abandonment (118). Some patients may use euphemisms or avoidance of statistical information to maintain hope (91). In cancer care hope has often been seen as a hope for cure or prolonged survival, but hope for patients with advanced cancer can be seen as a continually changing process (91). Patients find new sources of hope as

their disease progresses (117). To foster hope for patients in end-of-life care, it has been suggested that physicians should avoid creating unrealistic expectations and instead focus on realistic goals of care, such as good symptom control (87).

INFORMATION ABOUT TRANSITION TO END-OF-LIFE CARE

The transition to end-of-life care is also difficult for patients, next of kin and healthcare staff (26, 119). The specific communication between patients and physicians about transition to end-of-life care has not been extensively studied. The Swedish nomenclature of 'breakpoint communication' (*brytpunktssamtal*), or information about transition to end-of-life care, is not used much in the international literature. It has been suggested that ITEOL should be seen as a process and not a single patient–physician meeting (13, 20, 117).

Lundquist examined the timing of ITEOL at a Swedish palliative care unit and found that ITEOL was provided very close to death (median of four days), and often corresponded to transition to the dying phase, for example, when the patient entered the LCP. Lundquist also found that the ITEOL only was documented in the patients' medical records in 55% of cases (13). Friedrichsen et al. showed that patients with incurable cancer experience that their previous knowledge is important when receiving information about discontinuation of antitumoural treatment (120).

Lundquist et al. found that patients who had received ITEOL were more likely to also have received other measures that mark high quality end-of-life care (e.g., individual prescriptions of injectable PRN medications for alleviation of symptoms and end-of-life care provided at their preferred location) without signs of worse pain or anxiety (121). Aalbom et al. found that patients with cancer who had a documented diagnosis of being terminally ill had reduced hospital admissions and increased possibilities of dying at home compared to patients without a documented diagnosis of being terminally ill (122). Randén et al. found that, in Sweden, 57% of patients with disseminated cancer had no formal documentation of treatment discontinuation or end-of-life discussion (123). In one study by Valdimarsdottir et al. from 2004 in a Swedish population, 15% of wives of patients with prostate or urinary bladder cancer reported that they did not realise that the patient was going to die until 24 hours or less before death of the patient (82).

According to data from the SRPC, around half of all patients who died an expected death in Sweden during 2013, with maintained ability to express their will and take part in decisions concerning the content of medical care until days or hours before death, received documented ITEOL. Hospitals and nursing homes had a much lower proportion of patients who received ITEOL compared to specialised palliative care (28).

COMMUNICATION COURSES FOR PHYSICIANS AND NURSES

Friedrichsen et al. examined the effect of a half-day training intervention that focused on palliative care in general. After three months 31% of participants (mostly assistant nurses and home helpers) who responded to a course evaluation reported that ITEOL had become more frequent (27). No other studies increasing or improving ITEOL specifically were found in the literature.

Physicians often lack competence and training in communication skills for breaking bad news (124, 125). The Cochrane Collaboration has examined the current knowledge of the effect of communication skills training for healthcare professionals working with patients with cancer. Fifteen randomised controlled trials that met the eligibility criteria were found. There was some evidence that communication skills training improved communication skills, but studies of patient-reported outcomes such as mental and physical health, satisfaction or quality of life were limited (126).

Wilkinson et al. found that oncology and palliative care nurses who had been randomised to a three-day training course in communication had better communication skills than the control group, but there was no change in patient anxiety (127). With respect to healthcare professionals, studies have shown that a two-and-a-half- to three-day communication course is more effective than a shorter course (128), and equally effective as a five-day course (105). Knowledge that is acquired from communication courses is not always transferred to the clinical work. It has been suggested that interventions after the education, for example, clinical supervision, could facilitate the implementation of acquired knowledge (124).

REGISTRATION OF HEALTHCARE IN SWEDEN

Sweden has a long tradition of national, individual-based registers. Each citizen has a personal identity number, used, for example, in contact with the healthcare system and for registrations (35). The individual personal identity number, a unique ten-digit code, has been assigned all Swedish citizens since 1947 and is now assigned by the National Tax Agency (129). The Swedish population register has been in use for several hundred years (35). It was initially collected by the church to take census of the population and to enrol soldiers for the military (129).

Demographic and socioeconomic data about the Swedish population are collected by Statistics Sweden. The purpose of this data collection is to provide an overview of the social population structure, for governmental planning and for use in epidemiological studies (38, 130). The Swedish Patient Register collects data from hospital care, both inpatient and outpatient, but not from primary care. Collected data in the Patient Register include individual personal identity number, age, gender, home city, name of hospital, name of clinic, dates of admission and discharge, acute/planned care, diagnoses and surgical procedures (130). When analysing data from the Patient Register the incidence of certain diseases may be underestimated because the register does not contain information from primary care (130).

The Swedish Cancer Register is maintained by the NBHW. The healthcare service is obligated to report newly detected cases of cancer to the Swedish Cancer Register. The purpose of the register is to provide a basis for clinical and epidemiological research (131). The NBHW also register births, dispensed drug prescriptions and causes of death (130). The register about causes of death contains information about deaths in Sweden since 1952, and data are collected from the physician responsible for the deceased patient (132). The individual personal identity numbers make it possible to link information about the same individuals from different registers to monitor the health of the population or for research (133).

NATIONAL QUALITY REGISTERS

The national quality registers are financed by the Swedish government and the Swedish Association of Local Authorities and Regions (SALAR). The first Swedish national register was the national Knee Arthroplasty Register, which started in 1975 (134). The Swedish patient data law defines a quality register as an ‘automated and structured collection of personal data that were initiated with the purpose to systematically and continuously develop and safeguard quality of care’ (134, 135). A quality register collects data from different healthcare providers. Registers for quality purposes that only collect data from

one healthcare provider are not defined as quality registers, but internal quality systems (136). Swedish quality registers that receive funding from the national initiative of quality registers are usually referred to as national quality registers (136).

In the past 20 years, there has been an increasing number of national quality registers founded in Sweden. The quality registers are most often initiated by physicians. Many national quality registers focus on specific diseases or interventions, but some have a broader perspective (134). In 2014, there were 81 national quality registers and 24 quality register candidates that received financial support via the SALAR (136). Many of the national quality registers had collected data from over 80% of the target population (134). Somatic in-hospital care is best mapped with national quality registers, but there is a lack of quality register data regarding primary care, eldercare, psychiatric care and dental care (136). Because of the diversity in what the national quality registers aim to collect data about, they differ greatly in organisation and how data are collected (136). Only one national healthcare register collects data about cost effectiveness (136).

A Swedish investigation from 2010 stated that Sweden had the most extensive system of national quality registers compared to all other countries (133). Patients have the right to decline participation in a quality register, and to withdraw participation at any time after registration (134, 135). Healthcare providers participate in national quality registers voluntarily and there is no law that requires registration in national quality registers (136). While a quality register is legally intended to develop and safeguard quality of care, national quality registers are often described as having several purposes, and these purposes are described in numerous ways. The literature (133, 134, 136-138) variously suggests that the purpose of a quality register is to

- monitor, evaluate and compare quality of healthcare provided within a healthcare unit or system,
- monitor, evaluate and compare quality of healthcare provided between different health units or systems, and to reduce the differences,
- be a basis for achieving consensus,
- be a tool for introducing new routines,
- identify areas for improvement,
- improve healthcare quality,
- measure the effect of quality improvement projects,
- generate research hypotheses,
- enable clinical and epidemiological research and
- generate a basis for allocation of economic resources.

Quality registers provide data for open comparisons between the Swedish counties, published annually by the NBHW. In 2014, 186 quality indicators were published in the open comparisons (136). The national quality registers have been described as 'the Swedish gold mine' for research purposes (133),

but both ethical and methodological issues have been raised. The national quality registers do not cover many important parts of care, for example, rehabilitation (136). It is generally not known how many patients decline to participate in a quality register. Most published studies using Swedish quality register data are observational, and thus they have methodological disadvantages compared to, for example, randomised controlled trials (134).

The quality registers have been criticised for being too intrusive (133, 136). Registered data are often of a very personal and delicate nature, and merging of data from multiple registers for research purposes can be even more intrusive (136). Additionally, the documentation of patient data to both the medical records and to the quality registers takes time from patient work (133), making the overall advantage for patients questionable. One way of side-stepping this problem would be to automatically transfer data to registers from medical records, but this is currently only done for a few quality registers in Sweden (136).

The national quality registers have also been criticised for putting focus on easily measured data instead of more important factors and values that are not easily measured (136, 139). This can be even more problematic when data from quality registers are used as a basis for allocation of economic resources (136). There is a risk that incorrect registrations are submitted to enable the healthcare unit to qualify for certain quality goals rather than honestly reflecting the care provided (136), thus making the reported data less suitable for research purposes and possibly leading to unequal and unfair distribution of resources (140).

It has been argued that monetary bonuses should be based only on numbers of registrations, and not for reporting high quality (137), but that could theoretically also lead to ethical difficulties, because patients have the right to decline to participate in the registers, and an economic bonus for registration may influence the healthcare staff to not sufficiently inform patients about the register, the register purposes or their right to decline participation (141, 142). There is a risk of patients feeling obligated to participate in the register to receive the best care (142).

The use of quality register data for allocation of economic resources risks taking away power and authority from the healthcare professionals and giving too much power to administrators who do not have full knowledge and competence about the care (136). There is a risk that the national quality registers actually hinder innovation and development in healthcare (136). It has even been argued that quality registers could actually lower the quality by stating the 'lowest standard' in the measured items (141).

Some, but not all, Swedish national quality registers have been examined for validity issues (134). For example, Tomic et al. studied the completeness and validity of the National Prostate Cancer Register by comparing register data by cross-linkage to the Swedish Cancer Register and reabstracting data from

medical records (143). Some Swedish national quality registers cooperate with international registers, and there are similar healthcare quality registers in Norway and Denmark (136).

REGISTRATION OF PALLIATIVE CARE

THE SWEDISH REGISTER OF PALLIATIVE CARE

DEVELOPMENT

The Swedish Register of Palliative Care is a national quality register financed by the SALAR with an aim to evaluate and improve care at the end of life. The register was initiated by the Swedish Association for Palliative Medicine, an association of Swedish physicians (20). The SRPC was founded in 2005 and received status as a national quality register in 2006 (35).

The aim of the SRPC is to identify deficiencies in end-of-life care in Sweden and by that influence decision-makers. The aim is also to initiate a development process for learning and quality improvement by the care providers, even for those patients who die without being identified as 'palliative' (144). Influential for the development of the SRPC was a Swedish report that observed deficiencies and regional differences in end-of-life care in Sweden (12, 144). The vision of the SRPC is that all persons living in Sweden be ensured a dignified and, according to their needs, an optimal end-of-life care regardless of diagnosis, place of residence or level of care (28, 144).

The SRPC's core values are based on eleven basic rules that reflect aspects of end-of-life care, proposed by the British Geriatrics Society (Table 2, page 10) (35, 49, 144). Based on these core values, the SRPC has formulated measurable criteria of high quality end-of-life care (Table 3). The SRPC collects data reflecting the extent to which these criteria are fulfilled for patients during their last week of life (28).

Table 3. Measurable criteria of high quality end-of-life care formulated by the SRPC

The patient is informed about his or her situation.
The patient's next of kin are informed about the patient's situation.
The patient is assured good care, for example, regarding oral health and prevention of pressure ulcers.
The patient's pain is assessed using validated instruments and alleviated.
The patient's other symptoms are assessed using validated instruments and alleviated.
There are drugs to give by injection when necessary to alleviate breakthrough pain, anxiety, nausea and breathing difficulties.
The patient does not have to die alone.
The patient is given the opportunity to die in his or her preferred place.
The patient's next of kin is offered a follow-up appointment after death of the patient.

During 2010–2014 the SRPC received financial support from the government programme 'Better Life for Most Sick Elderly' (28, 35). Four other national quality registers focusing on elderly people with diseases were also part of this programme (28). In 2010, there was a monetary bonus available for counties

and municipalities with high levels of patients reported to the SRPC. In 2011–2012 there was a monetary bonus for high level of patients reported and for high levels of patients who had received documented ITEOL. In 2013–2014, the governmental programme included an economic bonus for counties and municipalities with high levels of patients reported to the SRPC if they also achieved an average improvement of more than 5 percentage points for patients 65 years and older in four items under certain conditions (ITEOL, prescription of PRN medication against anxiety, use of a validated tool for pain assessment and documented assessment of oral health) (28, 30, 35, 145-147).

In 2006, 4928 patients were reported to the SRPC, which corresponds to 5% of all deaths in Sweden during that year. In 2014, 60 353 patients were reported, which corresponds to 68.2% of all deaths in Sweden. The proportion of deaths in Sweden reported to the SRPC during 2006–2014 is shown in Table 4 (2, 28, 30, 35, 39, 144, 146, 148-150). The completeness of the SRPR is higher for patients with cancer. In 2014 89.5% of all patients who died from cancer were reported to the SRPC (30). The development of the SRPC is further described by Lundström et al. (35).

Table 4. Number of deaths reported to the SRPC and proportion of deaths in Sweden reported to the SRPC, 2006 to 2014

Year	Deaths reported to the SRPC (n)	Proportion of deaths in Sweden reported to the SRPC (%)
2006	4928	5%
2007	9803	10%
2008	15 518	16%
2009	21 399	23%
2010	31 273	34%
2011	47 833	53%
2012	57 349	62%
2013	59 922	66%
2014	60 353	68%

DATA COLLECTION

The SRPC collects data from all healthcare units where palliative care is given: hospital wards, nursing homes, short-term care homes, hospices and home care. Data are collected using two questionnaires developed by the SRPC, a healthcare unit questionnaire and the end-of-life questionnaire (ELQ) (35). The healthcare unit questionnaire is to be answered by the healthcare units once a year and describes some of the healthcare unit's resources and procedures for end-of-life care (148). This questionnaire was updated in 2012 (146).

The ELQ is the main source of register data in the SRPC. It is completed by healthcare staff after death of a patient and focuses on the last week of life. The healthcare teams are encouraged to answer the ELQ jointly, to promote more valid registrations and to get an opportunity to discuss and reflect on the end-of-life care provided (146). In 2013 68% of all registered ELQs were answered by an individual healthcare staff member, most often a nurse, and 32% of all ELQs were answered by a healthcare team together (28). Items concern

providing information to patients and next of kin, alleviating pain and other distressing symptoms, prescribing necessary drugs and fulfilling the wish of preferred place of death. The ELQ is found in the addendum.

Registration in the SRPC is completely web-based. It is possible to complete a paper version of the ELQ and later transfer the answers to the web form (28). All questions in the web form have to be answered before submission, leading to no missing data (144). Stored data are matched weekly with the central population register for validation purposes (35).

The first version of the ELQ was in use from January 2005 to April 2007. In May 2007 some linguistic clarification of the ELQ was done, and some questions were added (150); that version of the ELQ was in use until December 2010 (147). During 2010 the ELQ was modified based on the results from study I in this thesis, a study by Gholiha et al. (42), and from comments left by healthcare staff who had used the questionnaire (147). In January 2011, an updated version of the ELQ was launched. In that version, the role of the physician was emphasised more clearly, there was a larger focus on documentation, and more items about nursing and symptoms were added. In April 2012 a question about the physician's diagnosis of the transition to end-of-life care was added (28).

