Dying and Death in the Electronic Patient Record

A Qualitative Analysis of Textual Practices

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Dying and Death in the Electronic Patient Record:
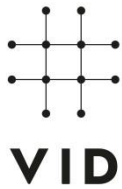**A Qualitative Analysis of Textual Practices**

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2. Hov, L., Pasveer, B., & Synnes, O. (2020). Modes of dying in the electronic patient record, *Mortality*, –15. DOI: 10.1080/13576275.2020.1865294

3. Hov, L., Tveit, B., & Synnes O. (2021, May). Nobody dies alone in the electronic patient record – A qualitative analysis of the textual practices of documenting dying and death. *OMEGA-Journal of Death and Dying*. doi:10.1177/00302228211019197

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Acknowledgements

With a retrospective glance at these five years, I can see that I have changed. I have been transformed from an uncertain student – unfamiliar with academia, preoccupied with doing the 'right things', and engulfed with low self-esteem to an academic ready to argue that I have accomplished an important project, which I hope will inspire others to think differently about the electronic patient record. However, this could not have been achieved without the support of my family, colleagues, and supervisors.

First, I want to thank the staff at the Centre for Diaconal and Professional Practice for believing in the project and giving me the opportunity to become a PhD scholar. The centre has been a haven in which I could explore and learn theories and methodologies. Discussions with fellow students and scientific employees cheering on each other is a good way to evolve.

Second, I want to thank my indispensable supervisors, Oddgeir Synnes, Bernike Pasveer, and Bodil Tveit, for their invaluable knowledge and belief in the project – and me. Their wisdom, enthusiasm, positivity, and goodwill have been inspiring and made this journey worth the effort. Also, thanks to Guri Aarseth for taking me in. Your knowledge, insight, reflections and enthusiasm in the work with the first article helped me persevere when I thought of leaving the PhD. I also want to thank Lisbeth Thoresen for believing in me and the project, helping me develop a project plan, and being part of the initial stages of the project.

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Abstract

In Norway, over one in four deaths occur in hospitals, places that operate primarily according to curative logic. One aim of the Norwegian health care system is that patients, at the end of life, should receive high-quality palliative care as defined by the World Health Organization, independent of whether they are dying at home or in a nursing home, hospice or hospital. Against this potentially challenging background, this project investigates the role of the texts about such patients written into the electronic patient record (EPR).

Starting from the view of (EPR) texts as active contributors to the whereabouts of (dying) patients, the EPR can be seen as an essential communication and coordination tool contributing to the types of knowledge that circulate about the dying patient and their treatment. This thesis aims to provide insights into how and what knowledge the EPR proposes as relevant by asking: What kind of textual practices of dying and death in medical wards are present in the EPR, and what do these practices achieve?

The selected methods were a qualitative document analysis combining elements from the fields of linguistics, literary criticism and science and technology studies. This effort resulted in three articles elaborating different aspects of how dying and death are documented in the EPR. The first article investigated the negotiations of the transition from curative to palliative care. It argued that the text often changes from being technical and conclusive to being uncertain and open to negotiations as a need to align the involved parties in the decision. The second article explored which aspects of dying the text is attuned to in patients' last 24 hours of life. It argued that the text has three hegemonic modes of ordering – numbering, timing, and classifying – which perform a dominant narrative in which dying is concealed. Yet, in between, there are traces of caring attention to and compassion for the dying patient. The third article considered how the moment of death is documented. It argued for what seem to be established ways of recording this moment as being manageable and portraying it as uneventful or good.

This exploration of textual practices suggests that, first, the EPR treats dying and death as observations and tasks to be solved in general biomedical terms, rather than probing the needs of the individual patient. Second, the EPR seems to avoid difficult topics, deliberations, and disagreements, and it never admits to failure. Finally, the EPR sometimes shows professionals' attempts to reveal individual patients' needs and suffering and the troubles of dying in a curative context.

Sammendrag

I Norge dør en av fire på sykehus: et sted som primært følger en kurativ logikk. Et mål for helsetjenestene i Norge er at pasienter ved livets slutt skal få palliativ behandling av høy kvalitet i tråd med WHO's definisjon, uavhengig av om de dør hjemme, på sykehjem, på hospice eller på sykehus. Mot denne potensielt utfordrende bakgrunnen undersøker dette prosjektet hvilken rolle teksten om døende pasienter skrevet i den elektroniske pasientjournalen (EPJ) spiller.

Med utgangspunkt i at (EPJ-) tekster er aktive bidragsytere til pleien og behandlingen av døende pasienter, kan den elektroniske pasientjournalen sees på som et viktig kommunikasjons- og koordineringsverktøy som bidrar til de typer kunnskap som sirkulerer om den døende pasienten, og til deres behandling. Denne avhandlingen tar sikte på å gi innsikt i hvilken kunnskap pasientjournalen foreslår som relevant og hvordan den gjør det, ved å spørre: Hva slags tekstpraksis om å være døende og å dø på medisinske avdelinger forekommer i den elektroniske pasientjournalen, og hva oppnår denne praksisen?

Den valgte metoden er en kvalitativ dokumentanalyse som kombinerer elementer fra lingvistikk, litteraturkritikk og science and technology studies.

Studien resulterte i tre artikler som utdypet ulike aspekter av hvordan den døende og døden er dokumentert i den elektroniske pasientjournalen. Den første artikkelen undersøker forhandlingene i overgangen fra kurativ til palliativ behandling, og argumenterer for at teksten ofte endres fra å være teknisk og konkluderende, til å uttrykke usikkerhet og en åpenhet for forhandlinger som et behov for å samle de involverte partene i avgjørelsen. Den andre artikkelen utforsker hvilke aspekter ved å være døende teksten er opptatt av i pasientenes siste døgn i livet. Artikkelen argumenterer for at teksten består av tre hegemoniske måter å rapportere på: nummerering, tidsfesting og klassifisering – som til sammen utfører et dominerende narrativ der døden er skjult. Likevel, innimellom, finnes det spor av omsorgsfull oppmerksomhet og medfølelse med den døende pasienten. Den tredje artikkelen undersøker dokumentasjonen av selve dødsøyeblikket og viser at etablerte måter å dokumentere dette øyeblikket på handler om å fremstille døden som enten begivenhetsløs eller god,

noe som gjør dødsøyeblikket håndterbart. Samlet sett har EPJ-sjangeren en biomedisinsk orientering.

Artikkelen viser også at i dokumentasjonen om døden ble det brukt dagligdagse fraser som

konnoterer død til søvn, noe som gjør døden mindre truende og mer verdig.

Denne utforskningen av tekstlig praksis antyder at EPJ-teksten for det første videreformidler den

døende pasienten og død som observasjoner og oppgaver som skal løses, snarere enn å undersøke

behovene til den enkelte pasient. For det andre ser det ut til at EPJ-teksten unngår vanskelige

temaer, overveielser og uenigheter, og den innrømmer aldri å mislykkes. Imidlertid viser EPJ-tekstene

noen ganger helsepersonells forsøk på å synliggjøre den enkelte pasients behov og lidelser, og

problemene ved å dø i en kurativ sammenheng.

I. Introduction

'The patient wakes up at one o'clock in the night, shouts and says that she does not want to lay in bed and die alone, gave her sedatives'.

As a nurse, I have experience from several medical wards, one intensive care unit (ICU), and a specialised haematological ward. This experience involves regular encounters with dying patients in a wide variety of circumstances: from the extreme hi-tech battle against death in the ICU to the peaceful expiration of life in a private room at a medical ward; from the sudden rupture of an aorta, leaving me completely helpless in the meeting with the patient's suffering, to sitting by the bed, holding the patient's hand as they let go; and from patients asking me to tell the doctor to let them die, to being present with a young woman when the physician tells her there is nothing more they can do.

These stories and meetings with patients at the ends of their lives have shaped me. They have become a part of me. As I became more experienced in my work as a nurse, I had a growing unease regarding the conditions under which patients die. In some cases, I experienced that we succeeded well in making the last days as good as possible, but in other cases, we seemed perplexed. We often lost sight of the patient's needs and best interests.

In an effort to improve the dying process of patients at my workplace, we implemented the newly adopted Liverpool Care Pathway. A part of this process is to assess the documentation of the last 20 patients that died. As I became familiar with this approach, I began to reflect on how we write about the patients' last days in the electronic patient record (EPR). As exemplified above, I was surprised to discover a specific and rather abrupt tone of voice, the absence of the patient's voice, and any personal details about their situation. The curt style seemed to be the typical way of connotating dying and death in all the records that I assessed. Thus, I pondered that if the EPR is one of the main sources of knowledge within and between healthcare professionals, how do they know

what goes on with their patients? How do healthcare professionals communicate with each other in an environment with such strict protocols?

My interest in the text of the EPR was evoked, and I wanted to discover more. From the outset, I was motivated by what seemed to be a mismatch between the (palliative) premises of clinical practice and the language of the EPR. Organisational documents such as the EPR have traditionally been approached as neutral containers of information (Prior, 2003). However, to explore what I apprehended as a mismatch, my starting point for this study was to approach the text of the EPR as an active contributor to what is included in the information about the patient and their context and how it is passed on. I came to recognise the EPR as having a constitutive role that affects professional practice by mediating and (re)producing certain understandings over others (Berg, 1996). Hence, I saw the text as performative in two main ways. First, it makes things happen: decisions about treatment written down in the EPR become orders for colleagues to follow. Second, it reveals knowledge and values in the ways the texts are written and how these parts of 'reality' are selected, determining for the reader what is perceived as relevant and important to document and what is not. Since this is the focus of the thesis, I will elaborate on the context.

Hi-Tech Medicine

Modern medicine is highly technical, and when a patient enters a hospital, the patient is, by default, tracked to be cured or at least stabilised (Chapple, 2010). It is not the medical wards' main priority to admit patients for dying. In Norway, there is increasing health political and professional attention towards the care and treatment services for dying patients (Helsedirektoratet, 2015). The aim is to strengthen palliative care by facilitating home deaths and improving palliative competence in nursing homes, as stated in several white papers from the Ministry of Health and Care Services: Meld. St. 24 (2019–2020), Meld. St. 29 (2012–2013) and Meld. St. 25 (2005–2006). Despite efforts to arrange for home death in Norway, only around 5000 out of about 40,000 deaths occurred at home in 2019, while around 11,000 deaths occurred in hospitals. Most of the remaining 24,000 deaths occurred in other health institutions (Folkehelseinstituttet, 2021). This shows that hospitals are

significant contractors of end-of-life care. Other Western countries are experiencing the same tendency (Broad, 2013; Davidson, 2013; Pollock, 2015; Virdun, 2015). This means that hospitals have a crucial role as gatekeepers of life and death boundaries (Hockey et al., 2010).

According to Walter (2017), one explanation for the high number of deaths occurring in a curative context may be the inclination to cure disease instead of 'providing the best frame for thinking about death or best context of managing dying' (p. 18). There is a tendency in society to think that there is always something more to be done, and this stands in the way of recognising the patient as dying and finding the optimal equilibrium of when to end curative or life-prolonging treatment. Kaufman (2005) observed that more time alive appears to be the criterion for success in a curative context, rendering death 'a failure of rescue, it becomes a technical problem rather than an existential one' (p. 17). Regarding the clinical practice of professional healthcare workers in hospitals, the consequence of this view is often rapid shifts between the discourses of heroic efforts to rescue and recognising dying with all its implications.

The difficulties of stopping the trajectory of curative treatment can also correlate with the aspect of how the high-tech environment of hospitals, alongside the general medicalisation of society, gears the doing of hospital work into an 'attempt for a diverse and array of possible treatments before accepting defeat' (Kellehear, 2016, p. 14). This may induce a situation in which the patients expect that there is always a solution to their condition, which Kellehear referred to as the *myth of medical rescue*. The reason for this myth, Kellehear (2016) noted, is that medicine controls and regulates our everyday life. This feeds into an understanding where we expect any medical problem to be solved because medical rescue holds all the answers to the failings of the body. Hence, an expectation arises: the personal experience of being mortal can always be avoided or at least postponed.

In the following section, the necessary contextual connections are established. Relevant here is the development of palliative care and the role of patient records, followed by how this thesis is situated.