During 2012, a questionnaire was developed that is meant to be answered by patients, for example, those undergoing palliative chemotherapy. The questionnaire consists of 14 items about information, decision-making, symptoms and support to next of kin (148). This questionnaire has been pilot tested, but has not been launched nationwide. Data collected with this questionnaire are not available at the SRPC website. A questionnaire to be answered by next of kin after death of a patient was developed in 2014, and pilot testing and evaluation are planned for 2015 (30).

USE OF SRPC DATA

Descriptive data are published continuously on the register website (http://www.palliativ.se). Individual healthcare units have continuous access to their own results online and can use them as a basis for self-improvement. Results from individual healthcare units are only accessible by the respective healthcare units themselves after login, but data covering bigger areas (hospitals, municipalities, counties) are accessible to the public. No personal identity numbers or other personal data on individual level are published (28, 35). Data from the SRPC have also been published in nationwide reports from SALAR (28). Lindblom et al. examined the impact of the SRPC on nurses in a grounded theory study and found that the feedback system could be important for improving the end-of-life care given (151). Several studies have used data from the SRPC (42, 45, 121, 131, 152).

PALLIATIVE CARE REGISTERS OUTSIDE SWEDEN

There are examples of quality registers regarding specialised palliative care in Denmark and Australia (153-155). No documentation of quality registers collecting national data about patient outcome measurements outside of specialised palliative care was found in the literature.

THE DANISH PALLIATIVE CARE DATABASE

The Danish Palliative Care Database (DPD) (*Dansk Palliativ Database*) collects data from Danish patients referred to specialised palliative care. Each patient is registered only once per healthcare unit. The patients reported in the DPD are mainly patients with cancer. The registration started in 2012. The aim was to build a basis for quality development and for research. Data collected includes clinical and sociodemographic variables, access to specialised palliative care (referred/admitted), waiting time after admission, proportion of patients dying from cancer admitted/not admitted to specialised palliative care, proportion of patients who were screened for symptoms at admission and proportion of patients discussed at a multidisciplinary conference. The data are reported in a web-based form completed by the healthcare unit. Overall completeness is 100%, and completeness for variables in the web-based form is 99% (153, 154).

THE AUSTRALIAN PALLIATIVE CARE OUTCOMES COLLABORATION

The Palliative Care Outcomes Collaboration (PCOC) was launched in 2006. It is a national Australian initiative that allows specialised palliative care services to collect data about palliative care quality. Collected data includes demographics, phases of illness, episodes of care, functional status and dependency and symptom scores. Scales used to measure these are the Resource Utilisation Groups – Activities of Daily Living (RUG-ADL), the Australian-modified Karnofsky scale and the Symptom Assessment Scale. Clinical measures are recorded by healthcare staff in the participating healthcare units (156). Data collection is prospective and built into routine clinical practice. Aggregate data are analysed and reported back to participating healthcare units every six months (155).

METHODOLOGICAL CONSIDERATIONS

VALIDITY AND RELIABILITY

Validity is defined as the degree to which an instrument truly measures the construct(s) it purports to measure. Validity can be divided into content validity, criterion validity and construct validity (157).

Content validity is defined as 'the degree to which the content of an instrument is an adequate reflection of the construct to be measured'. Face validity is a kind of content validity, and is defined as 'the degree to which an instrument indeed looks as though it is an adequate reflection of the construct to be measured'. Content validity and face validity are based on judgement, but are nevertheless regarded as important parts of validity testing. Criterion validity is defined as 'the degree to which the scores of an instrument are an adequate reflection of a gold standard'. Construct validity is defined as 'the degree to which the scores of an instrument are consistent with hypotheses based on the assumption that the instrument validly measures the construct to be measured', and is usually used when a gold standard is not available (157).

Reliability is defined as 'the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions'. Reliability can be tested in various ways, for example, testing over time, by different persons, or by the same persons on different occasions (158).

GENERALISABILITY

Generalisability, also known as external validity, is the ability to extrapolate study results from the study subjects to other persons who were not investigated (159). Determining whether study results can be generalised to other settings involves judgement of whether there are clinically meaningful differences between the study population and other populations (160).

POWER

A type I error occurs when the null hypothesis is rejected, even though it is true. A type II error occurs when the null hypothesis is not rejected, even though it is false. 'Power' is defined as one minus the probability of a type II error, based on the assumption that the null hypothesis is not true. Thus, power is the probability of obtaining a significant p-value when the null hypothesis is false (161, 162).

TRUSTWORTHINESS

The terms validity, reliability and generalissability are sometimes used in qualitative research, but the terms credibility, dependability and transferability are more often used to describe trustworthiness of a qualitative study (163). Transferability is 'the extent to which the findings can be transferred to other settings or groups' (163).

AIMS

STUDY I

The aim was to examine the validity of the ELQ from the SRPC.

STUDY II

The aim was to examine whether participation in the SRPC increases the quality of palliative care over a three-year period regarding eight items in the ELQ.

STUDY III

The aim was to examine whether an educational intervention for physicians and nurses in nursing homes and hospitals increases the proportion of patients who receive ITEOL.

STUDY IV

The aim was to describe how patients with cancer perceive the information they receive from physicians during palliative chemotherapy.

ETHICS

STUDY I

Study I was approved by the local ethics committee in Linköping, Sweden (registration number 226-08). The examination of the validity of the updated version of the ELQ was approved by the local ethics committee in Linköping, Sweden (registration number 2012/152-31). These surveys used register data and data from medical records of diseased patients. The results are reported at group level.

STUDY II

Study II was approved by the local ethics committee in Umeå, Sweden (registration number 2011-442-31M). This study used register data on diseased patients. The results are reported at group level.

STUDY III

Study III was approved by the local ethics committee in Umeå, Sweden (registration number 2011-442-31M). This study used register data on diseased patients. The physicians and nurses attending the educative intervention received written and verbal information prior to the start of the training and were free to decline participation. The results are reported at group level.

STUDY IV

Study IV was approved by the local ethics committee in Umeå, Sweden (registration number 2013/333-31Ö), and by the head of the surgical department. All participants received written and verbal information about the study prior to the interview, and written and verbal consent was obtained concerning data collection using interviews and medical records. They were informed that they could withdraw from the study at any time without affecting their future care. In the event that participants described any medical concerns during the interviews, there was a procedure for conveying these concerns to the responsible nurse, physician, or social worker if the participant gave his or her consent. The results, including quotations, are reported in such a way that no individual can be identified.

METHODS

THE END-OF-LIFE QUESTIONNAIRE

In studies I and II, the end-of-life questionnaire version that was in use from May 2007 to December 2010 was used. In study III, and when re-examining the ELQ validity, the ELQ version that has been in use since January 2011 was used. The ELQs are found in the addendum.

STUDY I

PLANNING AND SETTING

To enable examination of the validity of the ELQ, data from patients' medical records were compared to data reported to the SRPC for the same patients. Gholiha et al. showed that documentation of end-of-life care was insufficient to perform a comparison between data reported to the SRPC and data in medicals records from non-specialised palliative care settings in Sweden (42). Based on this knowledge, the units of specialised palliative home care and palliative ward 96 (same staff and management), both at the Linköping University Hospital, Sweden, were chosen. The reason was that these units had a special way of documenting important aspects of end-of-life care in computerised medical record modules included in the patients' regular medical records. These modules were only used if a physician had diagnosed the patient as having moved beyond the transition to end-of-life care. According to local routines at these palliative care units, the staff involved in the end-of-life care jointly completed a paper version of the ELQ after the death of a patient. Afterwards, a secretary transferred these answers to a web-based form on the SRPC's home page. It was not possible to submit the ELQ registration if a question was left unanswered in the web-based form.

To obtain a sufficient basis for statistical analysis, the sample size was set to 100 patients. Inclusion criteria required that patients had received end-of-life care and died either with support from the specialised palliative home care or at palliative ward 96 at the Linköping University Hospital, had been diagnosed by a physician as having moved beyond the transition to end-of-life care and accordingly the medical record modules about end-of-life care were used, had been reported to the SRPC, and had a completed paper version of the ELQ.

DATA COLLECTION

Data were collected in June and July 2009. Patients who had died at the units were identified through the units' own monthly lists of their deceased patients.

Data were collected from medical records of patients who had died from May 2009 and earlier, until 100 patients who met the criteria were identified. Overall, the medical records, paper versions of the ELQ and the register data from 169 consecutive patients who had died at the units between October 2008 and May 2009 were examined.

In 35 of these cases there was no end-of-life module where a physician had recorded the patient in the medical records as having moved beyond the transition to end-of-life care; in 33 cases a completed paper version of the ELQ could not be found at the units; and in one case the patient was not reported to the SRPC, despite there being a completed paper version of the ELQ at the unit: these patients were excluded, and 100 patients remained in the study.

Information from the end-of-life modules and other medical record notes about the patients' end-of-life care was used to complete the ELQ for the included 100 patients. Information about team satisfaction was collected from notes in the medical records written after death of the patients. The collection of data and the completion of the ELQ were performed without knowledge about how the staff involved in the end-of-life care of these patients had answered the ELQ.

DATA ANALYSIS

To examine the overall validity of the ELQ, data from the ELQs based on information from the medical records were compared to those from the ELQs reported to the SRPC by the units. The rate of identical answers in 21 out of the 27 items in the ELQ were analysed with $\chi 2$ analysis, using the statistics programme Statview. The six items in the ELQ of a purely administrative nature (questions 1, 2, 3, 5, 26 and 27) were not analysed. A level for each item of 80% congruity or above was considered acceptable.

To examine the extent of registration mistakes made in transferring the paper form to the web-based form, the paper versions of the ELQ filled out at the units were compared to data from the ELQs reported to the SRPC. The rate of identical answers in 21 out of the 27 items in the ELQ were analysed using the same method as above. A level for each item of 95% congruity or above was considered acceptable.

During the process of analysis, it was found that one patient had been incorrectly reported as having undergone a forensic autopsy (question 10). This error was caused by a mistake made when transferring the paper form to the web-based form. When a patient was reported in the web-based form as having undergone a forensic autopsy, no further question could be answered. Since this caused a systematic error, this patient was excluded when analysing questions 11–25 in the ELQs reported to the SPRC by the units.

ASSESSMENT OF THE VALIDITY OF THE UPDATED ELQ

In January 2011 a new version of the ELQ was launched. More items are measured (e.g., with addition of a question about assessment of oral care), and there is greater focus on documentation, thus now measuring more process quality indicators and fewer outcome indicators. To examine the validity of the new version of the ELQ, a similar data collection, and the same sample size, inclusion and exclusion criteria, and analysis methods were used as in the previous validity survey.

Since question 11a (about the physician's decision about transition to end-of-life care) was added in April 2012 and had thus not been used during the whole study period, the validity of that item could not be examined. The seven items in the ELQ of a purely administrative nature (questions 1, 2, 3, 27, 28, 29 and 30) were not analysed. Question 25 was not analysed, since data were not available in the data set. Congruity was analysed seperatly for the ten alternative answers in question 7 about cause of death.

STUDY II

PLANNING AND SETTING

In 2010 data about end-of-life care for 34% of all deaths in Sweden were reported to the SRPC. Descriptive data had been published continuously on the register website, and individual healthcare units had continuous access to their own results online and the opportunity to use these as a basis for self-improvement.

To examine whether participation in the SRPC was covariant with increased quality in end-of-life care, a cross-sectional study using SRPC data was planned. To examine change over time, data from all healthcare units that had reported patients regularly during a three-year period were used. Since national data were used, there would be a possibility to detect small changes over time.

Eight items from the ELQ were examined: ITEOL provided to patients; ITEOL provided to next of kin; whether six symptoms were fully alleviated during the last week of life; whether PRN medications in the form of injections for pain, nausea, anxiety and death rattle were prescribed at least one day before death; whether the patient had pressure ulcers (graded from 1 to 4 according to the EPUAP) (61) during the last week of life; whether next of kin and/or staff were present at the moment of death; whether the place of death corresponded to the patient's last spoken wish and whether next of kin were offered a follow-up appointment after death of the patient.

DATA COLLECTION

Data were collected from the SRPC database of completed ELQs from all patients reported by the healthcare units that had reported at least one patient to the SRPC each period during the periods of May 2007 to April 2008, May 2008 to April 2009 and May 2009 to April 2010. These time periods were chosen because May 2007 was the first month of usage of an updated version of the ELQ. Some units reported patients who eventually died at another type of unit, and these patients were excluded.

DATA ANALYSIS

Data were analysed using logistic regression in the statistical programme Stata V. 11.0 from StataCorp LP to examine whether there was a systematic change in the answers, indicating a possible change in the quality of end-of-life care. Each alternative answer to the eight questions were analysed separately. The eight items from the ELQ were dependent variables, and time (year of death) was the only independent variable. Subgroup analyses for the five most common places of death (hospices/palliative hospital wards, nursing homes, specialised palliative home care, hospital wards without palliative specialisation and short-term care homes) were performed. P-values below 0.05 were considered significant.

In the analysis of the item concerning information provided to the patient, only patients without cognitive impairment were included. Cognitive impairment was defined as having lost ability to express will and take part in decisions concerning the content of medical care weeks before death or earlier. Eleven healthcare units changed their unit type during the study period. These eleven units are reported in the results as they were defined at the baseline.

STUDY III

PLANNING AND SETTING

This study defined ITEOL as follows: an individually tailored and informed conversation with a physician that is documented in the medical records, about being in the final stage of life and about care being focused on quality of life and symptom relief. Because we found no previous study examining this outcome to base our power calculation on, we estimated that the intervention could increase the proportion of patients who received ITEOL by 20 percentage points. We based this assumption on what seemed to be a reasonable change based on the higher proportion of patients receiving this type of information in specialised palliative care. Power analysis with a power level of 0.8 and a significance level of 0.05 showed that at least 200 events (death of a patient reported to the SRPC) were needed to detect significant effects of the

intervention (i.e., 100 before and 100 after the intervention in both the intervention group and the control group). In a six-month period, each hospital or municipality reports around 50 patients to the SRPC. Based on this, we chose to include two hospitals and two municipalities in the intervention group to enable evaluation of the results six months after the intervention.

Exclusion criteria for hospitals and municipalities were more than 40% of patients receiving ITEOL at the start of the study, too large for an intervention due to practical reasons (university hospitals or municipalities with over 100 000 inhabitants) and different patient population compared to the intervention hospitals (hospitals not containing separate internal medicine and surgical departments). A table of random numbers was used by the head of SRPC to assign all included hospitals and municipalities a random order. The first two hospitals and the first two municipalities received the intervention. Matching criteria for the control group were proportion of patients who received ITEOL at baseline (+/-7 percentage points), number of municipality inhabitants (+/-10 000) and type of hospital (small hospital or county hospital). To minimise possible 'contamination' by the intervention locally, we excluded those municipalities where a hospital had received the intervention and those hospitals where the municipality had received the intervention. The next four hospitals and municipalities that matched these criteria were assigned controls.

INTERVENTION

We developed a half-day course that addressed how to diagnose the transition to end-of-life care and how to provide ITEOL, the role of physicians and nurses in detecting the need for ITEOL and the importance of team collaboration regarding information provided to patients in end-of-life care. The course was interactive and led by physicians and nurses with diplomas in palliative medicine and care. A plenary presentation of ethical and theoretical issues was mixed with interactive case discussions and discussions about practical methods for providing ITEOL. The case discussions were tailored to the common palliative patient population that the course participants meet in their daily work. Focus was on cardiovascular diseases in internal medicine clinics, cancer in surgical clinics and a mix of different causes of death with special focus on dementia in the municipalities. There were also discussions about the timing of delivery of ITEOL. ITEOL for next of kin, patients' wishes about place of death and individual prescriptions of injectable PRN drugs against pain, death rattle, anxiety and nausea were briefly discussed during the training. We chose a half-day course because a longer course seemed impractical for future application on a wider scale.

In the hospitals, department heads invited all physicians and one nurse per surgical and internal medicine ward. In nursing homes, the nurses responsible for the care in the municipalities invited one nurse per ward. The physicians responsible for municipal care were invited personally. Before starting the course, all participants were informed about the study. The interventions were

performed between February and April 2012. Six courses were performed, one for each municipality, surgical clinic and internal medicine clinic included in the study. A total of 89 physicians and 62 nurses attended the course. In the hospitals 71 physicians and 24 nurses attended the course, and in the municipalities 18 physicians and 38 nurses attended the course. Out of all invited physicians 60% attended the course in hospitals, and 69% attended the course in municipalities. Physicians and nurses attended the same course. Other professionals were not invited. The hospitals and municipalities in the control group did not receive any intervention or information about their participation in the study, but were informed about and aware of their participation in the SRPC.

DATA COLLECTION

The effect of the intervention was measured with register data from the SRPC. Data were collected from the intervention and control groups six months before and six months after the intervention. Patients were excluded when death was unexpected, when a forensic post mortem examination was performed or when the patients had lost their ability to express their will and take part in decisions concerning the content of medical care one week or earlier before death. The main outcome was the proportion of patients who received ITEOL. Secondary outcomes were the proportion of patients whose next of kin received ITEOL, whether the patient's last stated wish about place of death was known and whether there was an individual prescription of injectable PRN drugs against pain on the drug list before death. These aspects of end-of-life care were briefly discussed during the training.

DATA ANALYSIS

Data were analysed using the programme IBM SPSS 21. A multivariable logistic regression model was used to compare the outcomes between the intervention and control groups with the intervention, age, gender, the three most common causes of death (cardiovascular diseases, cancer, and pulmonary diseases) and time (death before or after the intervention) as explanatory variables. P-values, odds ratios and 95% confidence intervals were reported. With this approach, the model was corrected for possible effects on the outcome of changes in societal attitudes over time. This correction was chosen because at the start of the study there were ongoing national initiatives highlighting palliative care (e.g., development of national guidelines in palliative care). Chi-square test (gender and diagnosis) and Mann-Whitney U test (age) were used to compare the groups. The same tests were used to compare patients who were reported before and after the intervention and patients who were reported by hospitals and municipalities. A univariate logistic regression model was used to compare the proportion of patients who received ITEOL between the hospital and municipalities, before and after the intervention. P-values <0.05 were considered significant.

PARTICIPANTS AND SAMPLING

This qualitative study involved 15 patients at an oncology outpatient clinic at a surgery department of a middle-sized hospital in Sweden. Inclusion criteria were as follows: adult, Swedish-speaking, diagnosed with incurable cancer one month or more before the face-to-face interview, received palliative chemotherapy (intravenous chemotherapy that aimed to prolong life and/or to alleviate symptoms but not to cure) at least once during the last three months, and Eastern Cooperative Oncology Group (ECOG) scale of performance status (164) 1–3 (not completely disabled). Exclusion criteria were: not able to give informed consent and communication disabilities that would hinder interviewing.

Participants were recruited using purposeful sampling and aiming to include both women and men with a range of ages and cancer diagnoses. An initial sample size of around 15 patients was chosen based on previous experience in the research group, supported by the finding of Guest et al. that saturation occurred within the first 12 interviews, meaning that no new information or themes were observed in the data after that (165). Suitable patients who met the criteria were selected by the second author in consultation with the clinic's oncology nurses, and 16 patients were contacted by the first author about participation, via mail and telephone. No invited patient declined to participate. The participants were asked to choose a place for the interview. One of the 16 patients was excluded from the study at the interview meeting because of cognitive impairment. Information about cancer diagnosis, chemotherapy, and time of death was obtained from the medical records.

Out of the remaining 15 participants, nine were women and six men. The median age was 62 years, ranging from 41 to 71. Six patients had colorectal cancer, five had breast cancer, three had pancreatic cancer and one had cancer of the gall bladder. The number of months since palliative diagnosis at the interview ranged from two to 40 months, and the median was 16 months. One year after the last interview, five participants were alive. Median survival time after the interview for the deceased participants was 101.5 days, with a range from 35 to 593 days (Table 5).

Table 5. Demographic information about the 15 participants

Age (median and range)	62 years (range 41–71)
Women/men	9/6
Colorectal cancer	6
Breast cancer	5
Pancreatic cancer	3
Gall bladder cancer	1
Time since palliative diagnosis at interview (median and range)	16 months (range 2–40)
Deceased/alive at closing of the study	10/5
Survival time after the interview (median)	102 days (range 35–593)

INTERVIEWS

The interviews were conducted in Swedish by the first author between May 2013 and February 2014. All participants chose to meet for the interview at the oncology outpatient clinic. A semi-structured interview guide was used, containing question areas concerning perceptions of information about diagnosis, treatment, and future planning. Examples of initial questions and leading statements were 'What information have you been given about your disease?' and 'Tell me about your treatment'. Follow up questions, for example, 'Tell me more' and 'How did you feel about that?' were used. At the end of the interview the participants were asked if there was anything more they wanted to add. The interviews were audiorecorded and transcribed verbatim, and had median duration of 51 minutes, ranging between 36 and 89 minutes. Kirk et al. (166) have previously described a similar procedure of using content analysis to analyse semi-structured audiotaped interviews with patients with incurable cancer.

DATA ANALYSIS

After the interviews had been conducted, we assessed that data was saturated, and thus more interviews were not conducted. Qualitative content analysis using the manifest content of the interviews (163) was used, since the purpose of the analysis was to describe the participants' perceptions. The transcribed interviews were read and reread to gain an initial understanding of the text. Meaning units referring to the same central meaning, related to the objective of the study, were identified, condensed into fewer words with their essence preserved, and coded. Codes with closely related meaning units were sorted together into subcategories, which were then organised into categories to reflect the central content (Table 6). A category was defined as a 'collection of similar data sorted into the same place' (167). All authors discussed naming of the categories and subcategories to obtain the clearest descriptions possible.

Table 6. Illustration of the analytical process from meaning units to categories

Participant number	Condensed meaning unit	Code	Subcategory	Category
16	It's like living with a pistol against your head, and Russian roulette, and not knowing whether it's going to go 'click' this time or not.	A pistol against the head Russian roulette Click or not	A constant threat	Living with a death sentence
13	I have to have the supplement in order for it to work. My physician says they would prefer to not give it to me, but if you've got to have it, then that's just the way it is. The alternative is to just say to heck with it, and give up.	Must have the supplement If you have got to, that's the way it is The alternative is to give up	Only one option	Depending on chemo-therapy
16	The physicians said we may end up having to do chemotherapy once or twice a year. The other antitumoral treatment slows the progression of the disease but not sufficiently.	Maybe chemotherapy once or twice a year Other therapy not sufficient	Future planning is speculative	Living with uncertainty

RESULTS

STUDY I

This study evaluated two essential elements of the registration process: the congruity of data when comparing medical records with registered data, and mistakes made in transferring questionnaire responses from the paper form to the web-based form.

DEMOGRAPHICS

Cancer was reported as the main disease in 93 out of 100 patients. The places of death were the patient's own home with support from the palliative home care team (53/100), the palliative ward (46/100) and a nursing home with support from the palliative home care team (1/100). Although all included patients were diagnosed as having moved beyond the transition to end-of-life care according to their medical records, one out of the 100 patients was reported to have died unexpectedly.

COMPARISON BETWEEN ELQ REGISTRATIONS AND ELQS BASED ON THE MEDICAL RECORDS

A comparison between ELQ registrations and ELQs filled in based on the medical records showed a diverse congruity, ranging from 22% to 100% (Table 7). Eight items had a congruity of less than 80% and thus fell below the preset limit of acceptable validity. The reason for noncongruity was divided into three categories: lack of documentation in the medical records, systematic misinterpretation of questions and other (Table 7). Lack of documentation in the medical records caused a noncongruity between the ELQs reported to the SRPC and the ELQs filled out based on the medical records, although the staff may have known and reported the true answer. In a significant amount of the noncongruity found, no trend in how the answers differed was detected (Table 7).

Question 16 (whether VAS/NRS scale had been used for pain evaluation in the last week) showed a congruity of 29%. The discrepant answers in a majority of cases (n=48) were due to systematic misinterpretations: an underuse of the alternative 'The patient cannot participate' (n=37) and reporting that pain evaluation had been done by the patient, even though it had been done by staff, according to the medical records (n=11).

The overall congruity of question 17 (whether the patient had symptoms that were not fully alleviated during the patient's last week) was 22%. The question contained nine different alternative answers that could be combined. Studied

Table 7. Answers that differed between ELQ registrations and ELQs filled in from medical records per question, divided into three categories

Question	Overall congruity (n/%)	Noncongruity because of lack of documentation in the medical records (n)	Noncongruity because of systematic mis-interpretation of questions (n)	Other reasons for non-congruity (n)
4. Area code	99/100 (99%)	-	-	1/100
6. Date for admission	89/100 (89%)	-	6/100	5/100
7. Date of death	97/100 (97%)	-	-	3/100
8. Place of death	100/100 (100%)	-	-	-
9. Cause of death	94/100 (94%)	-	4/100	2/100
10. Forensic autopsy	99/100 (99%)	-	-	1/100
11. Expected or unexpected death	98/99 (99%)	-	-	1/99
12. Date of last physician examination	76/99 (77%)	18/99	-	5/99
13. ITEOL given to patient	43/99 (43%)	13/99	-	43/99
14. ITEOL given to next of kin	48/99 (48%)	4/99	-	47/99
15. Time for lost ability to express will	56/99 (57%)	14/99	-	29/99
16. Pain evaluation with VAS or NRS	29/99 (29%)	5/99	48/99	17/99
17. Symptoms not fully alleviated	22/99 (22%)	12/99	-	65/99
18. Consultation regarding symptoms	97/99 (98%)	-	-	2/99
19. Pressure ulcers last week of life	70/99 (71%)	9/99	-	20/99
20a. PRN medication against pain	88/99 (89%)	-	10/99	1/99
20b. PRN medication against death rattle	81/99 (82%)	-	14/99	4/99
20c. PRN medication against nausea	82/99 (83%)	-	10/99	7/99
20d. PRN medication against anxiety	84/99 (85%)	-	12/99	3/99
21. Company at moment of death	94/99 (95%)	4/99	-	1/99
22. Place of death in correspondence to the patient's wish	84/99 (85%)	6/99	-	9/99
23. Number of places for care the last two weeks	86/99 (87%)	4/99	-	9/99
24. Next of kin offered a follow-up appointment	96/99 (97%)	3/99	-	-
25. Staff satisfaction with the end-of-life care given	67/99 (68%)	32/99	-	-

individually, the congruity of the alternatives ranged from 54% (shortness of breath) to 82% (confusion). Both confusion and pressure ulcers (question 19)

were underreported. Confusion was documented in the medical records but not reported to the SRPC in 27 cases. Pressure ulcers were documented in the medical records but not registered to the SRPC in 16 cases, and a higher grade of pressure ulcers was documented in the medicals records than was reported to the SRPC in two cases.

Question 20 (whether or not PRN drugs were prescribed in the form of injections for four different symptoms at least one day before death) was not interpreted as intended. In 45 cases, the units had reported that a drug was prescribed, although this was not done until after the time specified in the question (one day before death). In one case the answer was positive, although a drug used to alleviate nausea was prescribed for other indications only.

COMPARISON BETWEEN ELQ REGISTRATIONS AND PAPER VERSIONS

Per item, ELQ registrations and paper versions had a congruity ranging from 91% to 100% (Table 8). One question (number 16 about pain evaluation) fell below the preset limit for acceptable congruity of 95%. The reasons for noncongruity were divided into three categories: question not answered in paper form (it was not possible to submit the web-based form without answering all questions), question answered technically incorrectly in the paper version and mistake or correction made in transferring answers to the web-based form. An example of a technically incorrectly filled-out paper version was in question 16, where two alternatives were chosen in six cases, which could not be submited in the web-based form.

VALIDITY OF THE UPDATED ELQ (PRELIMINARY RESULTS)

Preliminary results from the re-examination of the validity of the updated version of the ELQ are shown in Table 9. The items that fell below the line of 80% congruity when comparing the ELQ registrations and the ELQs based on the medical records were question 5 about date for admission, question 20a–f about symptoms, question 21 about pain assessment, question 23 about assessment of symptoms other than pain, question 27 about team satisfaction with care, and the alterative answer ‘other cause of death’ in question 7. The items about ITEOL given to patients (question 11b) and ITEOL given to next of kin (question 17) now showed congruity over 80% when comparing the ELQ registrations and the ELQs based on the medical records. The congruity when comparing the ELQ registrations and paper versions varied between 87% and 100%, and question 5 about date for admission, question 14a about pressure ulcer at death and question 20e1 about dyspnoea fell below 95% congruity.