The Development of Palliative Care

The ideal of palliative care has a strong position in society as it contains the necessary ingredients to ensure what is perceived as a good death. The rapid development in modern medicine caused by the breakthrough in science with discoveries such as antibiotics, chemotherapy, surgery and anaesthesia has considerably increased life expectancy and provided cures for diseases that had been mortal (Kübler-Ross, 1969/2003). Alongside this development, increasing attention was directed towards understanding the fear of death and how it seemed to considerably enter people's lives. This was suggested as being in step with medical developments, with the consequence that increased longevity resulted in decreased familiarity of death. The growing practice of moving death out of homes and into institutions has increased the difficulty in grasping the concept of death (Aries, 1981/2008; Glaser & Strauss, 1968; Kübler-Ross, 1969/2003). Another aspect in the development of modern medicine was the increased interest in pain, which entered the field of investigation in the 1950s (Clark, 1999). A part of this movement was Cicely Saunders, who developed her ideas on specialised care for the dying in the early 1960s. Saunders was professionally trained as a social worker, nurse, and physician, and she had developed a particular interest in pain in dying patients. In her work, she emphasised the need to approach pain by embracing its physical, psychological, social, emotional and spiritual aspects. This was her response to what she saw as shortcomings of end-of-life care at the time (Ellershaw & Ward, 2003). Saunders' approach to the dying patient's pain made her the initial impetus for the concept of 'total pain' and the hospice movement (Clark, 1999; Lawton, 2000), since she founded the first hospice, St. Christopher's hospice, in London (Clark, 1999). Concurrent with the development of 'total pain', Elizabeth Kübler-Ross developed a model for the stages of dying (Kübler-Ross, 1969/2003), which has contributed greatly to the understanding of the needs of the dying patient and the family (Kübler-Ross, 1974/1997).

Today, the concept of total pain still influences the values of care for the dying, and it became visible in the definition of palliative care by the World Health Organization (WHO). It explicitly states that no matter what type of disease, the aim of palliative care is to relieve suffering

at the end of life, 'be it physical, psychological, social, or spiritual' (WHO, 2021). The Lancet Commission on Access to Palliative Care and Pain Relief has recommended broadening WHO's definition, including an earlier integration of palliative care to a wider population of patients who suffer from multiple and often severe chronic conditions. This implies a change of focus to assessing who may benefit from palliative care based on the burden of living with severe illness, rather than a prognosis alone (Radbruch et al., 2020).

In a Norwegian context, there is an explicit expectation that palliative care should be offered in medical wards by 'all departments that care for cancer patients or other patients in need of palliative care and must provide good pain and symptom relief and good terminal care' (Helsedirektoratet, 2015, p. 133).

Despite this broadening of palliative care to be relevant in settings other than end-of-life care, in this thesis I have chosen to focus on the notion palliative care in relation to the last days of life of patients in hospitals.

The Electronic Patient Record

Documents are an essential part of modern society (Asdal & Reinertsen, 2020; Prior, 2003). Although the EPR is a quintessential part of modern healthcare service (Greenhalgh et al., 2009), the basis of EPR is the traditional medical record that has been a fundamental part of doing medicine since the time of Hippocrates (Hurwitz, 2006). It has uniquely enabled a deeper understanding of 'the social and technical structure of contemporary healing' (Risse & Warner, 1992, p. 185). In the nursing profession, documentation has been a vital part of professional practice since the time of Florence Nightingale (1859) (Dahl, 2002; Iyer & Camp, 1995;). A shared ground in the electronic documentation for both physicians and nurses is the use of internationally recognised coding systems to fixate diagnosis to the various conditions, providing direction to their professional practice (Bowker & Star, 2000).

As part of technological development, the EPR began replacing paper-based records in the early 1990s. This transition was saluted in healthcare services, with a shared understanding that the

EPR would improve all aspects of administering treatment and care, besides being cheaper and preventing errors (Greenhalgh et al., 2009). Still, the nursing documentation has frequently been criticised for poor quality (De Groot et al., 2019), and over the last decades, there has been a development towards more standardised language. Using standardised, unambiguous language in the EPR is crucial to rendering visible the professional and essential work of nurses (Lunney et al., 2005).

The medical service in Norway uses the Statistical Classification of Diseases and Related Health Issues (ICD-10) coordinated by WHO and adjusted to Norwegian conditions by the Norwegian Board of Health Supervision (Malt, 2019). Regarding nursing services, The Norwegian Directory of Health (Helsedirektoratet) recommends using the system called the International Classification for Nursing Practices (ICPN). The aim of the ICPN is to 'provide a framework for sharing data and for comparing nursing practice across settings' (NSF, 2021).

However, as forces seem to praise developments towards standardisation, critical voices state that 'computerised records jeopardise the human side of medicine and nursing' (Greenhalgh et al., 2009, p. 730), because healthcare professionals' attention is directed to data entry and protocols.

The rules for EPRs require texts to contain all relevant and necessary information about the patient, treatment and care (Helsepersonelloven, 1999). So, the information that the healthcare professional selects as relevant is based on the professional's knowledge and know-how intertwined with a legal obligation about the information that must be included in the text. Yet, investigation into how healthcare professionals experience the work of documenting in the EPR suggests that the EPR demands a specific kind of input that seems to disable the nuanced language needed to narrate the handicraft of care (Hämäläinen & Hirvonen, 2020; Kärkkäinen et al., 2005). This implies that, while documenting relevant knowledge adds and removes qualities of the care, treatment and events that occur, because the process of producing this text is steered into appointed directions, it changes its shape (Moser & Law, 2006). In addition, 'what counts as information is variable: it shifts from

situation to situation', it is heterogenous (Moser & Law, 2006), but with restricted and structured language that the EPR requires, the heterogeneity is limited to following a specific structure.

Situating the Thesis

This thesis was submitted to the PhD programme Diaconia, Values and Professional Practice at VID Specialized University. VID Specialized University refers to values as ideals and norms that influence our attitudes and concepts in doing healthcare services and professional practices as the performance of work that influences practices on both the personal and organisational levels (VID, 2021). So, in situating this thesis, my point of departure is an understanding of professional practice as the ways that people go about things, which through learning have developed knowledge and skills to execute certain tasks in a certain context (Molander & Terum, 2008). Also, the doing of the profession means employing established values. Therefore, by using values and professional practice as a backdrop for investigating the EPR text, I emphasise two aspects. First, the concept of accountability, as proposed by Kline and Preston-Shoot (2012), refers to the expectations of the practitioner to be accountable both towards an employer and the professional affiliation (e.g., nurses, physicians). This implies that healthcare professionals understand how to fulfil the expectations of both the organisation and the profession to which they belong (p. 26). Regarding documentation, being accountable means adapting to the norms and values of the organisation and those of the professional affiliation. Second, the hegemonic biomedical discourse is rooted in a tradition often perceived as unbiased and neutral, and thus may be unacknowledged (Jones et al., 2014). Here, I recognise values as omnipresent and infusing all texts, including those that appear objective and neutral but are not (Kelly et al., 2015).

In the conceptual and analytical framing of this thesis, and regarding the composition of supervisors with various backgrounds, this project is multidisciplinary, contributing to the ongoing and growing conversation between humanities and science known as health humanities. Health humanities acknowledge humanities as necessary and complementary to traditional biomedical science, enabling a re-description of healthcare services to increase the understanding of what goes

on (Jones et al., 2014). This study of the EPR attempts to understand the interwoven worldviews, layers of complexity, power, beliefs and values and unspoken issues that would not be recognised otherwise (Jones et al., 2014, p. 8). To address the issue of text as an active contributor to the realisation of decisions and the passing on of values, this study primarily aims to explore how dying and death are performed through textual practices in the documentation of the EPR.

Therefore, the backdrop for this project is the intersection of two realms: the text and the professional practice of documenting dying patients in a curative context. These realms are explored further below.

Research Contexts

The EPR documentation of dying and death in a curative context is the key phenomenon I seek to investigate in this study. In presenting the research context, I find several research fields to be imperative. The presentation is divided into three sections. The first section presents descriptive studies that focus on terminally ill patients in a curative environment. These studies are essential for establishing a rationale for why documentation about dying and death is a domain of potential tension between the ideals of palliative care and the aim to cure. The second section contains relevant research using EPRs to gain insight and knowledge about aspects of care for dying patients. The third section presents text analysis of professional texts in general, where it is the method of text analysis that has informed my work.

Dying in a Curative Context: in Practice

Over the last 50–60 years, there has been considerable development in the characteristics and epidemiology of terminal illness (Small & Gott, 2012). Still relevant in this field of study is Glaser and Strauss' (1968) ground-breaking ethnographic fieldwork of dying patients in the mid-1960s, which still inspires and influences contemporary research on practices of dying and death (Small & Gott, 2012). Through their work, Glaser and Strauss proposed that dying can be understood as following a trajectory – a shape and duration determined by a type of disease when the patient initially is recognised as dying, and the expectation as to how the dying will proceed (Glaser &

Strauss, 1968, p. 6). The patient's dying trajectory became important for knowing which signs of the patients' condition designated the passage from life to death. The elaboration on how time (to die) and shape (of the dying trajectory) could influence the work of healthcare professionals the patient. The patient's process of dying may be either *in step* or *out of step* with hospital time and how the hospital organises the work of caring for the dying patient (Glaser & Strauss, 1968, p. 1). For example, this means that the professional is either attuned to the patient's dying (in step) or continues to focus on curative treatment even though it is futile (out of step). The prediction of the time and shape of dying depends on the quality of care because being out of step may induce challenges to care at the end of life (Glaser & Strauss, 1968).

Seymour (2001) conducted an ethnographic study at intensive care units (ICUs) that is equally relevant today. She drew up a line from Glaser and Strauss (1966, 1968) into contemporary ICUs and explored how the trajectory of dying, which Glaser and Strauss referred to as 'the uncertain/unknown' trajectory, affects and raises dilemmas in ICUs. The uncertain/unknown trajectory appeared to be the least likely in the 1960s. However, because of recent developments in medicine and technology, the borders of cure have been expanded, and conditions initially considered deadly can now be cured. This has induced frequent fundamental dilemmas in organising modern hospitals because hi-tech treatment can impede the assessment of treatment level, decision making, ethics, costs and 'the constituents of appropriate care for dying people' (Seymour, 2001, p. 3). In addition, as Small and Gott (2012) specified, the population above 65 years old has increased. This implies that dying patients are older and have multiple and more complex morbidities. In the Western world, people are, on average, ill for six years before their death. This often induces multiple hospital admissions and 'long-term' dying that involves multiple professional teams and triggers other challenges in the care for the dying. Yet, a struggle that Small and Gott revealed from Glaser and Strauss' study, which is equally relevant today, is the reluctance to discuss prognosis with the patient and the lack of an open dialogue about death as a probable outcome for patients with severe illness.

Contributing to pinpointing fields of tension is the work of Kaufman (2005), who, through her hospital fieldwork, defined four topics that she argued have been missing in the contemporary conversation about dying in hospitals: 1) the hospital system organises how their resources are used in their daily activity around their admitted patients. In this system, the threshold of death is cultivated as a specific type of practice, involving technologies, bureaucracy and clinicians working with the patient; 2) the ongoing rhetoric in the hospital about the dying patient is unacknowledged in the public conversation for the potential insight it may provide in discussion about 'when to allow death to happen' (p. 8); 3) there is a gap between the healthcare professional's knowledge about how they assess the patient situation to unfold and the information that the patient and family possess; and 4) how dying and death occur in the hospital are complex cultural constructions. Also, what is right or wrong with today's practices of hospital dying is determined by trends and discourses in society and medicine (Kaufman, 2005, pp. 8–9).

Another contributor to the mosaic of potential challenges surrounding dying in a curative setting is Chapple (2010), who also conducted ethnographic fieldwork in hospitals. Inspired by the work of Kaufman (2005), she problematises a discourse in a curative context where rescue is perceived as the criterion for success, thus implying dying is a failure of rescue. The consequence of this imbalanced focus is an approach to dying as 'conflated with suffering, and no value apart from limiting suffering seems important once consensus about the dying has been reached' (Chapple, 2010, p. 19). A field of tension appears in how dying occurs in a curative context, where the main struggles seem to be related to how heroic medicines will cure, and how the constant focus on time, efficiency, and patient flow suppresses the space to provide holistic care (Chapple, 2010).