Table 8. Answers that differed between ELQ registrations and corresponding paper versions per question, divided into three categories

Question	Congruity between ELQs based on medical records and paper versions (n/%)	Question not answered in paper version (n)	Question answered technically incorrectly in paper version (n)	Mistake or correction in transferring to the web-based form (n)
4. Area code	98/100 (98%)	1/100	-	1/100
6. Date for admission	98/100 (98%)	-	1/100	1/100
7. Date of death	98/100 (98%)	-	-	2/100
8. Place of death	100/100 (100%)	-	-	-
9. Cause of death	97/100 (97%)	-	-	3/100
10. Forensic autopsy	100/100 (100%)	-	-	-
11. Expected or unexpected death	100/100 (100%)	-	-	-
12. Date of last physician examination	98/100 (98%)	1/100	-	1/100
13. ITEOL given topatient	99/100 (99%)	1/100	-	-
14. ITEOL given to next of kin	97/100 (97%)	-	1/100	2/100
15. Time for lost ability to express will	98/100 (98%)	1/100	-	1/100
16. Pain evaluation with VAS or NRS	91/100 (91%)	1/100	6/100	2/100
17. Symptoms not fully alleviated	96/100 (96%)	3/100	-	1/100
18. Consultation regarding symptoms	99/100 (99%)	1/100	-	-
19. Pressure ulcers last week of life	99/100 (99%)	1/100	-	-
20a. PRN medication against pain	100/100 (100%)	-	-	-
20b. PRN medication against death rattle	100/100 (100%)	-	-	-
20c. PRN medication against nausea	96/100 (96%)	3/100	-	1/100
20d. PRN medication against anxiety	100/100 (100%)	-	-	-
21. Company at moment of death	100/100 (100%)	-	-	-
22. Place of death in correspondence to the patient's wish	99/100 (99%)	1/100	-	-
23. Number of places for care the last two weeks	100/100 (100%)	-	-	-
24. Next of kin offered a follow-up appointment	100/100 (100%)	-	-	-
25. Staff satisfaction with the end-of-life care given	98/100 (98%)	2/100	-	-

Table 9. Validity of the updated ELQ (preliminary results)

Question	Congruity between ELQ registrations and ELQs based on the medical records (n/%)	Congruity between ELQs registrations and paper versions (n/%)
4. Date of death	99/100 (99%)	99/100 (99%)
5. Date for admission	78/100 (78%)	89/100 (89%)
6. Place of death	96/100 (96%)	100/100 (100%)
7.1 Cancer as cause of death	96/100 (96%)	100/100 (100%)
7.2 Cardiovascular disease as cause of death	100/100 (100%)	98/100 (98%)
7.3 Respiratory disease as cause of death	91/100 (91%)	99/100 (99%)
7.4 Dementia as cause of death	100/100 (100%)	100/100 (100%)
7.5 Stroke as cause of death	97/100 (97%)	100/100 (100%)
7.6 Other neurological disease as cause of death	98/100 (98%)	100/100 (100%)
7.7 Diabetes as cause of death	91/100 (91%)	100/100 (100%)
7.8 State after fracture as cause of death	99/100 (99%)	100/100 (100%)
7.9 Multimorbidity as cause of death	99/100 (99%)	99/100 (99%)
7.10 Other cause of death	75/100 (75%)	99/100 (99%)
8. Post mortem examination	100/100 (100%)	100/100 (100%)
9. Expected or unexpected death	100/100 (100%)	100/100 (100%)
10. Time for lost ability to express will	85/100 (85%)	98/100 (98%)
11b. ITEOL given to patient	85/100 (85%)	98/100 (98%)
12. Place of death in correspondence to the patient's wish	89/100 (89%)	100/100 (100%)
13a. Pressure ulcer at arrival to healthcare unit	91/100 (91%)	99/100 (99%)
13b. Documentation of pressure ulcer at arrival	7/8 (88%)	8/8 (100%)
14a. Pressure ulcer at death	81/100 (81%)	87/100 (87%)
14b. Documented pressure ulcer at death	21/24 (88%)	23/24 (96%)
15a. Assessment of oral health	89/100 (89%)	96/100 (96%)
15b. Oral health disorders	67/84 (80%)	81/84 (96%)
15c. Documented assessment of oral health	77/82 (94%)	81/82 (99%)
16. Company at moment of death	93/100 (93%)	99/100 (99%)
17. ITEOL given to next of kin	95/100 (95%)	98/100 (98%)
18. Next of kin offered a follow-up appointment	97/100 (97%)	98/100 (98%)
19. Parenteral fluids or enteral tube feeding	96/100 (96%)	100/100 (100%)
20a.1 Pain	79/100 (79%)	97/100 (97%)
20a.2 Pain relief	10/72 (14%)	70/72 (97%)
20b.1 Death rattle	76/100 (76%)	97/100 (97%)
20b.2 Death rattle relief	11/54 (20%)	53/54 (98%)
20c.1 Nausea	71/100 (71%)	98/100 (98%)
20c.2 Nausea relief	2/13 (15%)	13/13 (100%)
20d.1 Anxiety	60/100 (60%)	98/100 (98%)
20d.2 Anxiety relief	5/43 (12%)	42/43 (98%)
20e.1 Dyspnoea	63/100 (63%)	91/100 (91%)
20e.2 Dyspnoea relief	3/24 (13%)	23/24 (96%)
20f.1 Confusion	47/100 (47%)	97/100 (97%)
20f.2 Confusion relief	0/27 (0%)	27/27 (100%)
21. Pain assessment	73/100 (73%)	97/100 (97%)
22. Severe pain	84/100 (84%)	96/100 (96%)
23. Assessment of symptoms other than pain	71/100 (71%)	95/100 (95%)
24a. PRN opioid against pain	98/100 (98%)	98/100 (98%)
24b. PRN drugs against death rattle	100/100 (100%)	100/100 (100%)
24c. PRN drugs against nausea	97/100 (97%)	99/100 (99%)
24d. PRN drugs against anxiety	100/100 (100%)	100/100 (100%)
26. Consultation regarding symptom relief	87/100 (87%)	99/100 (99%)
27. Team satisfaction with care	48/100 (48%)	96/100 (96%)

During the studied three-year period, a total of 52 593 patients had been reported from 2058 healthcare units to the SRPC. Out of these, 17 343 patients were excluded because they had been reported by healthcare units that did not report at least one patient annually and 4967 patients were excluded because they had died at another type of unit than the reporting unit. A total of 30 283 patients reported by 503 healthcare units remained in the study (Table 10).

Table 10. Numbers of included and excluded patients

Reported patients during the study period, total	52 593
Excluded because patients were reported by healthcare units that did not report at least one patient each year during the studied three-year period	17 343
Excluded because patients had died at another type of unit than the reporting unit	4967
Remaining in the study	30 283

The 503 included healthcare units were 39 hocpices/palliative hospital wards, 233 nursing homes, 60 specialised palliative home care units, 88 hospital wards without palliative specialisation, 56 short-term care homes and 27 home care units without palliative specialisation (Table 11).

Table 11. Numbers of healthcare units included and patients reported during the study period divided into the different types of healthcare units (types of healthcare units at baseline are shown)

	Healthcare units included (n)	Patients reported during the total study period (n)
Hospice/palliative hospital ward	39	10 480
Nursing home	233	6807
Specialised palliative home care	60	4333
Hospital ward without palliative specialisation	88	6081
Short-term care home	56	2233
Home care without palliative specialisation	27	349
Total	503	30 283

Cancer was the main cause of death for 18 238 patients (60%), and 6354 (21%) were reported to have lost their ability to express will and take part in decisions concerning the content of medical care weeks before death or earlier (Table 12). A total of 16 342 women (54%) and 13 941 men (46%) were reported.

Some aspects of the care in specialised palliative units were high at baseline (the first year): In specialised palliative home care, 94% of the patients died at their preferred place of death, 97% of the patients' next of kin were offered a follow-up appointment and 93% of the patients had PRN pain medication prescribed. In hospices/palliative hospital wards, 92% of the next of kin were offered a follow-up appointment, 98% of the patients had PRN pain medication prescribed, 95% of the patients had PRN anxiety medication prescribed and 92% of the patients had PRN death rattle medication prescribed.

Table 12. Number of patients, number of patients with cancer as the main cause of death and number of patients with cognitive impairment in each year of the study, divided into the different types of healthcare units

	Type of healthcare unit	Year 1	Year 2	Year 3	Total study period
Number of patients (n)	Hospice/palliative hospital ward	2948	3739	3793	10 480
	Nursing home	1628	2691	2488	6807
	Specialised palliative home care	1097	1532	1704	4333
	Hospital ward without palliative specialisation	1333	2456	2292	6081
	Short-term care home	508	856	869	2233
	Home care without palliative specialisation	70	135	144	349
	Total	7584	11 409	11 290	30 283
Cancer as main cause of death (n/% of total)	Hospice/palliative hospital ward	2790 (95%)	3502 (94%)	3540 (93%)	9832 (94%)
	Nursing home	186 (11%)	305 (11%)	287 (12%)	778 (11%)
	Specialised palliative home care	994 (91%)	1375 (90%)	1518 (89%)	3887 (90%)
	Hospital ward without palliative specialisation	601 (45%)	975 (40%)	931 (41%)	2507 (41%)
	Short-term care home	214 (42%)	407 (48%)	450 (52%)	1071 (48%)
	Total	4814 (63%)	6631 (58%)	6793 (60%)	18 238 (60%)
Cognitively impaired*(n/% of all patients)	Hospice/palliative hospital ward	337 (11%)	312 (8%)	289 (8%)	938 (9%)
	Nursing home	834 (51%)	1444 (54%)	1206 (48%)	3484 (51%)
	Specialised palliative home care	71 (6%)	119 (8%)	108 (6%)	298 (7%)
	Hospital ward without palliative specialisation	249 (19%)	501 (20%)	445 (19%)	1195 (20%)
	Short-term care home	120 (24%)	130 (15%)	129 (15%)	379 (17%)
	Total	1627 (21%)	2527 (22%)	2200 (19%)	6354 (21%)

* Reported to have lost their ability to express will and take part in decisions concerning the content of medical care weeks before death or earlier.

The prevalence of six not fully alleviated symptoms (question 17 in the ELQ) decreased during the study period in the whole material: shortness of breath (10.4% to 8.6%, p<0.001), confusion (5.5% to 3.6%, p<0.001), nausea (4.3% to 3.7% p=0.036), death rattle (17.1% to 15.6%, p=0.003), pain (15.4% to 12.9%, p<0.001) and anxiety (17.6% to 13.6%, p<0.001). No decrease in symptoms was seen at nursing homes. Hospital wards (not palliative) showed decrease for pain only, while the other types of care units showed decreases in three or more symptoms.

The proportion of patients who were prescribed PRN drugs at least one day before death (question 20 in the ELQ) increased for all four symptoms during

the study period in the whole material: 89% to 90% for prescriptions against pain ($p<0.001$), 80% to 83% for prescriptions against death rattle ($p<0.001$), 55% to 82% for prescriptions against nausea ($p<0.001$) and 78% to 82% for prescriptions against anxiety ($p<0.001$). Prescriptions against nausea increased significantly in all types of care units. Nursing homes and hospital wards without palliative specialisation showed an increase in prescriptions for all registered symptoms.

The proportion of patients dying alone (question 21 in the ELQ) did not change in the whole material. In the subgroup analysis, a decrease from 25% to 22% was seen in hospital wards without palliative specialisation ($p=0.007$). There was an increase in the whole material of the proportion of patients whose place of death corresponded to their preferred place (48% to 50%, $p=0.001$) (question 22 in the ELQ). In the subgroup analysis, increases were seen in nursing homes (32% to 35%, $p=0.020$), short-term care homes (21% to 33%, $p<0.001$) and hospices/palliative hospital wards (60% to 66%, $p<0.001$).

An increase in the proportion of patients whose next of kin had been offered follow-up appointments after death of the patient (question 24) was seen in the whole material (72% to 74%, $p=0.001$). In the subgroup analysis, increases were seen in nursing homes (54% to 63%, $p<0.001$) and short-term care homes (38% to 70%, $p<0.001$). The total number of patients with pressure ulcers grade 1 (graded according to the EPUAP) (61) increased from 9.1% to 10.2% ($p=0.016$) in the whole material during the study period, and the number of patients with pressure ulcer grades 2–4 was unchanged.

No significant changes were seen regarding ITEOL in the whole material. ITEOL provided from physicians to the patient (question 13 in the ELQ) was 58% at both the start and ending of the study period (N.S.), and ITEOL from physicians provided to next of kin (question 14 in the ELQ) increased from 70% to 71% (N.S.). Increases were seen for ITEOL from physicians provided to the patients in short-term care homes (29% to 37%, $p=0.022$), hospices/palliative hospital wards (75% to 78%, $p=0.007$) and specialised palliative home care (76% to 81%, $p=0.005$). Increases were seen for ITEOL from physicians provided to next of kin in short-term care homes (53% to 62%, $p=0.004$) and hospices/palliative hospital wards (88% to 91%, $p<0.001$).

STUDY III

A total of 2812 patients were reported from the intervention and control groups during the six months before and after the intervention. Patients were excluded if a forensic post mortem examination was performed, death was unexpected, the ability to express their will and take part in decisions concerning the content of medical care was lost one week or more before death, or data were missing in any of these criteria. The analysis included 1431 patients (Table 13). In 16 cases, there was no next of kin, and these cases were excluded when analysing the proportion of patients whose next of kin received

ITEOL. The gender distribution was 53.3% women and 46.7% men, the mean age was 82.3 years and the three most common causes of death were cardiovascular diseases (34.6%), cancer (34.0%) and pulmonary diseases (11.8%).

Table 13. Numbers of included and excluded patients (all patients reported from intervention and control hospitals and municipalities both before and after intervention are shown)

Reported patients, total	2812
Excluded because of a forensic post mortem examination	5
Excluded because death was not expected	350
Excluded because there was no information about expected/unexpected death	152
Excluded because there was no information about ability to express their will	211
Excluded because patients were not able to express their will one week before death	663
Remaining in the study	1431

The patients reported from the intervention and control groups did not differ significantly regarding gender or age distribution (Table 14). The proportion of cardiovascular diseases and pulmonary diseases differed between the intervention hospitals and control hospitals (p=0.012 and p=0.014), but not between the intervention municipalities and control municipalities. The proportion of cancer did not differ between the intervention and control groups (Table 15). No significant changes were seen when comparing gender, age and diagnosis before and after the intervention.

Table 14. Comparison of age and gender between intervention and control groups

	Intervention group (n=500)	Control group (n=931)	Difference between intervention and control groups
Hospitals	Mean age 77.5 years	Mean age 79.2 years	N.S. (p=0.103)
	94 women (47.7%) 103 men (52.3%)	241 women (50.5%) 236 men (49.5%)	N.S. (p=0.507)
Municipalities	Mean age 85.4 years	Mean age 85.8 years	N.S. (p=0.230)
	168 women (55.4%) 135 men (44.6%)	260 women (57.3%) 194 men (42.7%)	N.S. (p=0.620)
All units	Mean age 82.2 years	Mean age 82.4 years	N.S. (p=0.760)
	262 women (52.4%)	501 women (53.8%)	N.S. (p=0.609)
	238 men (47.6%)	430 men (46.2%)	

As expected, the hospital and municipal patients differed regarding diagnoses, gender and age. The mean age was 78.6 in the hospitals and 85.6 in the municipalities (p<0.001). The gender distribution was 49.7% women and 50.3% men in the hospitals and 56.5% women and 43.5% men in the municipalities (p=0.010). Cardiovascular diseases were the cause of death in 30.3% of cases in the hospitals and 38.4% in the municipalities (p=0.001), cancer was the cause of death in 37.4% in the hospitals and 30.9% in the

municipalities (p=0.010), and pulmonary diseases were the cause of death in 13.6% in the hospitals and 10.2% in the municipalities (p=0.042).

Table 15. Comparison of the main causes of death between intervention and control groups

		Intervention group (n=500)	Control group (n=931)	Difference between intervention and control groups
Cardiovascular diseases as main cause of death (n/%)	Hospitals	46 (23.4%)	158 (33.1%)	p=0.0123
	Municipalities	119 (39.3%)	172 (37.9%)	N.S. (p=0.700)
	All units	165 (33.0%)	330 (35.4%)	N.S. (p=0.354)
Cancer as main cause of death (n/%)	Hospitals	78 (39.6%)	174 (36.5%)	N.S. (p=0.417)
	Municipalities	85 (28.1%)	149 (32.8%)	N.S. (p=0.164)
	All units	163 (32.6%)	323 (34.7%)	N.S. (p=0.425)
Pulmonary diseases as main cause of death (n/%)	Hospitals	37 (18.8%)	55 (11.5%)	p=0.0139
	Municipalities	30 (9.9%)	47 (10.4%)	N.S. (p=0.840)
	All units	67 (13.4%)	102 (11.0%)	N.S. (p=0.172)

The proportion of patients in the intervention group who received ITEOL increased from 35.1% (six months before the intervention) to 42.0% (six months after the intervention). At the same time, the proportion in the control group increased from 30.4% to 33.7%. The effect of the intervention was significant (p=0.005, OR 1.407 95% CI 1.111−1.783) in the multivariable model adjusted for age, gender, the three most common causes of death (cardiovascular diseases, cancer and pulmonary diseases) and time (Table 16).

Table 16. The proportion of patients who received ITEOL before and after the intervention in all units (odds ratios (OR) and 95% confidence intervals (CI) are reported)

	One to six months before intervention	One to six months after intervention	One to three months after intervention	Four to six months after intervention
ITEOL, intervention group	86/245 35.1%	107/255 42.0%	50/135 37.0%	57/120 47.5%
ITEOL, control group	134/441 30.4%	165/490 33.7%	74/241 30.7%	91/249 36.5%
Intervention effect, time adjusted	-	p=0.005 OR 1.407 (CI 1.111−1.783)	p=0.045 OR 1.330 (CI 1.007−1.758)	p=0.013 OR 1.421 (CI 1.078−1.872)

In the intervention hospitals, the proportion of patients who received ITEOL increased from 26.3% to 32.4%, and in the intervention municipalities the proportion of patients who received ITEOL increased from 40.7% to 48.4%, but the effect of the intervention was not significant in the multivariable model in either hospitals (p=0.301,) or municipalities (p=0.127) when analysed separately (Table 17).

Table 17. The proportion of patients who received ITEOL before and after the intervention in hospitals and municipalities (odds ratios (OR) and 95% confidence intervals (CI) are reported)

	Hospitals		Municipalities	
	Six months before intervention	Six months after intervention	Six months before intervention	Six months after intervention
ITEOL, intervention group	25/95 26.3%	33/102 32.4%	61/150 40.7%	74/153 48.4%
ITEOL, control group	51/218 23.4%	64/259 24.7%	83/223 37.2%	101/231 43.7%
Intervention effect, time adjusted	-	N.S. (p=0.301) OR 1.233 (CI 0.829−1.834)	-	N.S. (p=0.127) OR 1.272 (CI 0.934−1.734)

The proportion of patients who received ITEOL was smaller in the first three months (37.0%) than in the six months after the intervention (42.0%). The intervention had a significant effect on the proportion of patients who received ITEOL after the first three months (p=0.045), and when comparing the period before the intervention with the period four to six months after the intervention (p=0.013) (Table 16). The proportion of patients who received ITEOL differed between the hospitals and municipalities both before (24.3% and 38.6%, p<0.001, OR 1.961 95% CI 1.407–2.733) and after (26.9% and 45.6%, p<0.001, OR 2.279 95% CI 1.676–3.099) the intervention.

The intervention had no effect on the secondary outcomes in the multivariable model adjusted for age, gender, the three most common causes of death (cardiovascular diseases, cancer and pulmonary diseases) and time: 65.7% of patients had next of kin who received ITEOL before the intervention and 69.6% after the intervention (p=0.334, OR 1.125 95% 0.886–1.428), 88.3% of the patients had an individual prescription of injectable PRN drugs against pain on the drug list before death before the intervention and 89.0% after the intervention (p=0.139, OR 1.311 95% 0.916–1.877) and 39.1% of the patients' last stated wish about place of death was known before the intervention and 40.7% after the intervention (p=0.155, OR 0.849 95% 0.677–1.064).

STUDY IV

Three categories were disclosed during the analytical process: 'living with a death sentence', 'depending on chemotherapy' and 'living with uncertainty'. Each category arose from three subcategories (Table 18). Quotes from the interviews, marked with the assigned number for each participant, are shown in the next section as illustrations to the subcategories.

Table 18. Categories and subcategories

Category	Subcategory
Living with a death sentence	An incurable disease
	A constant threat
	Unknown survival time
Depending on chemotherapy	More time can be bought
	Only one option
	Therapeutic limits
Living with uncertainty	A wait for the next evaluation
	Outcomes are unknown
	Future planning is speculative

LIVING WITH A DEATH SENTENCE

AN INCURABLE DISEASE

The participants described being informed that they had a chronic disease. They compared their cancer disease to chronic illnesses, such as asthma and diabetes. They were aware that treatment would not cure them and that the cancer was going to shorten their lives. At the same time this was difficult to grasp, and met with anger and doubts. To understand the meaning of this message was a time-consuming process, but they appreciated that the information had been direct and honest. The participants expressed hope about miracles and new or experimental treatments with the possibility of a cure, but they also described their situation as impossible to influence in any way.

> *And there was no way the tumour could be removed either. So I got that information straight up, no beating around the bush, so to speak. Which was good. If it's too sugar coated, you're not sure of what you've heard. It has to be stated clearly.* [7]

A CONSTANT THREAT

The participants understood that they were not imminently dying, but they were also aware that their situation could change rapidly at any time. Sometimes the physicians had emphasised that the chemotherapy may have potentially life-threatening side effects. Some of the participants also had previous experiences of treatment underlining this threat. Even if the physicians had conveyed that the disease was under control for now, the participants nevertheless felt that there was always a risk that the disease would suddenly strike out and become much worse.

> *Some friggin' strong doses, right from the start... And I couldn't take it... So I was admitted to hospital, ended up staying 14 days... It almost finished me off. So the next time, when I got here, it was that physician... 'If you'd had one more [treatment]', he said, 'you wouldn't have had to come here anymore.'* [14]

UNKNOWN SURVIVAL TIME

The participants had discussed survival time in general terms with their physicians, and some participants had asked about explicit survival time or whether they would live long enough to experience a specific event. The physicians had given them some ideas of survival time (ranging from weeks to many years for different participants), but had also said that these prognostications were uncertain. The participants experienced that most physicians were cautious and did not dare to talk more explicitly about survival time. Some participants wished for more details based on general statistics, but comprehension was expressed for the fact that the physicians were not able to provide that. Other participants were uninterested in speculating about survival time with their physician or felt unsure whether they would be able to handle more explicit information.

> *...I understand the physicians who can't say anything. It's stupid. There are – it happens that they tell the patient, and then the patient outlives the prognosis by ten years. So obviously the physicians have to be careful about that.* [5]

DEPENDING ON CHEMOTHERAPY

MORE TIME CAN BE BOUGHT

After delivering the message about incurable cancer, the physicians had stated that there was palliative chemotherapy available. It had sometimes been explained that the chemotherapy could affect the cancer by stopping or reducing the growth rate of the tumours or even by shrinking them. It was also common that the physicians had used metaphors to explain the effect of chemotherapy: 'to hold the cancer in check' or 'to apply a brake on the cancer'. The participants perceived that the palliative chemotherapy had the ability to postpone death, and was regarded as a lifeline.

> *They [the physicians] don't say it... cures the disease; they say it keeps it in check... They, they don't say it cures the disease or removes the tumour; they want to give me more time. Slow things down a bit.* [11]

ONLY ONE OPTION

The participants reported that their only option had been to accept the palliative chemotherapy offered, even though their right to decline had been stressed. They perceived that chemotherapy was both physically and mentally important, and were willing to accept it in spite of potentially bothersome or dangerous side effects. The option of treatment was not perceived as a real option. The participants expressed that there was nothing else to choose from but an earlier death. If the start of chemotherapy was delayed or if a single dose of chemotherapy could not be given, the participants became very distressed

and worried about what would happen to the cancer without treatment. Having blood values too low for treatment could be experienced as a personal failure.

> *Like I said to the nurse just now, 'But what's going to happen now, if I don't get [chemotherapy]'? God! It'll be even worse! Can I cope with a week now without [chemotherapy]? I was, like, kind of upset, right? I am extremely goal oriented, and I said I consider it a personal failure.* [5]

THERAPEUTIC LIMITS

The participants were aware that the treatment might cease in the future. They had received verbal information about a future cessation of chemotherapy, and had also understood from previous occasional skipping of single treatments, reduced doses, or pauses due to side effects that their bodies would probably eventually be too worn down for more chemotherapy. In some cases, the physicians also had informed them about a risk of becoming unresponsive to chemotherapy. Most participants felt unsure of how long it would be possible for the chemotherapy to continue and had not discussed it with their physicians. Some participants had been assured that they could choose to decline future treatment if they felt too unwell to proceed.

> *When the day comes that I hear... if I learn, and when... that, 'No, you're so full of cancer now so there's no...' or 'Your body cannot take any more chemo'... because of course that could happen. – that it's just not possible any longer.* [9]

LIVING WITH UNCERTAINTY

A WAIT FOR THE NEXT EVALUATION

After the regular radiological examinations for chemotherapy evaluation, the participants usually met with the oncologist to discuss the next chemotherapy period. There were other physicians available at the surgical clinic for acute problems, but other than that the participants seldom met with physicians during a treatment period. Some participants perceived that the role of the oncologist was mainly to discuss cancer treatment. The time until the next radiology examination and evaluation was described as a wait and generated worries and fears about getting bad news from the physician.

> *It feels pretty hard, I have to say... I'm going to start taking this treatment. Then, then I'll wait for the next x-ray and... It feels sort of like a wait, somehow, when you have to wait for your next x-ray, and then the next x-ray.* [8]

OUTCOMES ARE UNKNOWN

What outcomes the oncologist expected from treatment had not been discussed in much detail with the participants. They had been informed by physicians

that outcomes of treatment are individual and that no one could know whether the current treatment was going to have any effect. No participant had been informed about how likely it was that the treatment would work, but some had been informed that the treatment was not going to work if they felt too unwell because of side effects. Apart from that, the participants had drawn the conclusion that the only way of knowing the outcome of treatment was to wait for the treatment evaluation.

> *But I understand now that no physician in the world can know how I'm going to react to the medication. That's, that's just how it is.* [4]

FUTURE PLANNING IS SPECULATIVE

In conversations with the physicians, participants perceived the medical plans as not spanning further than the next radiologic evaluation. Sometimes future treatment plans had been discussed, but only in speculative terms, for example, that the type of chemotherapy might be changed later. Some participants wanted more information about future plans, but others had drawn the conclusion that it was impossible for the oncologist to accurately answer questions about treatment planning in the longer term. This uncertainty about how and when chemotherapy would be evaluated and given in the future made their personal lives harder to plan.

> *Like the primary breast cancer. Then of course you can draw a map... It's like a finished template. Yeah, but you're going to get six rounds of chemo. And there there's the radiation... And perhaps this path isn't so straight, but has more twists and turns, and it's harder to make a map.* [15]

DISCUSSION

GENERAL CONSIDERATIONS

QUALITY IN END-OF-LIFE CARE AND THE SRPC

There is a need in palliative care for development of structured methods to assess quality and support improvement. This need is present both within and outside specialised palliative care. A majority of all dying patients in Sweden receive end-of-life care in nursing homes and in hospital wards without palliative specialisation. There is a need for the specialised palliative care to develop an accepted quality standard and to show that they deliver care fulfilling those quality criteria.

Compared to international registers, the SRPC is unique in that it is a nationwide register that collects data about end-of-life care regardless of diagnosis and place of care, covering almost 70% of all dying patients in the population and almost 90% of all patients dying with cancer. There are palliative registers in Denmark (153, 154) and Australia (156), but they both collect data only from specialised palliative care. Compared to other Swedish quality registers, the SRPC is one of few registers with a holistic perspective of care, regardless of place of care, and it also provides direct user feedback on the register's web page. Not all Swedish quality registers have examined their validity in collected data (134).

The SRPC was founded by professionals working with palliative medicine in Sweden. As there was no validated and research-based quality register on end-of-life care to compare with, the items in the original ELQ were based on clinical knowledge and general values of good end-of-life care among the founding members. The different constructions of healthcare systems internationally complicate international comparisons, but international cooperation in finding quality indicators and methods for quality improvement would be beneficial. Continuous re-evaluation of how to best illustrate and evaluate the quality in palliative care can be a way to approach the vision of good quality palliative care for all incurable patients according to their personal needs, regardless of diagnosis, place of residence, and level of care.

STUDY I – THE ELQ

With eight items below the line of 80% congruity, study I showed varied validity in the ELQ, which implied a need to modify the questionnaire. The preset limits of acceptable congruity were relatively low. A high validity level is preferable and a prerequisite for valid usage of register data for research purposes. The items in the ELQ differ much in complexity, and some deal with

'soft' values that are difficult to measure, for example, the items dealing with ITEOL, not fully alleviated symptoms and ability to express will and participate in decisions concerning medical care. For those questions, perhaps a lower limit of congruity has to be accepted.

Some questions were interpreted by the users at the healthcare units studied in a way that was not intended by the SRPC and needed clarification. For example, in the question about pain evaluation (number 16 in the ELQ) the answer 'The patient cannot participate' was not used as intended. Lack of consensus of terminology probably contributed to this, since it was not clear whether pain evaluation meant that the patient did the evaluation, or whether it could also mean that the staff did the evaluation. The item about pressure ulcers (question 19 in the ELQ) showed a need for clarification, as it did not specify how to answer, if the patient had two or more pressure ulcers that were of different grades during the last week.

The item about not fully alleviated symptoms (number 17 in the ELQ) had the lowest congruity in the ELQ, which probably was related to the complexity in the construction of the question (nine alternative answers that could be combined) as well as the complexity of measuring symptoms and assessing whether they were alleviated. Only 1% confusion was reported in the ELQ, while 28% had confusion according to their medical records. Other studies have found a prevalence of delirium of 32%-47% in patients with advanced cancer (168, 169), and of 88% in patients with advanced cancer at the end of life (170).

Although the setting was a healthcare unit specialising in palliative care that had a special way of documenting palliative aspects in its medical records, there was a lack of documentation in the medical records for some aspects of end-of-life care. The low congruity of the items about ITEOL given to the patient (number 13 in the ELQ) and to the patient's next of kin (number 14) were largely caused by lack of documentation. Better documentation about end-of-life care content would not only facilitate future retrospective audits, but would probably also increase the quality of end-of-life care, because it would provide more information to all physicians, nurses and other healthcare staff involved in the care of the patient. Documentation in the patient's medical record is also required by Swedish law (135).

Some validity problems related to the paper version of the ELQ were identified. It was not always clear in the paper form that several alternatives could not be used, which was a problem when the paper version was used by the healthcare team. All questions had to be technically correctly answered in the web-based form by the person who transferred the answers to the electronic form. Questions could also be left unanswered in the paper version, which was not possible when transferring to the web-based form. These findings suggested that the paper version of the ELQ should be modified to clarify this. Another way to avoid this validity problem could be to answer the ELQ directly using

the web-based form, but that is not practically possible for some healthcare units participating in the SRPC.

Since study I was conducted, the ELQ has been developed to promote more valid results and to more broadly reflect the challenges in end-of-life care. In the updated version of the ELQ, focus is more shifted from outcomes of care to processes of care, for example, symptom assessment and documentation. Preliminary results from the examination of the validity of the updated version of the ELQ show that validity problems still exist in some items, but the overall validity in the ELQ has been increased by the revision.