Cardona-Morrell et al. (2017) conducted a review of research illuminating how older patients with chronic comorbidities are most likely to die in hospitals. They included studies about the difficulties of recognising when patients are dying and how this induces inappropriate or *non-beneficial treatment*, which are common expressions used to describe hospital admissions and treatment of older patients where there is 'no hope of recovery or improvement in survival or quality

of life' (p. 39). They argued that not recognising patients as being near death induces several unfortunate consequences, such as unnecessary hospital admissions, anxiety and concern, and the use of resources that have limited impact on the patient's clinical state, amounting to the cost of unrequired care. In their conclusion, they stated that many hospital admissions for this group of people could have been avoided by strengthening community-based care and developing a standardised tool for admitting patients only on clinical indications. In an earlier review, they investigated the prevalence of non-beneficial treatment in hospitals in the last six months of the patient's life and suggested that there is, in general, a strong will to treat various conditions in severely ill patients. The researchers argued that this is caused by a lack of an agreed definition of futile treatment. The uncertainty of prognosis and time of death, along with social and ethical pressure on healthcare professionals, makes dying and death a difficult terrain to navigate (Cardona-Morrell et al., 2016).

Ellershaw and Ward (2003) conducted a review to assess the quality of palliative care for dying patients. One of their main arguments, based on their interpretation of the included studies, was the difficulty in diagnosing dying, especially in a hospital context where curative or life-prolonging interventions come at the expense of comfort for the patient. Elaborating on a similar topic, Virdun et al. (2017) conducted a meta-synthesis to identify elements in end-of-life care in hospitals that patients and families perceived as important. The basis for this investigation was that optimal palliative care for inpatient dying in hospitals cannot be guaranteed. Through their mapping, however, they showed how much expert – and compassionate – care means for the patient and family, which was a consistent finding throughout the included studies. They also specified the importance of optimal communication, supporting patient choices and preparing the family for the imminent death (p. 599).

From the point of view of healthcare professionals about collaboration to negotiate the withdrawal of curative or active treatment, Flannery et al. (2016) executed a critical literature review regarding end-of-life decisions in ICUs and the emotional challenges of these decisions for healthcare

professionals. Through their exploration of the topic, they observed that the basis of the less optimal surroundings for the decision-making process was 'a lack of standardised approach to end-of-life decision making' and ambiguity about the nurse's role in the decision-making process. This is because the nurse's contribution of competence was dependent on whether the physician included the nurse in the decision-making process.

These studies enlighten the tensions in the practice of palliative care in a curative setting that are useful in understanding the EPR text. As I see it, these studies display a core of consistency in what these struggles have concerned over the last 50 years. Although the development of medicine has changed tremendously, *time* and *communication* and a *focus on curative treatment* appear as the consistent source of conflict over the care of the dying.

Dying in a Curative Context: In Text

In selecting the research on text or textual documentation involving dying and death, the relevant studies were divided into two subcategories. Here, I present studies that have investigated medical records on the topic of dying in a curative context.

The medical record has been used as a source of information to explore aspects of palliative care in a curative context. How it has been used as a source varies, as shown in the selection of relevant studies. Goodlin et al. (1998) used information from the medical record to map out symptoms, treatment and orders to limit life-sustaining treatment. Their finding, which still seems relevant, suggested that patients diagnosed as dying received less aggressive treatment. Seah et al. (2005) used medical records to map out the care of older patients (> 75 years) in hospital in the last days of life. Like Goodlin et al. (1998), they stated that the common symptoms were dyspnoea, pain, fever and respiratory secretion. Several of the patients did not receive any treatment for these symptoms, but this proportion was lower for the patients that were recognised as dying.

Rashidi et al. (2011) investigated the experience of dying in very old patients who spent their last days of life in a palliative care unit. The medical record was used to map out consecutive patterns. By comparing symptom data and medication in patients aged above 80 with patients

between 50 and 70 years old, they found that older patients received significantly less pain

medication and sedatives, even though the symptom profiles were similar. Steindal et al. (2015)

conducted a similar study in a hospital context with data extracted from the EPR. They suggested

that pain intensity was poorly recorded for all patients, and in the administration of medication,

there were some differences between the younger and older patients in the types of medication that

was provided.

A few studies have investigated the content of the EPR to map out features in documenting

end-of-life care. Gholiha et al. (2011) investigated patient records at the end of life and found a lack

of documentation about physicians' communication with dying patients regarding the situation. Fins

et al. (2000) used the method of narrative ethics to gain insight into the documentation of dying

patients in hospitals by inviting healthcare professionals to reflect upon the content about how the

last days of life were described in the medical record. They specified how narratives could shape how

we conceive end-of-life care and how the narrative structure of the EPR impeded chaplains from

documenting their reflections of care in their work with patients. The researchers showed how the

pre-structured templates induced an increasing fragmentation of narratives, which may reduce the

possibility of documenting the nuances of patient care (Fins et al., 2000). Finally, they articulated that

end-of-life care is often enveloped by profound uncertainty in the prognostication of dying and

ambivalence about the goals of care, making control elusive (Fins et al., 2000). Hegarty et al. (2005)

executed retrospective case-note audits and interviews and found discrepancies between how often

the nurses became aware of the psychosocial, spiritual and cultural aspects of care and the

infrequency of documenting the same topics. Parish et al. (2006) conducted a similar methodology,

aiming to analyse end-of-life care in a hospital context. They found a lack of documentation and

appropriate assessments.

To my knowledge, little research has investigated textual practices for documenting the last

days of life and death in any context. The study by Habeck-Fardy (2019) is the only study I have found

that investigates the language about dying and death by analysing discharge summaries of patients

who died in hospitals. She reflects on what she refers to as the frequent use of euphemisms to convey death.

Dying in a Curative Context: Other Relevant Studies

The research on EPRs for this study, only to a small degree, concurs with the analytical approach I have chosen. Therefore, I have added studies of other types of professional texts. In these, the conceptual approach has been relevant for developing the analytical approach of my study.

There are not many studies that view EPRs as active contributors regarding dying in hospitals. However, several studies have approached other professional texts in this manner. Aarseth et al. (2016) and Aarseth et al.'s (2017, 2019) exploration of the effect of language on the certificate of disability is relevant in this respect. They used narratological linguistics to analyse the certificates written by general practitioners. They contended that the disability certificate had a symptom-oriented focus in which the patients were passive objects. Engebretsen (2005, 2007) approached texts as active agents that construed their own reality. Through a close deconstructive reading of child welfare records, he argued that considering the rhetorical phrases allows us to see the truths and presentations of events other than the one explicitly stated by the text. By being aware of the text's productive capacity, the executive officer may critically assess and question their own participation in the organisational language of the record (Engebretsen, 2005, p. 219). Another relevant study was Aaslestad's (2016) investigation of a century of medical records from a psychiatric hospital. In his reflection on these records, he stated that the way the patient is made audible or visible through the text is influenced by the historical context and the structure of the record itself (p. 178).

Aim and Research Questions

Based on the backdrop presented in the introduction and previous research, the overarching aim of this study is to contribute insights into what knowledge the EPR proposes as relevant about

dying and death in a curative setting in Norwegian hospitals and how it does this. To achieve this goal, the following overarching research question was posed:

What kinds of textual practices of dying and death in medical wards are present in the EPR, and what do these practices achieve?

To answer this question, I chose to approach the material with three research sub-questions:

1) How does the textual voice argue for the shift from curative to palliative care, and what characterises the language that documents the interaction with the patient and family (i.e. external voices) towards the turning point?

2) How do the EPRs from the last 24 hours of a patient's life articulate the dying process?

3) How is the moment of death documented, what kind of textual practices can be found, and how can they be understood as part of the EPR genre?

To explore these research questions, I analysed excerpts from 42 EPRs retrieved from 11 medical wards from 3 hospitals in Southeast Norway. The responses I propose in addressing the overarching research aim are not exhaustive. Rather, they are an attempt to explore selected aspects of the EPR as the only source of information and employing various text-analytical approaches conducted in close dialogue with a conceptual framework. My starting point is an understanding of texts as 'not a copy of events' (Raffel (1979), as cited in Berg, 1996, p. 500), but an active contributor to what knowledge is forwarded about patients at the end of life.

Outline of the Thesis

This study contains a synopsis and three individual academic articles. The introductory section situates this study, focusing on the right to die with palliative care, independent of context. As shown, I have stipulated a potential field of tension in the aims and practices of curative vs. palliative treatment, especially evident in a hospital context that is not particularly adjusted to palliative care. Legal requirements and obligations to the medical record also have been thematised,

followed by a presentation of the context of the research that has informed the project, retrieved from the research field of dying and death in a curative context, and research on professional texts.

Next, I present the conceptual framework for the study. Here, I elaborate on Bakhtin's concept of language as dialogic (Andersen 2002; Dentith, 1995) and insights from science and technology studies (STS) on texts as modes of ordering or infrastructuring organisation (Bowker & Star, 2000; Law, 1994). This is followed by how these concepts have triggered an approach to exploring how the intertwined layers of the EPR serve distinct purposes. Next, an account of the methodological aspect of the study follows, where I describe the research process. In this section, I elaborate on the study's credibility. In the final part of the section on methods, I address the topic of reflexivity and how working with texts about dying and death became an issue that affected the research process.

In the results section, I summarise the three papers, followed by the discussion, and how synergising the three articles generates new knowledge and understanding of the documentation about dying and death. Next, I discuss the main findings. Finally, I present a conclusion and some thoughts on potential ways for future investigations.

II. A Conceptual Framework for the Study of Dying and Death

in the Electronic Patient Record

In this section, I elaborate on the conceptual framework. The effort to develop a conceptual gaze includes a selection of what aspect of the text receives attention – what falls within the focus of the lens. To me, this process has been demanding since I experienced that well-established text analysis, such as (critical) discourse analysis or narrative analysis, did not allow me to grasp the aspects of the text that I perceived essential to understand the textual practices of documenting dying and death. This has led to a process in which establishing the conceptual framework became an ongoing interplay between theories and data, where I cultivated the conceptual aspects that revealed and guided me to the study's aim. So, presenting the conceptual framework also implies the presentation of a path created while walking. Hence, the conceptual framework for this project has been constantly evolving throughout the course of the project.

As presented in the previous section, investigations into medical texts often encompass an understanding where the investigated documents are viewed as containers of information about what occurred (Prior, 2003). In this study, I took another step and held the EPR more accountable by taking on a perspective that seeks to explore the potential consequences of how dying and death are documented, what kind of knowledge are forwarded, and what knowledge is omitted. So, I started by digging into the documentation to open the text for ways of seeing new kinds of knowledge and providing insights into dying and death in a curative (con)text, which I believe has been black boxed.

Although the literature informing my work can be situated in a diverse and interdisciplinary field, there are two main strings of theory that make up the bases that I will try to tie together: language as dialogic and language as performative. Thus, I anchor this project in the selected concepts from Bakhtin's language theories and selected concepts from STS. In the following, I argue that the relevant research fields relate, build and sometimes both challenge and complement each

other. Also, by situating the study like this, I can refer to selected parts of the literature while leaving other parts out.

Language as Dialogic

Mikhail Bakhtin (1895–1975) was a philosopher and linguist from Russia. His work originated during a period of censorship and political commotion in Russia. So, there still exists much uncertainty around his life and work. However, what is known is that he was among a group of intellectuals who discussed matters of philosophy. This group was influential in contemporary cultural life in Russia; hence, most of the members were made silent by execution or banishment. Originating in this complex context, Bakhtin's authorship remains disputed regarding the existing uncertainties attached to who has the copyright to the literature produced by Bakhtin and his fellow intellectuals (Andersen, 2002; Dentith, 1995).

The work of Bakhtin cannot be defined as a specific research tradition because 'his system of concepts is too peculiar and his method too unsystematic' (Andersen, 2002, p. 11). Yet, Bakhtin is regarded by many as one of the greatest philosophers of the twentieth century. His thoughts and ideas have become a catalyst for various directions in post-modernistic thinking, and his concepts have inspired researchers in various fields in the humanities (Andersen, 2002).

Using Bakhtin's work as a source in construing the conceptual framework is demanding. Consequently, when operationalising his dialogic universe in this project, my reading of his work has been supplemented with writings from academics who have specialised in his theories, namely Nina Møller Andersen (2002) and Simon Dentith (1995).