STUDY II – PARTICIPATING IN THE SRPC

Study II showed that participation in the SRPC was covariant with quality improvements in end-of-life care over time. The results implied that following the structured assessment of end-of-life care using the SRPC may have contributed to the improvements, both via registration after each deceased patient and via the possibility of immediate, web-generated feedback compared to similar healthcare units nationwide. To a certain extent, the identified improvements could also be due to better documentation and/or staff awareness.

The findings in study II are supported by the findings of Lindblom et al., that nurses using the SRPC experience an improvement in their performance in end-of-life care (151). Similar to the findings in this study, Currow et al. showed that there were significant improvements in palliative care during a three-year period where the participating palliative healthcare units routinely reported to the Australian Palliative Care Outcomes Collaboration and received systematic feedback (155). Study II also confirmed that the SRPC as a register was applicable in all kinds of healthcare units where end-of-life care is provided, including healthcare units outside specialised palliative care.

Improvements were seen in the prevalence of distressing symptoms during the last week of life and prescription of injectable PRN medication for symptom alleviation. Having a prescription for PRN medication does not necessarily mean that the patient suffers less from symptoms, but an adequate prescription is most often a prerequisite for providing immediate symptom relief. To a certain extent, the identified improvements could also be due to better documentation or staff awareness. The trend that lower grade of pressure ulcers increased during the study years could be because of a real increase in pressure ulcers or a sign of increased staff awareness combined with better documentation.

Almost half of the study patients with unknown wishes about preferred place of death could represent those who lost their ability to express their will and to participate in decisions concerning medical care content weeks before death or earlier. The other half of those with unknown wishes had probably been able to

declare their preference if they had been asked. The proportion of patients dying at a place they did not prefer could be close to the possible limit; it is probably practically impossible to fulfil every patient's wish.

STUDY III – THE EFFECT OF A HALF-DAY PHYSICIAN AND NURSE TRAINING IN ITEOL

Study III showed that more patients in end-of-life received ITEOL after an educative half-day intervention directed to physicians and nurses in nursing homes and hospitals. The intervention had an effect in the desired direction, but was smaller than estimated when planning the study. No previous studies in the palliative care field had examined how to increase the proportion of patients who receive information.

Study III was originally conceived as a pilot project prior to a planned national educative project about ITEOL planned by the SALAR as part of the programme 'Better Life for Most Sick Elderly'. This pilot project showed that an educative intervention about ITEOL is possible. No invited hospital or municipality declined participation. Out of the physicians invited, 60% attended the course in the hospitals and 69% in the municipalities. This can be seen as a high enough rate of participation, as an increase in the number of patients receiving ITEOL was seen, but it is possible that a higher proportion of physicians participating could have increased the proportion of patients receiving ITEOL more than was seen in this study. Although previous studies have stated that an educative intervention for healthcare staff needs to be longer to have maximal effect (105, 128), a half-day was the extent of the training that was deemed manageable. A longer education would probably decrease the proportion of physicians participating, and therefore it is not certain that a longer education would have given a better overall effect.

In this study, only 34% of all included patients received ITEOL, a comparatively low proportion since only hospitals and municipalities with a proportion of patients receiving ITEOL of less than 40% were included in this study. The nationwide proportion of patients who received ITEOL in Sweden in 2011 was 57%, according to SRPC data (148). More nurses attended the course in the municipalities compared to the hospitals. This was probably because each physician was responsible for more than one nursing home ward, and because the invitations were processed in different ways in hospital clinics and nursing homes for practical reasons.

Fewer patients reported by hospital wards (26%) received ITEOL than the patients reported by the municipal units (42%). Contrary to the findings by Brännström et al. (45), in this study there were more patients with heart diseases in the group where most patients received ITEOL (municipalities), and more patients with cancer in the group where fewer received ITEOL (hospitals). The differences in diagnosis, gender and age are probably not

enough to explain the inequality. One important factor could be that the duration of stay usually is much longer in nursing homes than in hospitals.

Education and training have been suggested as methods to change physicians' attitudes towards disclosure of prognostic information (171, 172), but to achieve and sustain improvements in healthcare, supportive organisational changes are generally needed (173). Friedrichsen et al (27) found that healthcare staff who were educated about palliative care, including ITEOL, expressed frustration because economic constraints hindered the incorporation of their acquired knowledge into their clinical work, suggesting that economic issues are important for ITEOL.

STUDY IV – PATIENTS' PERCEPTIONS OF INFORMATION FROM PHYSICIANS

Study IV showed that when patients with cancer met with their physicians the information they received was direct and honest regarding the fact that the cancer was incurable and would shorten their lives. They were also informed that the palliative treatment was not curative, could have life-threatening side effects, and might cease in the future. This prognostic information awoke strong feelings, and the participants perceived themselves as living with a death sentence and in uncertainty, and as dependent on chemotherapy. Compared with those in several other studies (83, 84, 95-100), the patients in this study seemed to be more aware of their prognoses and the goals of their care. No other study found has examined the perception that patients with incurable cancer have of information about survival time and of the risk of dying because of chemotherapy.

The participants perceived a dependency on palliative chemotherapy and the possible future cessation of chemotherapy as a threat to their existence. No other studies that describe this have been found in the literature. Similar to the results in this study, the feeling of having no choice other than the palliative chemotherapy offered was also found in a study by Schildmann et al. examining the perceptions and preferences for information of patients with pancreatic cancer (81). Similar to this study, Buiting et al. also found that the chemotherapy-free periods can be stressful for patients (111).

The participants reported that their physicians had sometimes used metaphors to explain palliative chemotherapy. Casarett et al. found that analogies and metaphors are frequently used by oncologists, and suggested that this may offer a way to improve patient–physician communication (174). The participants had not received much information about expected outcomes of palliative chemotherapy. Similar to the findings in this study, Audrey et al. found that at discussions of starting palliative chemotherapy, there was a consistency in informing patients about that the chemotherapy did not aim to cure, but the amount of information given about survival benefits varied (33).

The complexity of the topic may hinder adequate patient–physician communication.

The focus on short-term planning rather than longer term, shown by The et al. and Buiting et al. (108, 111), was also found in this study. This focus may be adopted by patients as a way of coping with the situation (111), but the physicians focusing too much on short-term planning can also potentially hinder good patient–physician discussions about ending chemotherapy (175) and may in that aspect be an obstacle for the patient's' decision-making.

METHODOLOGICAL CONSIDERATIONS

QUALITY REGISTERS FOR RESEARCH PURPOSES

The multiple purposes of the quality registers – monitoring, evaluating and improving quality in healthcare both internally and externally; supporting research; and in some cases forming a basis for allocation of economic resources – poses a challenge for the use of quality register data in research. During the Swedish debate, it has been argued that it is not certain that all quality registers can be used for all these purposes. The basis for research may suffer if too few items are measured, but this may be acceptable in order to not overload the registers (138). Too many items could lead to a decrease in reporting to the register, a decrease in the use of the register for improvement purposes and to unacceptable time required for register completion, which may shorten professionals' time with their patients. Research using data from quality registers where only a few items are measured could be merely hypothesis-generating rather than a solid basis for epidemiological studies (138). Another important consideration when performing research on quality register data is the issue of different case mixes between different healthcare units, which can result in invalid data comparisons.

The phrasing of questions in the data collection questionnaire can be crucial for the purpose to which the data are most suited. The way the questions are optimally phrased could differ for different purposes. While the researcher normally would like to collect as much information as possible (for example, with graded scales), the questions for monitoring purposes could be phrased in a dichotomised way where the cut-off limit is at the 'good enough' level. This is probably often the best way to collect data for monitoring purposes, since it is easier to collect and illustrate the data visually. If the questions are too simplified, users could think that the questionnaire does not describe the true situation in an adequate way, which would give them less motivation to participate or to deliver valid answers.

In some cases there has been a monetary bonus available for healthcare providers reporting high quality of provided care (28, 35, 137). To use quality register data as a basis for allocation of economic resources may bias data in a

way that decreases the validity when used for research purposes. How to best use a quality register for research purposes should be further investigated to fully utilise the 'Swedish gold mine' of quality register data.

METHODOLOGICAL CONSIDERATIONS OF SRPC DATA FOR RESEARCH PURPOSES

There is lack of consensus in the palliative care area; for example, central palliative care terms such as 'actively dying', 'end of life' and 'transition of care' are not properly defined and are used in different ways in the international literature (19). This ambiguity of palliative care definitions is reflected in the SRPC data collection. The SRPC has been criticised for using unclear and vague terms, which makes it unclear how data gathered from the SRPC should be interpreted (20). Some terms used in palliative care are perhaps more suited to patients with cancer than to patients with other life-threatening illnesses and can lead to uncertainty in how to best perform and name items concerning high quality end-of-life care. An example of this perceived uncertainty is that verbal feedback during the intervention conducted in study III in the municipalities highlighted that uncertainty is sometimes experienced when assessing the transition to end-of-life care for elderly patients with multiple diseases and slowly progressing diseases such as dementia.

The current version of the ELQ is improved concerning validity compared to the original version, now showing acceptable validity for most items depicting processes of care. Some items in the ELQ still have low validity, predominantly items concerning outcomes of care, and should accordingly be interpreted cautiously. No reliability study of the ELQ has been conducted. Furthermore, the SRPC data are retrospectively collected and thus data may be influenced by recall bias, especially when there is lack of documentation in the medical records. A benefit of collecting data retrospectively is that it offers the only way to determine a specific time limit, since there is no way to know beforehand exactly when the last week of life begins for a patient. The ELQ is completed by healthcare professionals. For items in the ELQ concerning outcomes of care, it would be preferable to have patient-generated data, as these would be more accurate (57, 58), but it is not ethically or practically possible to measure patient-generated data from dying patients on a large scale.

The patient population reported to the SRPC is diverse, and the SRPC data are collected from various different types of healthcare units, which have different case mixes. An illustration of this is that dying patients in hospitals generally are younger compared with dying patients in nursing homes (28). This is a complication when performing direct comparisons between different types of healthcare units, but comparisons between units of similar structure can be a source for identifying plausible reasons for differences and inequality in palliative care. The most valid comparison of register data probably is to compare the same unit with itself over time.

STUDY I – THE ELQ

There is a methodological problem when defining medical record data as the gold standard. There is a general lack of documentation in the end-of-life care area (42), which was also seen to a smaller extent in this study. The documentation in the medical records could perhaps also be wrong or incomplete, while the healthcare staff completing the ELQ might have known the true answer. The underreporting of pressure ulcers shown in this study indicated that data in the medical records are not used as a source of information when answering all of the ELQ items. The problem that the gold standard used to validate quality register data may be incorrect has been the case for validity studies in other quality registers (134). Data from observation of the given care could theoretically be a better gold standard, but would be challenging to collect, both practically and ethically.

Registrations from 100 patients were examined. This sample size was large enough to identify reasons for nonvalidity in the ELQ, but a larger sample might have been able to identify other, less common reasons for low validity. Data were collected from two connected healthcare units. To include more healthcare units would have decreased the risk of the results being influenced by the local work culture and routines.

The study setting chosen was specialised palliative care. With the palliative specialisation, the healthcare units had more knowledge about the items covered in the ELQ, which may have caused them to misinterpret the questions in the ELQ to a lesser extent than a healthcare unit without palliative specialisation would do. Most patients cared for at these units died from cancer. It is possible that the questions in the ELQ are formulated in a way that best suits end-of-life care for patients with cancer, and that the ELQ is not as well suited to gather important aspects of end-of-life care for patients with, for example, cardiovascular diseases or dementia. Thus, it is not clear if the results in this study can be generalised to other settings.

STUDY II – PARTICIPATING IN THE SRPC

Study II was a cross-sectional study without a control group. This makes it impossible to rule out other reasons for the measured improvement, and causality between participation in the SRPC and the measured improvements of end-of-life care cannot be proved. That the healthcare units can monitor web-generated feedback of their individual results at the SRPC homepage is one of the possible mechanisms for the detected improvements. This study did not examine to what extent this had been done during the study period. Since this study only included healthcare units that had chosen to participate in the SRPC, it is not clear whether the results can be generalised to all healthcare service.

Factors that were not measured in this study could have influenced the healthcare units to improve the quality of the end-of-life care they provided.

During the period studied, there was an increased focus on end-of-life care and the dying process in medicine and in public discourse. No national healthcare programmes on palliative medicine or palliative care were launched, but some local areas started local palliative care programmes during the period studied.

A limitation was that data were reported by the included healthcare units themselves. There was a risk for recall bias at the healthcare units when the ELQs were completed retrospectively, but all involved units were unaware of this study during registration. The results could also have been affected by a change in the interpretation of alternative answers, the response shift.

The different types of healthcare units in this study care for different patient populations, which can be exemplified by the differing prevalence of cancer (11%–94%) and cognitive impairment (7%–51%). The different types of healthcare units face different challenges concerning end-of-life care, and direct comparisons should be handled with care. Nursing homes and short-term care homes showed the most marked improvement, while the specialised palliative healthcare units performed well in many items before start of the study period, leaving limited room for further improvements. For this reason, it is likely that a similar study including only healthcare units without palliative specialisation could have shown greater overall improvements.

STUDY III – THE EFFECT OF A HALF-DAY PHYSICIAN AND NURSE TRAINING IN ITEOL

ITEOL was defined as a conversation where information was given at one occasion. This gives a simplified picture of the information process. In real life discussions between physicians and patients over prognostic issues often consist of multiple conversations, both formal and informal (20). It would have been preferable to have access to more information about the information-giving process, but it was not deemed practically possible to collect this kind of more extensive data from the participating healthcare units using the ELQ.

During the study period, nationwide guidelines in palliative care were launched (4), and the government ran the programme 'Better Life for Most Sick Elderly', which included an economic bonus for hospitals and municipalities that increased their proportion of patients receiving ITEOL (148). The inclusion of a control group in this study enabled an adjustment for concurrent known and unknown environmental factors, but did not enable adjustment for their possible enhancing effects on the intervention. Because the control group did not receive a placebo intervention, it cannotbe excluded that the effect was partially caused by the study invitation, which could have caused increased attention to ITEOL.

Nor can it be excluded that hospitals and municipalities assess the patients' ability to express their will and take part in decisions concerning the content of medical care differently, which could have influenced the results. Religious

beliefs and educational level may affect the patient's comprehension of ITEOL, but data about these parameters were not available in the SRPC. The study also did not examine the physicians' and nurses' views of the education, which could have increased the understanding of the learning process about ITEOL and the way that ITEOL is experienced in practice by physicians and nurses.

No significant changes in the proportion of patients who received ITEOL were seen when the hospitals and municipalities were analysed separately. One possible explanation for this is that the sample size in the subgroups was too small to detect a small difference between the patients reported by the intervention units and the control units. In addition, although there were no significant differences regarding distribution of diagnoses when comparing the intervention and the control patients in the whole material, the patients from the intervention hospitals and control hospitals differed regarding distribution of cardiovascular diseases and pulmonary diseases. As a result of this difference, the results from the hospital subgroup should be interpreted with care.