Bakhtin approached language as a living dialogue (Andersen, 2002, p. 11), rooted in the idea that 'communicative acts only have meaning, only take on their specific force and weight, in particular situation or contexts' (Dentith, 1995, p. 3). Hence, a dialogue is a continuous interplay between a 'me' and 'you' that makes up the language (Andersen, 2002, p. 34).

So, according to Bakhtin, what does it mean that language is dialogic? The word dialogue comes from the Greek word 'dialogos', where 'dia' means *between* and 'logos' means *words* –

between words. For Bakhtin, this space between words was more of a philosophy of life than a theory. He argued that at the nucleus of both the linguistic and the literary is the dialogical space. A dialogical space between the 'I' and 'you' permeates all aspects of human interaction (Andersen, 2002, p. 34). His concept of 'the dialogical language' is presented in his work as an understanding of the reciprocal exchange between at least two poles. Bakhtin stated that the dialogical aspect of language infuses all features of human relations, and he argued that 'living means to participate in a dialogue' (in Andersen, 2002, p. 36 [my translation]).

Bakhtin argued for an inclusive understanding that recognises a dialogue to be everything from a greeting to multi-volume works (Bakhtin, 1986; Andersen, 2002). I have chosen to use his theory of dialogical language as a starting point to explore text on a sentence level and as an overarching perspective to investigate the EPR as a genre. Applying Bakhtin's theory as the conceptual framework for this study allows for the recognition of EPR as dialogic language – as the interplay between the various authors, the EPR and its potential readers.

The EPR as Communicating Experience

I found it relevant for the aim of this study to investigate the text both on the sentence level and as a complete text. To develop a toolkit suited to investigate the sentence level, I supplemented Bakhtin's theory with aspects from systemic functional linguistics (SFL) (Halliday, 2013). This theory views language as a tool for representing and communicating our experience of reality (Halliday, 2013; Maagerø, 2005). Although Halliday did not particularly emphasise Bakhtin as an inspirational source for his system, others have connected the two perspectives. Joki (1993) stated that 'Bakhtin's and Halliday's concepts are prompted by the same sociolinguistic phenomenon' (p. 83); hence, the overarching understanding of what we speak or write is adjusted to the situation in which the utterance is made. A text (written or spoken) is an artefact 'that gets its meaning by selecting from the same meaning-making resources' (Halliday, 2013, p. 4). Hence, any text is in an interplay with context, making it possible to investigate text and to understand the relation between the language and the culture that also influences language (Maagerø, 2005).

According to SFL theory, language holds basic functions called metafunctions (Halliday, 2013; Maagerø, 2005). First, the ideational metafunction expresses our experience by construing a representation of reality in line with how we conceive it. Second, the interpersonal metafunction acts as a channel for our social relationships with others. These two functions work in the language simultaneously, but for the language to appear coherent and give meaning, and not seem fragmented and without consistency, Halliday also proposed a third function: the textual metafunction (Maagerø, 2005, p. 98). These metafunctions are in a consistent interplay, and they are present in all kinds of utterances (p. 99).

In this project, I have taken a particular interest in the interpersonal metafunction and supplemented Halliday's theory with Martin and White (2007) and their focus on how the writer addresses the reader. Martin and White (2007) expanded Halliday's interpersonal metafunction by addressing the language's evaluative capacity by exploring how the textual voice reveals 1) feelings, values, and attitudes, 2) construing authority/status, 3) constructing alignment, and 4) negotiation of the writer–reader connection. My argument is that tuning into the text's evaluative capacity enables the analysis of the text. Attention is directed towards the textual voices, their stance towards other voices, their preferences and their positioning towards the reader. In addition, this approach is useful in analysing how utterances express uncertainty or subjectivity as dialogically expansive by displaying an openness to alternative voices or are dialogically contractive through opposing, ignoring, suppressing or rejecting the presence of alternative voices (Martin & Rose, 2003). This way of approaching the text helps in exploring the subjective tensions and struggles in the professional environment, especially in complex situations, such as documenting the decision-making in the transition from curative to palliative treatment.

The EPR as Genre

'Speech genre' is another of Bakhtin's concepts chosen as a strategy to explore *the bigger picture* of textual patterns and practices. A speech genre can be viewed as 'typified forms of situated utterance' (Prior, 2009, p. 18). Thus, by adding the concept of genre to the study's conceptual

framework, my purpose is to take a step back from the sentence level and explore how the typical EPR is structured both regarding the content and shape of the typified language. All utterances written or spoken are made within an area of utilisation, and the utterances reflect the goals and purpose relevant to the specific area (Bakhtin, 1998, p. 1). Bakhtin argued that genres infuse all forms of utterances, and while learning how to speak, we also learn how to shape the utterance regarding the relevant genre (Andersen, 2002; Bakhtin, 1998). In the further elaboration of genre, Bakhtin distinguished between primary and secondary genres. He included colloquial language in the primary genres, while secondary genres represent the more complex compound of text as manifested in novels, dramas and scientific work (Andersen, 2002, p. 86). The EPR text, as I see it, belongs to the group of secondary genres, where the text is expected to follow a typical, rather stringent, pattern. This means that utterances (e.g., in the EPR) comprise words, combinations of words, phrases, and sentences that mostly stay within the limits of this sphere of utterance, making the genre relatively stable. This also makes it possible to some degree to predict how different topics are addressed by the author of the text because any utterance is not only governed by the context that is uttered. It is also influenced by other voices uttered on a similar topic, either to confirm or to oppose what is uttered (Bakhtin, 1998; Andersen, 2002). Continuous opposition to the relatively stable genre structures influences and challenges the genres and thus creates a space for development (Poirier, 2004).

Furthermore, I perceive Bakhtin's genre theory to be complex and multifaceted, making it necessary to work with selected parts regarding this study's purpose. Thus, a genre analysis with a pragmatic conceptual framework is fruitful for exploring how the EPR text relates to a given context. I investigate the EPR by looking into normative unwritten and written and learnt rules for documentation. In the investigation into the potential field of tension that dying and death seem to represent, the concept of genre might help to illuminate various practices, utterances and voices that are present in the EPR.

The EPR as a Social Actor

Seeing language in the EPR genre as dialogic provides an understanding of how the EPR not only represents the patient's situation but also influences how and what aspects of the patient's situation and treatment become known and communicated (Emmons, 2009). This knowledge is also part of the hospital as an organisation; thus, it documents what has happened and contributes to the hospital workflow. I have drawn elements from science and technology studies (STS) to further conceptualise the EPR as a social/organisational actor that proposes (or contributes to propositions for) how to order the hospital's workflow around, and care for its patients.

The EPR can be understood as being part of a hospital's infrastructure: the underlying force or machinery that makes it at all work. In the hospital organisation, an infrastructural component is like a cogwheel built into the very core of the hospital's work (Star, 1999). However, infrastructural components are typically embedded in the background, so they are often taken for granted. Technical objects, such as the EPR, are a self-evident part of the work routine. Thus, it is only by lifting them out of this background – as I have done in this thesis – that we can see that they are not innocent and neutral. Rather, they are part and parcel of the organisation of care by imposing certain frameworks. That is, the shape and formatting of the EPR, and the selection of words and phrases, passes on specific knowledge about the patient and omits other things. Thus, I argue that it is not only the genre and the dialogical language that influence how the text is shaped, but also the documentation system itself. Who requests/presents a hierarchy of patterns of how and what to document? What comes to be documented in the EPR, and what does not, is part of the hospital's 'politics of voice and value' (Bowker & Star, 2000, p. 230). These are enacted and become visible through the templates, the workings of the documentation system and the specific norms and practices of documentation. The politics of voice and value are part of the infrastructure of the EPR format, which in turn may then be confirmed and reproduced by the way this technology is embedded in practice. Viewing the infrastructure of the EPR as a part of how these organisations

deal with dying patients contributes to an increased understanding of how they 'order' the patients' situations in specific ways.

Working with this notion of the EPR as a component of the hospital's infrastructure, I have used Law's notion of modes of ordering to further conceptualise the EPRs' active contribution to the ways in which dying and death come to be understood. Law developed this notion in his *Organising Modernity* (1994), a fieldwork study of how a science institution works. He probes into the patterns of priority and hierarchy in the institution and explores all kinds of work that occur in the doings of an organisation. This work, despite a lack of formalisation and regulation, somehow enables the organisation to stay on track. Law's point of departure is that organisations are messy, incoherent and heterogeneous, and by looking behind the established truth of the organisation, he elaborates on a complex web of orderings more or less rooted in, but also constitutive of (or infrastructuring) the organisation's scientific practices. He argues that it is not only people that establish order, but orderings are effectuated within and by assemblages of many elements acting together. This allows for an exploration of how the EPR works to uphold the hospital's curative hegemony and how it embodies and contributes to keeping the organisation going in a specific way, but also of where possibilities occur to do things otherwise.

Synthesising the Concepts

To establish a conceptual framework inspired by language as dialogic and productive, a notion that has been at the periphery of this project from the beginning seemed purposeful to use in synthesising different approaches: Bakhtin's concept of *heteroglossia.* Adding heteroglossia to the conceptual framework opens up a reflection on how the hegemonic discourses of medicine *and* organisational considerations are in constant interplay.

The word heteroglossia means differentiated speech and is a key term in Bakhtin's stratification of language into genres, argots, jargons, dialects and sociolects and the mixture of these (Andersen, 2002, p. 80). Frank (2012) proposed heteroglossia to understand the ways in which stories are pieced together from numerous codes of 'language usage and genre' (p. 35), thereby

making the term represent the generalised utterances of a speech community, rather than a particular individual utterance. According to Dentith (1995), Bakhtin proposed heteroglossia as tensions in language that influence what is uttered. Bakhtin argued that language comprises both centripetal and centrifugal forces that steer utterances between a centre and a periphery. Also, every utterance made in any context intersects with these forces, where the centripetal force pulls utterances towards an established norm or expectation, and the centrifugal force challenges or opposes the established norm (Andersen, 2002). Dentith (1995, p. 35) argued that, according to Bakhtin, these forces are also influenced by historical forces external to language; thus, Bakhtin proposes an understanding where the context outside the text influences the direction of the utterances produced.

The concept of heteroglossia is complicated and developed to think about the use of language in general. Yet, here, I argue that adding the perspective of heteroglossia to the conceptual framework of this study reflects the EPR text as comprising an interplay between professionals and organisations loyal to the hegemonic discourse. Finally, heteroglossia also opens up an investigation to better understand the centrifugal force present in textual practices that are breaching the dominant narrative or discourses of the EPR.

Critical Reflections on the Conceptual Framework

The overarching research question of this study has been answered by sub-questions that conceptually pull in three somewhat different directions. This implies that I have juxtaposed three concepts in the analysis of the sub-questions. Flick (2004, p. 178) refer to this juxtaposition of theoretical concepts in research as the triangulation of theories. Triangulation has the advantage of multiple access to the data to discover things that would remain unseen from a singular approach (Flick, 2004; Polit & Beck, 2021). In this section, I elaborate and critically reflect upon how these conceptual frameworks relate to one another, why the perspectives were productive and how they supplement and differ from one another.

Yet, before doing so, it is necessary to address how my situatedness as a nurse has influenced the establishment of the conceptual framework. My approach to studying what healthcare professionals write about dying and death in the EPR originated from my background in nursing practice and research. Smith (2013) stated that nursing research differs from other academic disciplines in its relation to theories, because in addition to the traditional academic knowledge base, nursing research also aims at both improving nursing practices and developing knowledge about the phenomenon, which is of concern to the discipline (p. 4). Hence, it is a feature of nursing research to use theoretical aspects pragmatically and in close deliberation with the empirical data, rather than staying loyal to a specific academic discipline. The theories that constitute the framework in this study originate from three traditions, but by using them as conceptual lenses to analyse the EPR, they complement each other and contribute to the development of new insights which, I hope, influence the field of nursing and, more broadly, health humanities research.

Having said that, how do the conceptual lines of enquiry relate to, challenge and support each other in this study? What have I been able to write that I could not have done without them? To start with, viewing the EPR as an active contributor to the practices of nurses and physicians rather than a passive source of information has been a cornerstone of this project. Language, including the language of the EPR, is a form of social interaction. At the core of Bakhtinian thinking is a recognition of a dialogical universe between the 'I' and 'you' permeating human interaction (Andersen, 2002, p. 34). In this dialogical universe, our words exist in an ongoing interplay shaped by what has already been said and what is expected to be said about a topic. Andersen quotes Bakhtin: 'The word is a two-sided act. It is decided both by the one who has the word and by to whom it is addressed. The word is a shared mutual ground between the sender and the recipient, for the speaker and his addressee' (Andersen, 2002, p. 35 [my translation]). Thus, Bakhtin put forward an understanding of language as reflexive, purposive, responsive and sensitive towards the person who states the words and the person *who is addressed by the words*. However, such qualities can 'work' only when they are part of a space or context shared with 'an addressee' for the words to have meaning at all.

Approaching the EPRs as a dialogue permitted analysing them as being filled with intentions and purpose rather than as passive containers of information about past events (Prior, 2003) – as permeated with power, tensions, voices, positions, propositions and views. Still, by having established this as a base for the project, I experienced that, even though I was shedding light on the dialogical aspects of the text, I needed to gain a deeper insight into the ways in which dying and death were attended. Although the dialogical perspective was useful to get a sense of the text, I needed concepts that would enable a more nuanced and detailed understanding. The question thus was whether there would be ways to supplement this perspective to provide insights into these similarly essential aspects of the EPR. This work took on two directions, namely SFL and STS.

SFL recognises texts as 'the process of making meaning in context' (Halliday, 2015, p. 3). In its core, SFL is a systemic approach to language, where language is proposed as 'a network of connected choices' recognising that the words we use are relevant to the meanings that are realised (Maagerø, 2005, p. 22). So, each time we choose one way to put our experience into words, it is at the cost of another way of saying the same thing. This view of the use of language has helped to unpack the negotiations in the turning points at a micro-level to get a better understanding of how these decisions are composed and what this composition can tell us. So, in the first study, when investigating the decisions to move from curative to palliative treatment, the SFL approach allowed for an investigation of the text at a micro-level by proposing a way to analyse the very selection of words on the sentence level, based on the perception that we always have a purpose or intention with what we do/say/write (Maagerø, 2005). Doing this enabled an understanding of the texts as active choices made by the writer to pass on selected information that also allows for an elaboration of what was said and what went missing or was omitted in the specific choice of words to denote the turning point. This analysis thus also implicitly pointed to the possibilities of events being worded differently.

These two linguistic approaches (Bakhtin and SFL) allowed thinking of the *texts* as the *subject matter* in itself. This conceptual lens is anchored in what is (not) written as being shaped into the

particular EPR genre. However, by working with the data, I started to see the texts as consisting of something more, that they are also infused by what appeared as contextual matters. In this work, I chose to implement elements of science and technology studies to understand the order and logic of the EPRs. I looked at how the texts were structured, and how this structuring would propose specific ordering of what matters when documenting dying and death in a hospital setting, at the cost of other possible orderings. Just like the choice of specific words, here too things could have been otherwise. Accessing the texts for how they would contribute to conceptualizing dying and death, I could show how the texts of the EPR quite consistently made dying and death appear as neat, undramatic, manageable and neutral, and as removed from the drama, the urgency, and the distress of dying and death. Like this, the EPR renderings of dying and death largely contributed to the rationale of the hospitals' curative order, but there were still only very small openings created by staff to document the breadth of the encounters when they cared for such patients or for other aspects of 'palliative care' to enter.

So, in this section, I have attempted to make an overarching connection between the selected concepts and how they are operationalised on different levels of the text, highly influenced by my situatedness as a nurse with the strength and limitations this implies. Consequently, with all these aspects and conditions in play, there is an acknowledgement that this endeavour could have been solved differently.

III. Methods

In this section, I present how this project was conducted. The goal is to describe what and why things have been done during the project. Hence, writing this section encompasses putting together the bits and pieces that make up this project. It is about making transparent the reflections and choices handled along the way, thereby making sense of how the study was conducted and how I ended up where I did.

It is a core criterion for scientific knowledge to be systematic and critical. In addition, it must be apparent how the data, reflections, interpretations and conclusions are included in the larger context in which the researcher has positioned the project (Malterud, 2017, p. 17). It is also a clear expectation that the researcher approaches the project with an open mind, prepared to investigate all aspects, and not only those who confirm the researcher's preconception (Malterud, 2017, p. 19). So, my aim is to be transparent with the construction of the project by elaborating on how I have been working with the conceptual frameworks and methodology and analysis to render visible the road from an outline to a completed work. The section focuses on the bits and pieces that have contributed significantly to the research process, guided by the relevant research literature.

Figure 1

The progression of the study that connotes to main headings in the following text: planning, data collection, systematising the material and analytical writing.
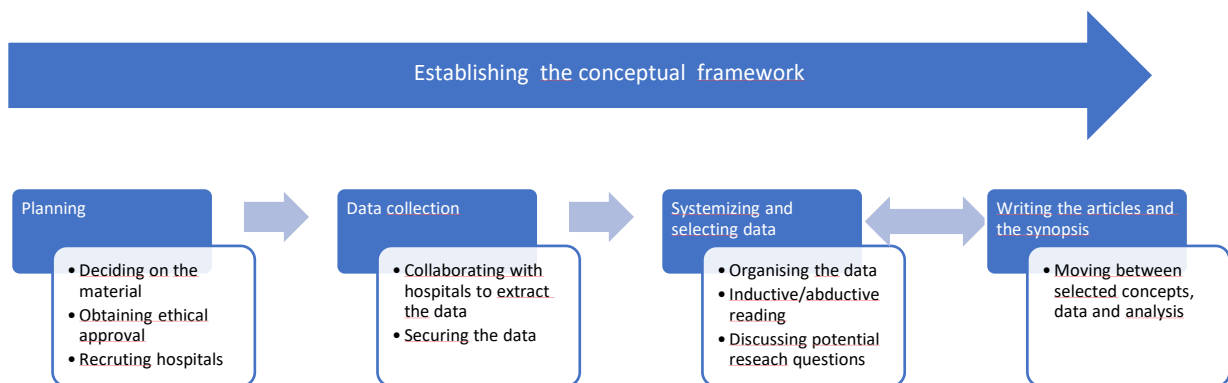
Planning

Unlike other qualitative research approaches, such as interviews and ethnographic fieldwork, the literature explaining the best way to move forward to prepare for a document analysis is limited. Besides the obvious ethical considerations to secure anonymity, I based my choices on prior experience from the work with my master's thesis on EPR texts (Hov, 2014) and relevant literature from research on medical records and caring for dying patients in a curative context. In the following, I explain how this work moved along.

I aimed to make certain that we collected material rich enough to ensure necessary strength. To my knowledge, the content of the EPR is relatively stable and similar across hospitals and wards, and this is also confirmed by research on the medical record (Class, 2014; Poirier, 2004; Pomata, 2014; Risse & Warner, 1992). Consequently, I set out to collect between 50 and 60 EPRs from four hospitals, thereby aiming for purposive sampling to compose sufficient data to enlighten the research question in the best possible way (Malterud, 2017, p. 58). Based on my experience with the master's thesis on a related topic (Hov, 2014), I planned to include EPRs from four medium-sized hospitals that had 3 or 4 different medical wards each.

The EPRs are often extensive documents, containing information from numerous hospitalisations over several years. However, it was not necessary for me to access the complete record. Hence, in deliberation with the supervisors, I set a time window from which the extract would be drawn. This was likeliest to contain the knowledge I sought. Due to the sensitivity of the material, it was also imperative that I did not get access to more information than was strictly needed to answer my research question. This made it crucial to delimit the excerpt period, yet the time window had to be extensive enough to get an understanding of the course of events leading up to death. Previous research on documentation of dying in hospitals paired with my own experience suggested that most patients are not diagnosed as dying until shortly before death (Kaufman, 2010; Kennedy et al., 2014). Hence, I used this presumption in the decision to settle on the length of the

excerpts, and I chose to set the time window of each excerpt to include documentation written in the last three or four days of the patient's life.

Another aspect of what data to include in the project was to assess whether the EPR text alone would be a sufficient source of information to address for a satisfactory enlightening of the research question. So, for a long time, we deliberated on the idea of supplementing the data with interviews with healthcare professionals. Over time, after gaining deeper insight into the collected material, I realised that the 42 EPRs were rich enough to answer the overarching research question. So, in deliberation with my supervisors, I decided not to conduct interviews.

Data collection

A total of 11 hospitals were approached about taking part in the study. Some of them rejected participation straight away, while others rejected participation after assessing the project. I was told that they rejected participation either because they did not have time to participate or because they were in the midst of reorganisation. One hospital promised to respond with a final decision that did not happen. In the end, three hospitals agreed to take part in the project.

To access the data from the participating hospitals, we needed to establish a connection to a person at each hospital with access to the EPR system. In two of the three participating hospitals, the hospital administration appointed a person to be our contact. When planning for the data extraction in the final hospital, I was told by the administration that they could not spare a person to retrieve the records. However, I was informed that if I could find a person employed at the hospital that met their approval, they would allow that person to extract records from the EPR system. So, in deliberation with the supervisors, we enquired about persons in our circle of acquaintances who met the hospitals' demands. We recruited a person who had a part-time position at the medical ward whom the hospital also accepted.

Before the extraction of data started, I arranged for one meeting where I explained the inclusion criteria to ensure that there was no miscommunication about what I needed. I held another meeting when collecting the dataset. The contacts were asked to start searching for the most recent

deaths that met the criteria for inclusion, and they confirmed that they were familiar with how to execute such searches in the documentation system. It was essential for the project to gather data without having any influence besides the inclusion criteria on which records were selected. Thus, I had no communication with the contacts between the first meeting and when I personally met them to collect the data when the extractions were finished.

At two hospitals, the data were anonymised. In the third hospital, the process became more problematic in an unforeseen way. The first two contacts had offices suited to handle sensitive data, but the third had difficulty getting access to a separate office to execute the extraction and anonymisation. In this case, the contact kept me informed of the difficulties. Since the problem persisted, the extraction ended after gaining access to 4 of the 20 EPRs I had hoped to get. We never spoke about topics related to the content of the EPRs.

As a guideline for the contacts, I established the following criteria for inclusion: age above eighteen, securing a gender balance, information about where the patient was admitted, death had to be documented as expected in the EPR, and preferably, the patient should have been staying at the same ward for the whole excerpt period (3–4 days). In addition, the contact at the hospitals was encouraged to extend this time window in their selection of EPRs if it made the excerpt more informative (e.g. if the patient were admitted five days prior to dying, the excerpt was extended to the whole admission period).

When I received the material, there was a slight deviation between the data that I requested and the data provided. In the data provided, all the subjects were above 18 as requested, but regarding gender balance, the distribution of EPRs was 18 women and 24 men. Since gender did not become a topic for further investigation, I decided that the imbalance was acceptable. Also, I asked for excerpts from the patients last 3–4 days, but 11 of the extracts comprised the documentation from the patients last 5 days of life, and two from the patients last 6 days.

In two cases, there had been attempts to resuscitate the patients, but a decision to cease the attempt was made shortly after resuscitation was initiated. In addition, the patients were not given invasive respiratory support. Since the physician still concluded with death being expected in the case summary, I chose to include these data as well.

Another deviation was that 13 of the 42 patients were transferred to the ICU in the days prior to their death, and most of these 11 patients were re-transferred to a medical ward before death. It appeared that two patients died in the ICU, which I address belove under 'Deviation from the Criteria for Inclusion'.

Describing the Data

The data were in their original form, electronic files in the distributed information and patient data system (DIPS, 2021c), which all the included hospitals used. However, to access them, the data were printed out so the contacts could anonymise them using black markers. In hard copy, the EPRs amounted to approximately one thousand A4 pages, but not all pages were full of text. The data contained 961 notes written mainly by nurses and physicians. Occasionally, other groups of healthcare professionals, such as physiotherapists, nutritionists and occupational therapists, provided documents.

From the outset of the study, I planned to use all documentation about dying and death, independent of professional affiliation. Hence, documentation from nutritionists, physiotherapists, and occupational therapists was also read and systemised, but as the patient approached death, according to the EPR, these professions seemed to withdraw their work with the patient. Consequently, their documentation did not contribute to any information about the patients' dying and death, so it was not a part of the analysis.

On average, each EPR extract extended over approximately four days and contained six to eight notes written by physicians and 13 or 14 notes written by nurses. 37 of the patients were above 65 at the time of death, with a peak in the age group of 81–85, which coincides with average life

expectancy in Norway. Fourteen patients died without being diagnosed as dying, and the hospital chaplain was referred to in 5 of the 42 EPRs.