STUDY IV – PATIENTS' PERCEPTIONS OF INFORMATION FROM PHYSICIANS

Qualitative content analysis using the manifest content of the interviews was chosen for study IV, since the purpose of the analysis was to describe the participants' perceptions and not to search for the underlying meaning in the data. The study design of face-to-face interviews facilitated examining the process of information giving rather than observing an individual meeting, and also minimised the risk of interfering with the patient–physician meeting. It is possible that the participants did not remember the source of information correctly during the interviews, which cannot be excluded, since no observation of the patient–physician meeting was performed. It cannot be stated to what extent the participants misunderstood the information they had received. Patients have many other potential sources of information about cancer and cancer therapy, for example, friends, family and media. Patients also, most likely, have some form of prior understanding of cancer and cancer therapy before being diagnosed.

All participants were patients at the same hospital, and thus had met a small number of physicians who potentially shared the same way of communicating with patients about these issues. Patients who had declined all chemotherapy could have gotten another type of information about prognosis and treatment, or perceived it differently, but they were not included in the study.

Face-to-face interviews in a separate room with one interviewer were chosen to enable the participants to talk freely about personal issues, such as fear of death. There are examples in the literature of interviewing patients with incurable cancer in the participants' homes (115, 166), but the interviews in

this study were conducted at the outpatient clinic, which was a familiar environment chosen by the participants.

FUTURE STUDIES

THE ELQ

The reliability of the ELQ should be examined to identify reliability problems and develop the ELQ further. The validity of the ELQ was examined in specialised palliative healthcare units with mainly patients with cancer. The validity of the ELQ should be examined in other types of healthcare units that participate in the SRPC (for example, nursing homes and hospital wards without palliative specialisation), but the presumed remaining lack of documentation would possibly make such a study more difficult or even impossible to perform. Similarly, the validity of the ELQ for a study population of patients dying from diseases other than cancer, for example, cardiovascular diseases or dementia, should be examined.

Not every important aspect of end-of-life care is covered by the ELQ, for example, the experience of the patient's next of kin. Other ways to collect data on patients in end-of-life care should be reviewed, such as collecting and analysing data from a similar questionnaire answered by next of kin. It would also be important to collect data from earlier phases of the incurable disease trajectory. A similar questionnaire to be answered by patients with a progressive incurable disease but not in the end of life should be developed to further the knowledge about these patients.

QUALITY IN PALLIATIVE CARE

Data from the SRPC can offer an easily assessable and efficient way to monitor improvements and identify areas that need further attention. The problem of lack of consensus is a problem not only for clinical work but also for research and should be addressed. Defining quality indicators in palliative care is one area that needs attention. No cost effectivity studies have yet been performed about the use of the SRPC for quality improvement.

More studies are needed to investigate the possibility of quality improvement in end-of-life care in other ways, such as using guidelines and standardised care pathways or providing more training for healthcare professionals. Lessons from the discovered misuse of the LCP should be taken into account if implementing care pathways in palliative care. Methods to promote greater use of the continuous feedback of the individual unit's own SRPC registration should also be reviewed.

COMMUNICATION

Further research is needed to investigate other ways to increase the number of patients receiving ITEOL, and to confirm the results from study III in other geographical areas and when positive environmental factors highlighting palliative care issues are not influencing the results. The results can be used for power calculations when planning future studies on the subject. Examining the physician's and nurses' view of the education should be considered for a future study, which can be used to improve the education further and to gain deeper understanding of how ITEOL is experienced by physicians and nurses in clinical work.

The participants in study IV perceived that their disease was incurable and deadly, and that conditions for future treatment and survival were uncertain. Honest prognostication, handled with care, is considered an important part of palliative medicine. Additional research on optimal information strategies may bring knowledge about this further forward. How to inform honestly and according to the legal requirements but in a way that allows the patient to maintain hope is a question for further research. How patients who decline chemotherapy perceive the given information about palliative chemotherapy is currently unknown.

REGISTER DATA IN FUTURE PALLIATIVE CARE RESEARCH

It is important that the Swedish gold mine of quality registers be used in an ethical way for research purposes. Because of the Swedish individual ten-digit identity codes, it is possible to merge quality register data, such as data from the SRPC with data from other registers about the same individual. If the SRPC were run together with diagnosis-specific registers, it would be possible, for example, to examine and compare palliative end-of-life care between specific cancer diagnoses. An ethically correct study design is of great importance to maintain patients' integrity when performing such studies.

CLINICAL IMPLICATIONS

The ELQ is useful for collecting data about end-of-life care and for evaluating the care given, and study II suggests that participating in the SRPC can increase the quality of end-of-life care. The ELQ can be used as a reminder checklist for staff involved in end-of-life care, stressing the importance of, for example, pain evaluation or prevention of pressure ulcers. Completing the ELQ after the death of a patient also provides an opportunity for reflection and communication in the team. This should be balanced against using the required time for clinical work instead. With enough time and resources, and a work climate that facilitates open reflection and an ambition for further improvement, the ELQ, including the user feedback function, can be a useful tool for improvement of end-of-life care.

Patients receiving end-of-life care are a vulnerable patient group, and their care should be given in accordance with the best possible standard. It is very important that the 'softer' values of end-of-life care, such as information (e.g., ITEOL) given to patients and their next of kin, are brought to the table when discussing quality in healthcare.

Even in a healthcare unit exclusively specialising in palliative care, with a developed way of documenting end-of-life care, there was not enough information in the medical records to answer all items about end-of-life care in the ELQ. For example, documentation about pain and other symptoms was often sparse. It does not necessarily mean that documentation should increase, since it is time consuming and does not always benefit the patient. The medical records are a way of transferring information about the patients to other staff members, but documentation is also done because of legal issues. The issue of what information should be documented in the medical records and to what purpose deserves more discussion. Generally, documentation of evaluation after measurements have been carried out, for example pain evaluation after giving PRN pain medication, should be emphasised more in palliative care.

Physicians and nurses can be educated to increase the proportion of patients receiving ITEOL and a half-day education can be sufficient to achieve measurable improvement. A large-scale nationwide ITEOL education project is not planned at the moment, and the project 'Better Life for Most Sick Elderly' has ended. If more education about ITEOL should be performed on a larger scale, it is not clear who should be in charge of this. However, advisory palliative care teams can be useful educators of healthcare professionals who work outside of the specialised palliative care. Support from the heads of the departments as well as collegial support is presumably needed to achieve a substantial increase in the proportion of patients who receive ITEOL.

Information giving and communication about diagnosis, prognosis and end-of-life care should be seen as very important components of both oncology and palliative medicine, as well as of all other clinical specialities caring for incurably ill patients. Honest prognostication is considered an important part of palliative medicine, but it should be handled with great sensitivity. It should be kept in mind that patients do not always ask about issues that they wish to receive information about, and that there are patients who want limited or no prognostic information.

There has been much focus in research on informing about diagnosis, but how to proceed with information to patients already knowing their diagnosis has not been researched in much detail. Patients who receive palliative chemotherapy are a large patient group, which is expected to become even larger in the future when the antitumoral treatments become more and more effective. That the participants in study IV were aware of the palliative nature of their disease indicates that they had good communication with their physicians about prognostic issues, but they also perceived that conditions for

treatment and their whole existence were uncertain, which indicated that this communication also created a sense of insecurity. Perhaps the healthcare service could dispel some of the perceived uncertainty by communicating more clearly about treatment planning and the outcomes expected from treatment.

Palliative chemotherapy was experienced as a temporary lifeline by the participants in study IV. To face the cessation of a temporary lifeline may understandably be experienced as a threat. Great responsiveness to patients' perceptions and concerns should be used when talking to patients about pausing or ceasing chemotherapy. Perhaps a way to increase the patients' understanding of palliative chemotherapy would be to educate the public, who probably have obsolete knowledge about chemotherapy.

CONCLUSIONS

This thesis has shown that a national quality register has the potential of contributing to quality improvement in palliative care. It has also shown that patients undergoing palliative chemotherapy perceive that their disease is incurable and deadly, and that conditions for future treatment and survival are uncertain. The SPRC is a quality register that collects unique data about end-of-life care, and participation in the SRPC was covariant with quality improvements in end-of-life care over time. The main tool for data collection, the ELQ, showed varied validity, which improved after revision. It is possible to increase the number of patients who receive ITEOL through an educative half-day intervention directed to physicians and nurses. The SRPC can be used to follow quality development and in selected cases function as a basis for epidemiological studies and clinical trials.

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APPENDIX 1

END-OF-LIFE QUESTIONNAIRE IN USE BETWEEN MAY 2007 AND DECEMBER 2010 (SWEDISH VERSION)

1. Enhetskod_____(erhållen efter anmälan om deltagande via hemsidan www.palliativ.se)

2. Personnummer_____

3. Namn på den avlidne_____(tilltalsnamn + efternamn)

4. Postnummer_____

5. Kön □ man □ kvinna

6. Datum då den avlidne skrevs in på den enhet där dödsfallet inträffade (för primärvård/hemsjukvård=”aktiv hemsjukvård”)_____

7. Avliden datum_____

8. Dödplatsen beskrivs bäst som:
□ särskilt boende
□ korttidsplats
□ sjukhusavdelning – ej palliativ
□ hospice/palliativ slutenvårdsplats
□ eget hem, med stöd av avanc hemsjukvård
□ eget hem, med stöd av basal hemsjukvård
□ övrig_____

9. Grundsjukdom som ledde till döden:
□ Cancer
□ Hjärtsjukdom
□ Lungsjukdom
□ Demens
□ Stroke
□ Annan neurologisk sjukdom
□ Infektion
□ Diabetes
□ Övrigt, nämligen_____

10. Kommer den avlidne att genomgå en rättsmedicinsk obduktion?
□ ja □ nej
Om svaret är JA på fråga 10 är enkäten färdig. Vid dödsfall orsakat av sjukdom besvara även följande frågor.

11. Dödsfallet var utifrån sjukdomshistorien
□ väntat □ oväntat □ vet ej

12. Vilket datum, senast före dödsfallet, undersökte/besökte läkare vårdtagaren/patienten?_____

13. Har ett informerande samtal, om att hon/han var döende, förts med vårdtagaren/patienten under den sista tiden i livet?
□ nej □ ja, av läkare □ ja, av sjuksköterska
□ ja, av både läkare och sjuksköterska □ vet ej

14. Har ett informerande samtal, om att vårdtagaren/patienten var döende, förts med närstående?
□ nej □ ja, av läkare □ ja, av sjuksköterska
□ ja, av både läkare och sjuksköterska □ vet ej

15. Hur lång tid före dödsfallet tappade vårdtagaren/patienten sin förmåga till självbestämmande?
□ timmar □ dagar □ veckor □ månader □ år □ vet ej

16. Har VAS/NRS-skala (0–10) använts för skattning av smärta under sista veckan i livet?
□ ja □ nej □ patienten kan ej medverka □ vet ej

17. Markera det/de symtom som inte lindrades helt sista veckan i livet.
□ andnöd □ rosslighet □ annat_____
□ förvirring □ smärta □ inga besvärande symtom
□ illamående □ oro/ångest □ vet ej

18. Har specialkompetens utanför teamet/avdelningen konsulterats avseende patientens icke lindrade symtom?
□ nej □ ja, yrkesgrupp/specialitet_____

19. Hade vårdtagaren/patienten trycksår sista veckan i livet?
□ grad 1 □ grad 2 □ grad 3 □ grad 4 □ nej □ vet ej

20. Fanns senast ett dygn före dödsfallet vid behovsläkemedel i injektionsform ordinerade för
smärta □ ja □ nej
rosslighet □ ja □ nej
illamående □ ja □ nej
oro/ångest □ ja □ nej

21. Vem/vilka var närvarande vid dödsögonblicket?
□ personal □ närstående □ personal och närstående □ ingen

22. Överrenstämde dödsplatsen med vårdtagarens/patientens senast uttalade önskan?
□ ja □ nej □ vet ej

23. På hur många andra platser än dödsplatsen (ex: hemmet, olika avdelningar, säbo, korttid) vårdades vårdtagaren/patienten under de sista två veckorna i livet?
□ 0 □ 1 □ 2 □ 3 □ >3 □ vet ej

24. Har närstående haft eller kommer de att erbjudas ett särskilt eftersamtal en tid efter dödsfallet?
□ ja □ nej □ vet ej

25. Är ni nöjda med den vård vid livets slut som ni kunde ge vårdtagaren/patienten?

1	2	3	4	5
□	□	□	□	□
inte alls				helt och hållet

26. Datum för besvarandet av frågorna_____

27. Ifyllt av_____(Namn)
□ läkare □ sjuksköterska e-postadress_____

APPENDIX 2

END-OF-LIFE QUESTIONNAIRE IN USE BETWEEN MAY 2007 AND DECEMBER 2010 (ENGLISH VERSION)

1. Unit code_____ (received at registration of participation through the website www.palliativ.se)

2. Social insurance identification number_____

3. Name of the deceased_____(used first name and surname)

4. Area code_____

5. Sex □ Male □ Female

6. Date of admission to the unit where death occurred (for primary care/home care = "active home care")_____

7. Date of death_____

8. The place of death is best described as a:
□ Nursing home
□ Short-term care home
□ Hospital ward – not palliative
□ Hospice/palliative hospital ward
□ Own home, with support from specialised palliative home care
□ Own home, with support from basal home care
□ Other_____

9. Main disease that caused death:
□ Cancer
□ Heart disease
□ Lung disease
□ Dementia
□ Stroke
□ Other neurological disease
□ Infection
□ Diabetes
□ Other, namely_____

10. Will a forensic autopsy be performed?
□ Yes □ No
If the answer to question 10 is yes, then the questionnaire is completed. If death was caused by disease, please also answer the following questions.