As one of the criteria for inclusion, I was interested in all the documentation made in the excerpt period. However, in the process of transforming documents from electronic files to paper print, they were sorted chronologically (based on when the document was opened in the filing system) and not by the healthcare profession. This deviated from how the healthcare professionals see the EPR in their clinical practice, because in the journal system (DIPS), where they mainly access the documentation written by their fellow professionals, they must click their way into the documentation of other professions.

In addition, according to the nurse standard for documentation, the structure of the documentation must be anchored in the nursing process, which is a problem-solving, interpersonal, and interactional process (NSF, 2007). This is to ensure structure in the retrieval of information, establishing nursing diagnosis, planning and carrying out nursing actions and assessment (NSF, 2007, p. 7). Concurring with the development of evidence-based medicine in nursing documentation, there is also an increased focus on using coding systems to ensure that treatment and care are according to standards (NSF, 2021). So, shortly after the patients are admitted to the hospital, nurses are instructed to create a care plan in the EPR system. Also, this care plan is written into a pre-made structure where the nurse selects the relevant information connected to the nursing process.

Although it is an interesting aspect of nursing documentation, because of limitations in the software, it was possible for me to access the complete nursing plan in only the few cases where I had accessed the whole hospital stay or to the parts of the care plan where changes were made in the last days that I could access. It is hard to assess what I have lost by not having complete access to patients' care plans. However, the care plans I *did* have access to did not inform any of the analysis in the three articles since the content of the information in the care plan did not reveal knowledge I perceived relevant to the research questions I aimed to answer.

Systematising the Data

Documents are a unique source of information because they are produced without the intervention of the researcher (Silverman, 2014). This sets an interesting but demanding starting point regarding not being part of the data production. Another relevant aspect is that these texts are written with a specific purpose into a digital structure construed to be operationalised in specific ways, probably because of the predetermination of content, rigid structure and a lack of intervention that made me struggle with finding the 'right' way to approach the material. It felt like approaching a wall of impenetrable words. Hours were spent mapping out all bits and pieces of the text to gain an overview of the data. My first impression was that dying and death were difficult to discover. Hence, after some time, I started to gather what I perceived as somewhat relevant information about dying and death into an Excel spreadsheet. Here, I established categories that I perceived at the time to be relevant to discovering patterns in the text. The categories were as follows:

- If a decision to end curative or life-prolonging treatment was documented

- If the patient received palliative care

- If the patient was conscious

- If a decision to resuscitate was made

Also, I noted the keywords from each case that informed me of the course of the events or that caught my attention in any way.

As a part of this process, I also provided each EPR with a code in which the first number represented the number that our contact at the hospital gave, and the second number represented the total number of EPRs from each hospital. I had 18 EPRs from one hospital, 20 from another, and 4 EPRs from the last hospital (e.g., the number 0118 would then represent the first EPR from the hospital that had provided us with 18 EPRs, and so on). This system made it easy for me to trace the extracts back to their origin.

As I was still not sure about how best to work with the data, I started to work with the differences and similarities in the documentation by nurses and physicians. One distinct difference between documentation by nurses and physicians is that the physician's notes are called 'journal notes' by the software, and they do not have predetermined templates, while the nurses' notes are referred to as 'shift notes', and they are connected to 12 predefined functional areas (see Table 1.), where the nurse selects the functional area they find relevant to the content of their documentation.

Table 1. Functional areas in nurse shift notes	
1. Communication/senses	7. Activity/functional status
2. Knowledge/development/mental	8. Pain/sleep/well-being
3. Respiration/circulation	9. Sexuality/reproduction
4. Nutrition/fluids/electrolyte balance	10. Social/discharge planning
5. Elimination	11. Spiritual/cultural/lifestyle
6. Skin/tissue/sore	12. Other/doctor-delegated tasks

In this work, I created an additional Excel spreadsheet where I mapped out who authored the notes (professional affiliation), what kind of note/template was used (and if a nurse's note; which functional area was the documentation related to), if the patient or family was offered to talk with the hospital chaplain, whether the patient was transferred to the ICU during the excerpt period, and a column for phrases, which I found imperative for addressing the overarching research question.

Analytical Writing: Getting Lost and Finding a Way

The multidisciplinarity of the supervisory team was essential to how I worked with the text and for the selection of theories and analytical methods. Together with the supervisors I tried out different analytical approaches mentioned in the section about the conceptual framework before I could make a path that seemed to work.

When the material was mapped out, the initial plan was to use the overall description of the text as a topic for the first article. However, after the midterm evaluation, I was questioned about what new knowledge would be provided, other than showing the (low) frequency of documentation of dying and death. Agreeing to this, I started exploring other ways to work with the data, and after some time, I realised that the key to accessing the full complexity of the data lay in delimitation. That is, I had to set limits on the material and use the articles to enlighten different aspects of the documentation. My overall impression at this point was that there was little information about dying and death in the texts, but there was some. So, I started to work with the text that contained information about death and dying and worked my way from there.

The most obvious place in the text where death was a topic was in what I referred to in article one as the turning point note – the transition from curative to palliative treatment. In these deliberations, it is life that is at stake and the physician's realisation that death is likeliest to happen, no matter what actions are taken. I found a turning point note in 16 of the 42 EPRs. Focusing on these notes delimited the material considerably and reduced the amount of text to analyse from several hundred pages to 10–15. This reduction of text material allowed for a more precise text analytic tool kit. Through my work with Guri Aarseth, who became co-author of the first article, I became familiar with the works of Halliday. Halliday's theory of functional grammar made sense and enabled me to capture and explore what occurred in the sentences in which the course of treatment was changed. Soon, I experienced the text differently because I noticed all the reservations, uncertainties, and deliberation that the turning point notes contained, and I chose to use these textual reservation strategies as our entry point to these notes. Thus, I chose an analytical approach inspired by Halliday's functional grammar (Halliday, 2013; Maagerø, 2005) supplemented by the works of Martin and White (2007) and Martin and Rose (2003).

In the process of working with the first study, I became more skilled in exploring the text in depth. Besides considering what is there, I began to reflect on how documenting in specific ways also revealed something about a frame of reference that may provide knowledge about the professional's

orientation. Through this work, I became attentive to three consistent frames of reference in the text: time, numbers and categories. Covered in presumptions from my previous work as a nurse, it was essential for me to investigate these frames of reference with an open mind. Also, I had Bernike Pasveer as a co-supervisor, and her extensive research and knowledge of STS became a source of inspiration for me to try approaching texts inspired by ethnography and STS. Bernike Pasveer introduced me to the works of Law (1994), and I soon became very engaged with the notion of organisational patterns as performative and started to elaborate on how time, numbers and categories proposed patterns loyal to doing the organisation. Again, to ensure that the material I analysed was related to dying, I chose to delimit the information for the analysis to the text written in the last 24 hours of life for all the included EPRs. The discharge summaries concluded all the deaths as expected, although they were not recognised by the healthcare professionals prior to the death. This meant that dying was occurring although it was not identified by the healthcare professionals.

The first two articles revolved around the textual practices in the documentation in the days and hours leading up to the time of death. So far, I had not worked with death itself as it occurs in the EPR. Given that I, from the starting point, had an interest in how both dying and death were documented, it made sense to thematise death in the third article. From the outset, I thought it interesting to explore how the moment of death was documented since it often seemed to transgress the established ways of writing. In this work, I expanded on my initial approach and found it fruitful to investigate the EPRs as genres – understood as spheres of communication that govern what utterances are made and how they are made (Bakhtin, 1998).

Research Ethics

The research ethics in this project are complicated. I recognise that the dying patient is vulnerable and that the EPRs are sensitive data. Here, I will argue how I have conducted a responsible investigation of the medical records.

A debatable feature of this project is the absence of consent from the patients that their EPR could be used for research after their death, since I did not ask the families' permission. The requirement for consent is highly valued in research ethics, and it is an important principle for securing individual protection (Ruyter, 2003; Silverman, 2014). Concurrently, it should not 'prevent important research on vulnerable groups' (Ruyter, 2003, p. 129). My reason for not asking for consent is anchored in the construction of the study of not being interested in singular cases, but rather the dominating features of the text as an entirety and not the person behind the text. Hence, each individual was protected by making their data anonymous, which I believe was in line with good research ethics. However, it is debatable whether the patient's family could have been asked for permission, and that could have been a good alternative.

The project was assessed by the Regional Ethics Committee, where I asked for an exemption from consent. The committee wrote in their assessment (2016/2035 [my translation]):

> A fundamental ethical principle that is expressed through the demand for consent for the release and treatment of healthcare information is the right to decide over the use of the information in research. The main rule is that consent can be abandoned only if the public utility is great and the consideration of the participants' welfare and integrity is protected. In the committee's view, this project has sufficient public utility to be carried out as described in the application and protocol, and the protection of the participants seems taken care of by the records being anonymised prior to delivery to the researcher. Based on this, the committee has reached the decision that health information may be collected and anonymised prior to delivery to the project.

According to the anonymisation of record data, I used the guidelines of the Data Inspectorates (Datatilsynet, 2015). Following the guidelines, I observed that the anonymisation is taken care of by ensuring that the information I have access to is not possible to attach to an individual person. To ensure this, I asked for the following information to be removed before I gained access:

- Birth number

- All proper names (patients/family name, name of institutions, healthcare professionals' name, name of the employer),

- Place of living (address, municipality)

- Diagnostic code

- Name of ward where the patient was admitted.

- All dates

It is difficult to assess the delineation for re-identification of the patients, but as I have interpreted the inspectorate guideline (Datatilsynet, 2015), general information about the patient's course of the disease and documentation of the patients' medical condition connected with underlying disease is not a risk for reidentification and thus need not be removed. In addition, the project was approved by the data protection officer at two of the three hospitals. The third hospital agreed to participate after assessing the protocol in a hospital board meeting.

Adding to the medical record, I also asked for the following information:

- Age (to reduce the risk of reidentification) was reported in 5-year intervals.

- Information on whether the patient was admitted from home or another institution.

- Gender.

I also requested that our contact exclude EPRs that belonged to patients with either rare diseases or a public position that could induce a possible risk of reidentification.

After receiving the anonymised data in paper form from our contacts at the hospitals, they were scanned and stored in the VID server, according to guidelines. Also, I have sole access to the electronically stored material. In my work with the articles, I extracted and coded the extracts from the data. The material was coded by combining two numbers. The first number represented the chronology in which I received the material from the hospital, and the second number represented the hospital. In the published articles, these numbers were re-recoded so that it is not possible for others to deduce which records came from the same hospital. In addition, I chose to recode the data

differently in each article so that it was not possible to puzzle the pieces together by considering examples from the three articles. Hence, I felt confident that no one could reveal the identity of any patient. In addition, if in the worst case someone could suspect they knew to whom the text belonged, I could not confirm this because the EPRs were anonymised to me as well.

Credibility

A generic feature of qualitative research is that the findings, results or reflections are judgement dependent. Thus, they are always exposed to a suspicion that the researcher could have adjusted their arguments according to their own biases or predispositions (Patton, 2014). The literature on research ethics has specified that well-known research terms like reliability and validity are interpreted differently in assessing the value of qualitative research (Corbin & Strauss, 2014). Some qualitative researchers have thus argued for the use of the alternative concept of credibility (Corbin & Strauss, 2014). I will discuss methodological limitations and strengths, advantages, and disadvantages relevant to this project by applying this concept of credibility.

Credibility in qualitative research implies that 'the research is trustworthy and believable in that they reflect participants, researchers, and readers' experience with phenomena; concurrently, the explanation the theory provides is only one of many possible plausible interpretations from data' (Corbin & Strauss, 2014, p. 346). So, trustworthiness in this project implies being accurate in all aspects of the research process. This means that every step from planning and gathering the data to publishing the articles and synopses follow a reasoning where the connected dots make sense.

Richness of Data

In qualitative research, sample sizes are characterised by purposeful strategies rather than inflexible rules (Patton, 2015, p. 311), and in general, sample sizes are based on informational needs in the specific case (Polit & Beck, 2021, p. 502). However, a guiding principle commonly used is the notion of saturation of data, which denotes the point in the sampling process where new information is not obtained. Yet, the notion of saturation has been criticised for both creating an idea of an objective point at which further information is redundant and implying that only a certain amount of

data are needed to fully understand the field of investigation (Malterud, 2017, p. 65). Instead, Malterud suggests aiming for sufficient *information power* to answer the research question. I see both notions, saturation and information power, as relevant to how I have approached the work to secure sufficient richness of data, and my own role as a researcher interpreting the data being crucial in deciding when enough data were gathered. In what follows, I describe and discuss how I worked with this aspect of the study.

In terms of securing sufficient richness of data, I have worked from the overarching goal to have enough data to generate in-depth knowledge to elucidate patterns in and develop understandings from the EPR texts (Malterud, 2017; Patton, 2015; Polit & Beck, 2021,). I started out with a targeted sample size of 50-60 EPRs, a number which was based mainly on my own prior work with records, but also the time and funding available.

The EPRs were collected in a period of some months in the spring of 2017, and the work to assess the sufficiency of data started immediately after receiving the records from the first hospital. This data inclusion period allowed me to start systematising, mapping, and executing a preliminary analysis. When I received the data from the second hospital and gained an overview, I was surprised to discover how similar the EPRs were in terms of content. It seemed as if there were established ways to document dying and death. Even though I spent an enormous amount of time with the records, I could not distinguish through the documentation which records belonged to which hospital in terms of how the healthcare professionals documented the last days of the patient's life. The words and phrases used for dying and death across hospitals and wards appeared to be homogenous in the preliminary analysis of the dataset. Moreover, the variations appeared to be related to structural differences in how the hospital or the EPR was organised, and not the textual practices themselves. For example, one hospital appeared to have a palliative team, so the team was mentioned and documented in some of the EPRs from that hospital. In another hospital, the physicians opened the case summary document almost always in the first 24 hours after the patient had been admitted, so it was often one of the first documents in the EPR when printed out in

chronological order. These minor variations did not come across as crucial for assessing information power or saturation. So, when the difficulties extracting data from the third hospital surfaced, I deliberated with my supervisors, and we decided that a point had been reached where the richness of data was adequate to answer the overarching research question satisfactorily.

Deviation from the Criteria for Inclusion

The selected records did, in some ways, deviate from the criteria for inclusion I had developed. This was especially true about the criterion that the patient should stay in the same medical ward throughout the excerpt period. In the material I received, 13 of the 42 patients were transferred to the ICU in the days leading up to their death. To preserve the 'richness' of data, I chose not to exclude these materials. But why did I include them and how has this affected my results?

First, I do not know why so many of the records contained cases where the patient was transferred to the ICU since I specifically asked for such records to be excluded. What I do know is that the conclusion that 13 patients were transferred to the ICU was based on my reading and interpretation of the texts, because I did not have access to specific documentation about the ward(s) where the patients were admitted. Rather, 'transfer to ICU' emerged from working with the data, noticing that some patients were moved to an ICU. It varied from record to record how clearly this was documented, but in several cases I had spent a lot of time reading and systematising the text before realising that the patient had been transferred to another department. So, an event that would have a clear demarcation line in the workings of the hospital did not manifest itself clearly in the text of the EPR. In some cases, the EPR contained a transfer note. In other cases, the transfer was apparent from references made in the text, such as the use of non-invasive respiration support. This is not traditionally offered at general medical wards. This probably indicated that the patient had been moved to another department. Even less clear was any transfer back to the medical ward, which in several cases was proposed by the physician in the journal note as a necessary measure, but not articulated otherwise.

So, this issue of 'transferral' became part of my data rather than a criterion to exclude these EPRs altogether: apparently transfers were not very prominent in ordering and selecting what professionals chose to jot down in the EPRs. In addition, whether transferred or not, all texts contained the same distinctive features of prolonged curative attention and an underarticulation of the many complexities of dying and death in a curative context. So, given the qualitative and explorative nature of this project, where new insights emerged throughout the process of working with the data, my assessment was that, rather than treating records of the patients who appeared to have been transferred to ICU (and back) as deviations, they would need to be treated as data – and the (vaguely documented) transfers as contributing to the findings of this study. After all, these data also provided insight into the constant negotiations and insecurities of curative versus palliative care that occurs around the patient, often up until the very moment of death.

Situatedness of Knowledge

Haraway (1988) calls for an awareness of the researcher's own situatedness in the development of knowledge. The reason for doing so is the problematic notion of objectivity that holds a high position in research as a gold standard for assessing the quality of research. Throughout the history of science, the notion of objectivity has been used as a way to authorise knowledge by suggesting that objectivity is necessary for trustworthiness. However, this is problematic because, in essence, all knowledge is situated (Haraway, 1988); it is a product of the researcher with all that it entails.

As a nurse with work experience from medical wards and documenting in the EPR, this project started off from a deep unease about how and what was documented about dying patients, and this problem forms the very starting point of this study. But this unease did not come from nowhere: it was connected to and fed by studies like those by Glaser and Strauss (1968), Kaufmann (2005) and Chapple (2010) together with my own experience and the paradigm of palliative care. All of them point to the problematic nature of dying in a curative context. My own position, however, tended to be not only inquisitive but also very normative in that I tended to be looking for

confirmation of my suspicion that dying and death were underattended in medical wards, at the expense of proper care to the dying patients' and their families' non-curative needs. My conceptual framework, as well as frequent deliberations with the supervisory team, forced me to distance myself from this preoccupation and look closely at the various performativities of the EPR texts. My finding – that the texts contributed to hospitals' curative rather than also employing a palliative logic to deal with dying and death – are still in line with my unease. I can now pinpoint very precisely how the texts do this ordering and, given the assertion that texts not only represent but also order, I can now also suggest that 'things might be otherwise'.

Transferability

What does this limited set of data – a small albeit saturated set of EPRs from three Norwegian hospitals – imply for the transferability of the results of this study? How are they relevant beyond the immediate contexts of the data? According to Guba and Lincoln (1985, p. 124), the notion of transferability is relevant when assessing whether findings of one study are applicable to other contexts. Thus, they define transferability as 'the degree of congruence' between the context in which a study is conducted and the contexts to which it wants to contribute (p. 124). So, to ensure the transferability of a qualitative study, it is the researcher's essential responsibility to provide enough descriptive information and a thorough elaboration on the conditions and limitations of the findings for others to assess their relevance for other, similar contexts (Polit & Beck, 2021, Malterud, 2017).

I will argue that the results of this study are appropriate in other settings. This is based on the process of extracting the EPRs as detached from the specifics of these hospitals and the saturation that suggests similar findings if more data were added. Also, the findings, although specific in how they have been produced, quite solidly fit with what we know about dying in hospitals from other studies. I would expect comparable results to appear from data from other hospitals if analysed in a similar way.

Translation

English is the chosen language for the project, and the EPRs are written in Norwegian. This implies that nuances in meaning might be lost, and new meanings that I might not be aware of could be added through the translation of the extracts. In trying to secure the translations, they were discussed in the supervisory team and with other colleagues. In cases of uncertainty, I investigated other research articles to see what words they used. This issue was especially prominent in cases of work-related to phrases like 'tilsyn', 'fastvakt' and 'ukontaktbar', and when translating words that seemed to contain plural meanings like the Norwegian term 'uro', which, in English, can mean uneasy or anxious. Other examples were euphemisms like 'sovne stille inn', which were translated to 'sleep in'. Probably 'sovne stille inn' could be juxtaposed with the commonly used 'passed away' in English (Rawlings et al., 2017), but I found the connotation of sleep to be a relevant finding; thus, I chose not to use 'pass away'.

In working with the articles, in the cases where several words could be used in the translation to English, I have elaborated on why I have selected the word of choice, thus trying to be as transparent about this as possible.

Being Touched by the Texts and Keeping a Distance: Reflexivity

In this section, I consider the emotions the work with the text and the details aroused for me and some of the challenges I faced in working with the EPRs. A reflection on how working with dying and death in research may influence the researcher, as has been thematised in several studies, is important to be aware of in the research process (Hockey, 2007; Valentine, 2007; Woodthorpe, 2009). As a novice researcher, I was not prepared for the emotional reaction triggered by reading the EPRs. At one point, these emotions became overwhelming and made it difficult to work with the material without feeling emotionally affected. Thus, in retrospect, I find it relevant to explore what that meant for the project – not with the intention to self-indulge but rather to explore the challenges that my emotions created and the potential depth they can add to the research experience (Woodthorpe, 2009).

As mentioned in the introduction, witnessing dying and death was not new to me. Through my work as a nurse in various medical wards caring for severely ill and dying patients, death is something I have encountered several times. Over the years, I have learnt how to handle these meetings in a professional manner. Yet, as a newly educated nurse, I remember this as hard work that led to many sleepless nights imprinted by feelings that fluctuated between feeling empathic towards the patient and family and the breath-taking feeling of death within proximity activating my fear of death of someone close to me or myself.

The initial work with the texts triggered a similar process in me. At some point, I was completely stunned and could work with the text only for short periods at the time. I still wonder why this reaction was so strong. In retrospect, the explanation that I find most likely was that in the initial phase of the project, I read the text as what actually happened and not as textual practices developed over time to serve a specific purpose. Hence, I was struck by the lack of care and compassion and the handling of the patients as objects without any regard for the individual patient. Now, having worked out how I can cope with the texts, I notice that the reflections and emotional distress that the texts inflicted have contributed to a cultivated sensitivity towards the text. They have created a sensitivity for the gaps and cracks and ways where empathy for the patient and situation seep in, because, at first glance, these aspects of the text were tough to spot.

To me, this emotional infliction was induced when, through the texts, I met my own mortality: these words or something like them may very well be written about me some day. Also, as Hockey (2007) stated, 'As mortal beings, researchers in the area of death and dying live with the knowledge of retrospective or prospective experience of bereavement' (p. 444). I believe that acknowledging my own mortality and bereavement history contributes to and is essential in comprehending what is at stake for the patients and the family in the text, as well as the healthcare professionals. Thus, I argue that this positioning makes me more sensitive to nuances and details in the text, and it enhances my understanding and reflections on the data. Both on behalf of the patient, by feeling empathic towards their situation as dying, but also sensing the potential

conflicting interests and compassion in the groups of healthcare professionals, their good intentions,

lack of time and resources, and sometimes helplessness when arriving at the point where there is no

cure. This experience of reflexivity called forth a need to approach the data in a way that to me feels

ethically and methodologically acceptable (Valentine, 2007, p. 174).

IV. Results

The study led to the production of three articles. Each one is based on the work done for this study, and they are described and discussed in this summary. The articles contribute to the field of palliative care and end-of-life care and EPR studies in different ways. The first paper presented a detailed analysis of the language in play when curative treatment is stopped, while the second and third papers investigated patterns of documentation from the perspective of STS (second article) and genre analysis of the transition to death (third article). Against this background, the overall question asked in this study is: What kinds of textual practices of dying and death in medical wards are present in the EPR, and what do these practices achieve?

Summary of Articles

While the articles discuss different aspects of documentation, they are also closely interrelated. They are joined together by the shared focus on the texts' capacity to contribute to passing on specific kinds of knowledge, and how the textual practices both on the sentence level and in the orientation to specific topics mould the knowledge that the text passes on. The various conceptual approaches have enabled me to investigate and analyse different aspects of the texts.

Study One: Negotiating the Turning Point in the Transition from Curative to Palliative Treatment: A Linguistic Analysis of Medical Records of Dying Patients

The first paper in the project was published in *BMC Palliative Care* in June 2020 (Hov et al., 2020a). Since many patients die in a hospital environment (Folkehelseinstituttet, 2021), I wanted to explore the textual practices in how healthcare professionals in general medical wards document the decision to move from a curative to a palliative trajectory. Thus, this paper aimed to investigate how the textual practices that argue for a shift from curative to palliative treatment and how the textual representation of these turning points involve different voices and viewpoints.

The analytical approach in this study has its origin in Bakhtin's concept of dialogical language and Halliday's functional linguistics (Halliday, 2013; Maagerø, 2005), supplemented by Martin and White's language of evaluation (Martin & Rose, 2003; Martin & White, 2007). The empirical data

comprised all documented turning point decisions in the material, in which made-up extracts from 16 of the 42 EPRs.