11. According to the deceased's medical history, death was
□ Expected □ Not expected □ Don't know

12. Which date, closest before death, did a doctor visit/examine the patient/person receiving care?_____

13. Has an informing conversation with the patient about impending death taken place, during the last period in life?
□ No □ Yes, by a doctor □ Yes, by a nurse
□ Yes, by both a doctor and a nurse □ Don't know

14. Has an informing conversation with the patient's next of kin about the impending death of the patient/person receiving care taken place, during the last period in life?
□ No □ Yes, by a doctor □ Yes, by a nurse
□ Yes, by both a doctor and a nurse □ Don't know

15. How long before death did the patient/person receiving care loose his/her ability of self-determination?
□ Hours □ Days □ Weeks □ Months □ Years □ Don't know

16. Have a VAS or NRS scale (0–10) been used for evaluation of pain during the last week of the patient's life?
□ Yes □ No □ The patient cannot participate □ Don't know

17. Mark the symptom(s) that was/were not fully alleviated during the last week of life.

□ Shortness of breath	□ Death rattle	□ Other_____
□ Confusion	□ Pain	□ No distressing symptoms
□ Nausea	□ Anxiety	□ Don't know

18. Has special competence outside the team/ward been consulted regarding the patient's not completely alleviated symptoms?
□ No □ Yes, profession/speciality_____

19. Did the person receiving care/patient have pressure ulcers in the last week of life?
□ Grade 1 □ Grade 2 □ Grade 3 □ Grade 4 □ No □ Don't know

20. Was medication prescribed for use as needed in the form of injections, at least one day before death, for

Pain	□ Yes □ No
Death rattle	□ Yes □ No
Nausea	□ Yes □ No
Anxiety	□ Yes □ No

21. Who was present at the moment of death?
□ Staff □ Next of kin □ Staff and next of kin □ No one

22. Did the place of death correspond with the person receiving care's/patient's latest spoken wish?
□ Yes □ No □ Don't know

23. In how many other places (e.g. home, different wards, nursing home, short-term care home) than the place of death was the person receiving care/patient cared for during the last 2 weeks of life?
□ 0 □ 1 □ 2 □ 3 □ >3 □ Don't know

24. Have the next of kin had or will they be offered a follow-up appointment some time after death?
□ Yes □ No □ Don't know

25. Are you content with the end-of- life care provided for the person receiving care/patient?

1	2	3	4	5
□	□	□	□	□
Not at all				Completely

26. Date the questions were answered_____

27. Answered by_____(name)
□ Doctor □ Nurse E-mail address_____

APPENDIX 3

END-OF-LIFE QUESTIONNAIRE IN USE FROM APRIL 2012 (SWEDISH VERSION)

1. Enhetskod_____(fylls i automatiskt i den digitala enkäten)

2. Personnummer på den avlidne personen (12 siffror)_____

3. För- och efternamn på den avlidne personen_____

4. Dödsdatum (åååå-mm-dd)_____

5. Datum (åååå-mm-dd) då personen skrevs in på den enhet där dödsfallet inträffade (för hemsjukvård, ange datumet då den aktiva hemsjukvården inleddes)_____

6. Dödsplatsen beskrivs bäst som:
□ särskilt boende / vård- och omsorgsboende
□ korttidsplats
□ sjukhusavdelning (ej hospice / palliativ slutenvård)
□ hospice / palliativ slutenvård
□ eget hem, med stöd av avancerad hemsjukvård
□ eget hem, med stöd av övrig hemsjukvård
□ annan, nämligen_____

7. Grundtillstånd som ledde till döden (fler än ett svarsalternativ är möjligt):
□ cancersjukdom
□ hjärt- / kärlsjukdom
□ lungsjukdom
□ demens
□ stroke
□ annan neurologisk sjukdom
□ diabetes
□ tillstånd efter fraktur
□ multisjuklighet
□ övrigt, nämligen_____

8. Kommer den avlidne personen att genomgå obduktion?
□ ja, rättsmedicinsk □ ja, vanlig klinisk □ nej
Om svaret är JA, rättsmedicinsk – besvara endast fråga 28–30. Om svaret är NEJ eller JA, vanlig klinisk – fortsätt till fråga 9.

9. Var dödsfallet väntat utifrån sjukdomshistorien?
□ ja □ nej □ vet ej

Om svaret är JA eller VET EJ, besvara samtliga följande frågor. Om svaret är NEJ, besvara endast fråga 14, 16, 18, 28–30.

10. Hur lång tid innan dödsfallet förlorade personen förmågan att uttrycka sin vilja och delta i beslut om den medicinska vårdens innehåll?
□ bibehållen förmåga till livets slut □ timme/timmar □ dag/dagar
□ vecka/veckor □ månad eller mer □ vet ej

11a. Finns det i den medicinska journalen ett av ansvarig läkare dokumenterat beslut om att behandlingen/vården övergår till palliativ vård i livets slutskede?
□ ja i fri text □ ja som klassifikationskod □ nej □ vet ej

11b. Fick personen ett s.k. brytpunktssamtal, alltså ett individuellt anpassat och i den medicinska journalen dokumenterat informerande läkarsamtal om att han/hon befann sig i livets slutskede och att vården var inriktad på livskvalitet och symtomlindring?
□ ja □ nej □ vet ej

12. Överensstämde dödsplatsen med personens senast uttalade önskemål?
□ ja □ nej □ vet ej

13a. Hade personen trycksår vid ankomsten till er enhet (ange högsta förekommande grad)?
□ ja, grad 1 □ ja, grad 2 □ ja, grad 3 □ ja, grad 4 □ nej □ vet ej
Om svaret är JA (grad 1–4), besvara fråga 13b. Om svaret är NEJ eller VET EJ, fortsätt till fråga 14a.

13b. Dokumenterades trycksåret?
□ ja □ nej □ vet ej

14a. Avled personen med trycksår (ange högsta förekommande grad)?
□ ja, grad 1 □ ja, grad 2 □ ja, grad 3 □ ja, grad 4 □ nej □ vet ej
Om svaret är JA (grad 1–4), besvara fråga 14b. Om svaret är NEJ eller VET EJ, fortsätt till fråga 15a.

14b. Dokumenterades trycksåret?
□ ja □ nej □ vet ej

15a. Bedömdes personens munhälsa någon gång under den sista veckan i livet?
□ ja □ nej □ vet ej
Om svaret är JA, besvara fråga 15b. Om svaret är NEJ eller VET EJ, fortsätt till fråga 16.

15 b. Noterades någon avvikelse vid bedömningen?
□ ja □ nej □ vet ej
Om svaret är JA eller NEJ, besvara fråga 15c. Om svaret är VET EJ, fortsätt till fråga 16.

15c. Dokumenterades bedömningen av munhälsan?
□ ja □ nej □ vet ej

16. Var någon närvarande i dödsögonblicket?
□ ja, närstående □ ja, närstående och personal □ ja, personal □ nej □ vet ej

17. Fick personens närstående ett s.k. brytpunktssamtal, alltså ett individuellt anpassat och i den medicinska journalen dokumenterat informerande läkarsamtal om att personen befann sig i livets slutskede och att vården var inriktad på livskvalitet och symtomlindring?
□ ja □ nej □ vet ej □ hade inga närstående
Om svaret är JA, NEJ eller VET EJ, fortsätt till fråga 18. Om svaret är HADE INGA NÄRSTÅENDE, fortsätt till fråga 19.

18. Erbjöds personens närstående ett efterlevandesamtal 1–2 månader efter dödsfallet?
□ ja □ nej □ vet ej

19. Hade personen dropp/sondtillförsel av vätska eller näring under det sista dygnet i livet?
□ ja □ nej □ vet ej

20. Förekom något av följande symtom (20a–f) vid något tillfälle hos personen under den sista veckan i livet?
20a. Smärta □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 20b.
smärtan lindrades: □ helt □ delvis □ inte alls
20b. Rosslighet □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 20c.
rossligheten lindrades: □ helt □ delvis □ inte alls
20c. Illamående □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 20d.
illamåendet lindrades: □ helt □ delvis □ inte alls
20d. Ångest □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 20e.
ångesten lindrades: □ helt □ delvis □ inte alls
20e. Andnöd □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 20f.
andnöden lindrades: □ helt □ delvis □ inte alls
20f. Förvirring □ ja □ nej □ vet ej
Om svaret är JA, besvara följdfrågan. Om svaret är NEJ eller VET EJ, fortsätt med fråga 21.
förvirringen lindrades: □ helt □ delvis □ inte alls

21. Skattades personens smärta vid något dokumenterat tillfälle under den sista veckan i livet med VAS, NRS eller något annat validerat smärtskattningsinstrument?
□ ja □ nej □ vet ej

22. Hade personen svår smärta vid något tillfälle under den sista veckan i livet (t.ex. VAS/NRS > 6 eller svår smärta enligt något annat validerat instrument)?
□ ja □ nej □ vet ej

23. Skattades personens övriga symtom vid något tillfälle under den sista veckan i livet med VAS, NRS eller något annat validerat symtomskattningsinstrument?
□ ja □ nej □ vet ej

24. Fanns det en individuell ordination av läkemedel i injektionsform vid behov på läkemedelslistan innan dödsfallet?

opioid mot smärta	□ ja □ nej □ vet ej
läkemedel mot rosslighet	□ ja □ nej □ vet ej
läkemedel mot illamående	□ ja □ nej □ vet ej
läkemedel mot ångest	□ ja □ nej □ vet ej

25. Hur lång tid innan dödsfallet undersöktes personen av en läkare senast?
□ dag/dagar □ vecka/veckor □ månad eller mer □ vet ej

26. Konsulterades kompetens utanför teamet/avdelningen för personens symtomlindring under den sista veckan i livet? (fler än ett svarsalternativ är möjligt)
□ ja, smärtenhet □ ja, palliativt team □ ja, annan sjukhusenhet
□ ja, paramedicinare □ ja, andlig företrädare □ nej □ vet ej

27. Hur nöjda är ni i arbetslaget med den vård ni gav personen under den sista veckan i livet?
□ 1 = inte alls □ 2 □ 3 □ 4 □ 5 = helt och hållet

28. Datum (åååå-mm-dd) för besvarandet av frågorna_____

29. Enkäten är besvarad av:
□ enskild medarbetare □ fler i arbetsgruppen gemensamt

30. Ansvarig uppgiftslämnare (namn)_____
□ läkare □ sjuksköterska □ annan personalgrupp
e-postadress_____

APPENDIX 4

END-OF-LIFE QUESTIONNAIRE IN USE FROM APRIL 2012 (ENGLISH VERSION)

1. Unit identification code_____(is automatically answered in the digital questionnaire)

2. Personal identity number of the deceased person (12 numbers)_____

3. First and last name of the deceased person_____

4. Date of death (year/month/day)_____

5. Date (year/month/day) when the person was admitted to the unit where the death occurred (for home care, please state the date when home care was initiated)_____

6. The place of death is best described as:
□ Nursing home – permanent stay
□ Nursing home – short-term stay
□ Hospital ward (not hospice/palliative in-patient care)
□ Hospice/palliative in-patient care
□ Own home with support from specialised home-care team
□ Own home with support from general home-care team
□ Other, specify_____

7. Disease/basic state that caused the death (more than one answer is possible):
□ Cancer
□ Cardiovascular disease
□ Respiratory disease
□ Dementia
□ Stroke
□ Other neurological disease
□ Diabetes
□ State after fracture
□ Multimorbidity
□ Other, namely:_____

8. Will there be a post-mortem examination of the deceased?
□ Yes, forensic □ Yes, regular clinical □ No
If the answer is Yes, forensic, only answer questions 28–30. If the answer is No or Yes, regular clinical, go to question 9.

9. Based on the disease trajectory, was the death expected?
□ Yes □ No □ Don't know
If the answer is Yes or Don't know, answer all the following questions. If the answer is No, answer only questions 14, 16, 18, 28–30.

10. How long before death did the person lose the ability to express his/her will and take part in decisions concerning the content of medical care?
□ Retained ability until end of life □ Hour/hours □ Day/days
□ Week/weeks □ Month or more □ Don't know

11a. Do the medical records include a documented decision by the physician responsible to shift treatment/care to end-of-life care?
□ Yes, in free text □ Yes, as a classification code □ No □ Don't know

11b. Did the person receive information about the transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief?
□ Yes □ No □ Don't know

12. Was the place of death in line with the person's last stated wishes?
□ Yes □ No □ Don't know

13a. Did the person have pressure ulcers upon arrival at your unit (specify highest grade occurring)?
□ Yes, grade 1 □ Yes, grade 2 □ Yes, grade 3 □ Yes, grade 4 □ No □ Don't know
If the answer is Yes (grades 1–4), answer question 13b. If the answer is No or Don't know, skip to question 14a.

13b. Were the pressure ulcers documented?
□ Yes □ No □ Don't know

14a. Did the person die with pressure ulcers (specify highest grade occurring)?
□ Yes, grade 1 □ Yes, grade 2 □ Yes, grade 3 □ Yes, grade 4 □ No □ Don't know
If the answer is Yes (grade 1–4), answer question 14b. If the answer is No or Don't know, skip to question 15a.

14b. Were the pressure ulcers documented?
□ Yes □ No □ Don't know

15a. Was the person’s oral health assessed during the last week of life?
□ Yes □ No □ Don't know
If the answer is Yes, answer question 15b. If the answer is No or Don't know, skip to question 16.

15b. Was any disorder noted during assessment?
□ Yes □ No □ Don't know
If the answer is Yes or No, answer question 15c. If the answer is Don't know, skip to question 16.

15c. Was the assessment of oral health documented?
□ Yes □ No □ Don't know

16. Was anyone present at the time of death?
□ Yes, close friend(s) or relative(s) □ Yes, close friend(s)/relative(s) and staff
□ Yes, staff □ No □ Don't know

17. Did the person's close friend(s)/relative(s) receive information about transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief?
□ Yes □ No □ Don't know □ Had no close friend(s)/relative(s)
If the answer is Yes, No or Don't know, go to question 18. If the answer is Had no close friend(s)/relative(s), skip to question 19.

18. Was/were the person's close friend(s)/relative(s) offered a follow-up talk within 1–2 months of the death?
□ Yes □ No □ Don't know

19. Did the person receive parenteral fluids/nutrition or enteral-tube feeding during the last 24 hours of life?
□ Yes □ No □ Don't know

20. Did the person display any of the following symptoms (20a–f) at any time during the last week of life?
20a. Pain □ Yes □ No □ Don't know
If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20b.
Pain was relieved: □ Completely □ Partially □ Not at all
20b. Death rattle □ Yes □ No □ Don't know
If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20c.
Death rattle was relieved: □ Completely □ Partially □ Not at all
20c. Nausea □ Yes □ No □ Don't know
If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20d.
Nausea was relieved: □ Completely □ Partially □ Not at all
20d. Anxiety □ Yes □ No □ Don't know
If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20e.
Anxiety was relieved: □ Completely □ Partially □ Not at all
20e. Dyspnoea □ Yes □ No □ Don't know
If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 20f.
Dyspnoea was relieved: □ Completely □ Partially □ Not at all
20f. Confusion □ Yes □ No □ Don't know

If the answer is Yes, answer the following question. If the answer is No or Don't know, skip to question 21.
Confusion was relieved: □ Completely □ Partially □ Not at all

21. Was the person's pain assessed at any documented time during the last week of life using VAS, NRS or another validated pain-assessment tool?
□ Yes □ No □ Don't know

22. Did the person experience severe pain at any time during the last week of life (e.g. VAS/NRS > 6 or severe pain according to another validated pain-assessment tool)?
□ Yes □ No □ Don't know

23. Were the person's other symptoms assessed at any time during the last week of life using VAS, NRS or another validated symptom-assessment tool?
□ Yes □ No □ Don't know

24. Was there an individual prescription of injectable PRN drugs on the drug list before death?

Opioids against pain	□ Yes □ No □ Don't know
Drugs against death rattle	□ Yes □ No □ Don't know
Drugs against nausea	□ Yes □ No □ Don't know
Drugs against anxiety	□ Yes □ No □ Don't know

25. How long before death was the person last examined by a physician?
□ Day/days □ Week/weeks □ Month or more □ Don't know

26. Were specialists outside the team/ward consulted concerning the person's symptom relief during the last week of life (more than one answer option is possible)?
□ Yes, pain clinic □ Yes, palliative-care team □ Yes, other hospital unit
□ Yes, social worker/physiotherapist/ occupational therapist/dietician
□ Yes, spiritual counsellor □ No □ Don't know

27. How satisfied is the team with the care delivered to the person during the last week of life?
□ 1 = Not at all □ 2 □ 3 □ 4 □ 5 = Completely

28. Date (year/month/day) of answering the questions_____

29. The questionnaire was answered by:
□ A single employee □ Staff jointly

30. Name of registrant_____
□ Physician □ Nurse □ Other staff
E-mail address_____