The 16 turning point notes were analysed word by word, and through this process, we became attentive to how the text usually shifts from statements about the patient's clinical status and technical findings to displaying uncertainty and openness to negotiation with different textual voices. We subsumed these patterns under the following themes: 1) positioning of the textual voice, 2) representation of external voices, and 3) subtle traces of disagreement and differing perspectives between the professionals. Using these themes, we could enlighten how the turning point notes revolve around practicalities and harmonisation of the participants rather than the patients' experience and quality of the end of their lives. Thus, when an EPR text proposed a transition to palliative care, the turning-point argumentation primarily revolved around practicalities and the need to harmonise and align the participants in the text. Thus, we believe that relevant information about the patient's experience and quality of life in the last days was lost. A text containing more nuanced descriptions of events could contribute more knowledge about the individual patient, so it would be easier for colleagues to be aware of the individual patient's needs.

Study two: Modes of Dying in the Electronic Patient Record

The second paper was published in *Mortality* in December 2020 (Hov et al., 2020b). Spending time reading and rereading the texts made me ponder some textual practices and textual viewpoints that seemed to point not to the obvious passing of knowledge about the patient but rather about the organisation and its infrastructure. The objective then became to explore what the EPR contributes to the ordering of things that occur around the dying in a busy medical ward. We analysed all documentation written in the last 24 hours of the patients' lives. Through this work, we articulated what we saw as three hegemonic modes of ordering in the EPR. We called them numbering, timing and classifying. Our core argument here is that these orderings perform a dominant narrative that is loyal to heroic curative medicine. In this way, dying seems to be sequestered and made subordinate – even invisible. One prominent feature is how frequent references to time pass on knowledge about

the value of time in terms of time to be near, time to die, not being there on time, the distribution of the healthcare workers' time, and so on. Equally, the frequent use of numbers and classifications in the EPR text was geared to passing on knowledge efficiently, where the human body and life are reduced to the functioning of organs and/or the number of activities done to the patient. Yet, between the efficiency and lack of time, we also found traces of, and attempts at, compassion, engagement and attentive palliative care.

Study three: Nobody Dies Alone in the Electronic Patient Record – A Qualitative Analysis of the Textual Practices of Documenting Dying and Death

The third paper was published in *OMEGA – Journal of Death and Dying* in May 2021 (Hov et al., 2021). In the overarching research question, we aimed to investigate documentation about dying and death, and having written two articles on dying in the EPR, the time had come for the documentation of death. We had noted the frequent use of euphemisms in documenting the moment of death from the initial readings in which we were interested in getting a deeper understanding of this textual practice. So, by approaching the documentation of the moment of death, we chose to do so by analysing this part of the EPR using the concept of genre as a point of departure. We wanted to elaborate on what kind of textual practices are in use and how they can be understood. By analysing the text from all included EPRs, we established four distinct patterns in how the moment of death was documented: a) registering the bare minimum of information, b) registering a body stopped working, c) documenting dying quietly and placing it in peaceful surroundings and d) highlighting the accompanied death. The overall argument arising from these patterns was how the textual practices of documenting the moment of death in the EPR made the transition from alive to dead appear manageable and sanitised, uneventful, or good, with a lasting tendency to hide potentially difficult topics like dying alone and suffering at the moment of death. While the rest of the EPR genre is permeated with biomedical language, this part of the documentation stands out, leaving the door ajar for other discourses, and it can be seen as trying to accommodate the ideal of a dignified death.

Summarising the Findings

The overarching research question I asked in this thesis is what kind of textual practices of dying and death in medical wards are present in the EPR, and what do these practices achieve?

To summarise the findings of the three articles, they may be placed in chronological order to provide insight into the documentation of three crucial turning points of care: from a curative to a palliative regimen, to the modes of dying in the last 24 hours of life, to the actual death of the patient. The conceptual approaches used in the articles highlighted different aspects of the text, where the main findings suggested a web of well-established textual practices loyal to the hegemonic discourse of biomedicine and the doings of the hospital organisation in a context where dying does not belong. By attending to the care for the dying patient as a set of tasks to be done, or as the biomedical 'failure' of the patient's body, the EPR texts tended to sanitise and silence death and dying.

Yet sometimes the text opened up. In each article, I show that there are breaches that challenge this biomedical and curative hegemony. There are examples of vulnerability, uncertainty, compassion, suffering, and affect. In a few cases, the patient's voice enters the text in clear opposition to the aim of the ongoing curative treatment.

In the following section, I discuss how these findings provide new insight into the textual practices of dying and death in a curative context.

V. Discussion

The overarching research question of this thesis was: What kind of textual practices of dying and death in medical wards are present in the EPR, and what do these practices achieve? In the following, I pick up key points from the articles, elaborate on aspects from the studies, and discuss what could be different to encourage the documentation of dying and death become more sensitive to palliative care. I start by discussing the potential consequences of the lack of flexibility that the EPRs display regarding how the dying patient becomes visible in the text. Next, I discuss the EPRs' legal obligation to contain sufficient information to provide individual care and how my findings suggest that by hiding the individual patient in generic categories, the EPR might fail to meet these obligations. Then, I discuss how textual practices produce objectivity by proposing all aspects of the patient in a biomedical discourse. Then, I discuss the concept of *heteroglossia* as a way to elaborate on what I see as the main dialogical flows that provide insight into the complex interplay of the textual practices of dying and death in the EPR. Finally, I discuss the potential implications for palliative care.

Lack of Flexibility in the Documentation of Dying and Death

First, I address how the textual practices about dying and death lack the flexibility that might allow deliberation and reflection to enter the text. Previous research has revealed difficulties in recognising and diagnosing dying, and this challenge may come at the cost of reducing and overlooking the quality of palliative care (Ellershaw & Ward, 2003; Virdun, 2017). One consequence of this is an imbalance between the professionals' aim to cure and the patients' failing condition. This relates to Glaser and Strauss' (1968) notion of being out of step. This is further elaborated by Cardona-Morell et al. (2016) and Cardona-Morell et al. (2017). They problematised the frequent use of futile treatment in older patients with comorbidity and chronic illness while acknowledging the web of ethical, relational and medical complexity that this decision to diagnose dying involves. The

population described in those two articles had many similarities in age and sickness history with the population in this study where the average patient age was above 80 and most of the patients were admitted to hospital with chronic illness and often with comorbidity. In addition, as noted in the first article, most of the patients were diagnosed as dying less than 24 hours prior to their actual death, and a considerable number of the patients were not diagnosed as dying at all (Hov et al., 2020a). One consequence of this is that the orientation of care is being directed towards cure or stabilisation rather than palliative care (Chapple, 2010; Kaufman, 2005). Hence, the consistent channelling of focus to find a solution to the patient's problem in a curative trajectory seems to close off any deliberation of how best to care for the patient, be it curative, palliative or an integration of these. Often, there was no deliberation of the turning point in the EPRs. It was only the conclusion that was documented (Hov et al., 2020a), thereby omitting the content of professional deliberations leading up to the turning point. Hence, the EPR operated with a binary understanding of the patient's condition as being either curative or palliative. This reflected an orientation, which to a very small degree (or not at all) 'allows' for uncertainty or deliberations to enter the EPR text. Instead, the EPR text jumped from one decision/statement to the next, and it documented only the 'facts'. Also, in Hov et al. (2020b) and Hov et al. (2021), the findings suggested that documentation leading up to death showed little interest in addressing aspects that did not work as intended, thus forwarding an understanding of being infallible.

Another implication of this dichotomous approach is that by not being open about the patient's condition as potentially deadly, it may be that healthcare professionals were blind to the patient's condition or the patient's perception of their condition. This is especially evident in cases where the patient was not recognised as dying before their actual death, implying that there probably were instances where a patients' needs for closure, presence, comfort and other aspects of palliative care go unnoticed by the professionals. Although Cardona-Morrell et al. (2016) stressed the complexity of predicting when death is approaching in as an extremely difficult task, I argue that making room to attend to such deliberations and struggles would improve the quality of these

decisions and provide a greater acknowledgement of their nuances and complexities. Not knowing

the outcome of treatment is an uncertainty that cannot be eliminated. However, passing on

knowledge about the uncertainties would support the work of other professionals with the patient.

This makes the uncertainties and potential disagreements, as well as the patients' individuality,

experience and opinion, visible, and it might shape an EPR that provides more detailed insight into

the patient's situation. This could be an important support for healthcare professionals in their

decision-making.

In this light, current developments towards the increasing use of standardised EPR texts

should be regarded with caution, as it is likely that this will strengthen the tendencies noted in this

study to push further into the background any knowledge that cannot easily be numbered,

categorised or otherwise rendered neutral, objective and biomedical. Here, I agree with Aarseth

(2019), who argued that recognising medical texts as having an agenda in themselves 'can hardly be

overestimated' (p. 98), and this is very true for the EPRs' strong focus on the ideals of neutrality,

efficiency and curation.

Relevant and Necessary Information

Having elaborated on the need for greater flexibility in the EPR format for (palliative)

deliberations of dying and death, I now discuss how the legal obligation of documenting what is

'relevant and necessary' merges in the EPR text. The Health Personnel Act specifically states that the

EPR 'must contain relevant and necessary information about the patient and the provided

healthcare' (Helsepersonelloven, 1999, § 40 [my translation]). Although 'relevant and necessary' are

terms that allow for varying interpretations, there are clear expectations about the content of the

text. Hence, I find it both relevant and necessary to discuss how the EPR documentation about dying

and death fulfils this obligation. As presented in the introduction, WHO (2021) recognised palliative

care as an essential part of people-centred care in healthcare services, and in this, relieving suffering

'be it physical, psychological, social, or spiritual' is a fundamental ingredient. My study points to a

general lack of forwarding knowledge about the patients' suffering of any kind, along with a textual

practice that typically excludes the patient's views on treatment levels and the content of care (Hov et al., 2020a, Hov et al.; 2020b; Hov et al. 2021). Rather, there seems to be a stronger inclination for the author of the text to assert that the expected/prescribed parts of their work with the patient have been executed. This might indicate that medical professionals are aware of and thus write for a super-addressee as a potential recipient of the text (Engebretsen, 2007). A super-addressee in this case may be the supervisory authority at the hospital, the patient's family, and with the recent development of patient access to the document, the patient also can be a potential reader of the text. Finally, when the patient dies, death is often proposed as being uneventful or good (Hov et al., 2021).

In the few cases where suffering is present in the text, it is often made visible by connecting it to physical distress, such as pain or dyspnoea, where the textual practice is to respond by the administration of medication. This finding concurs with previous studies that investigated the medical record to map out symptom management (Goodlin et al., 1998; Seah et al., 2005). My assertion of the legal demand and political will, alongside the professional guideline, is that it is fair to expect knowledge about patients' potential suffering to be under the umbrella of relevant and necessary information. So, why is it mainly the physical aspects of the care of the patient that are perceived as necessary and relevant for the EPR?

The harmonisation of opinions in decision making, omitting the difficult aspects of dying and paraphrasing death as sleep (Hov et al., 2020a, 2020b, 2021) appear as strategies to remove or avoid potential discomfort. Ramvi and Gripsrud (2017) pointed to a general lack of time and space for healthcare professionals to talk about the loss of patients. In line with this, I argue that the difficult detail of dying is omitted from the text because, in clinical work, there is little tradition of talking about death as anything that might affect healthcare professionals. In a context where there is a discomfort in society to handle death (Kellehear, 2016; Walter, 2017) and a lack of focus on dying in the curative setting (Kaufman, 2005; Chapple, 2010), the textual practices in the EPR can be seen as a strategy of smoothing over difficult aspects of dying and death. This strategy may also contribute to

making it easier for the healthcare professionals to move on to the next patient (for the professional in both roles of writer and reader). Thus, keeping the narrative of dying and death as sanitised and biomedical as possible could temporarily ease the hardship of working with dying patients by keeping death at a comfortable distance. Another explanation can be that the orientation towards cure stands in the way and contributes to maintaining a lack in the development and a scantiness of training to put other aspects of dying and death into words. This then creates a spiral that reproduces the textual practices that do not allow much more than the mechanical and task-oriented part of dying to become a part of the documentation.

Producing Objectivity

Having discussed the inflexibility of EPR documentation and the general terms in which relevant and necessary information is provided by the EPR. I now want to address the issue of how the EPR produces knowledge as neutral and objective. The conducted studies point to aspects in textual practices that encourage dying and death to remain largely invisible. In the few cases where dying and death are thematised, it is mostly done using impersonal language often efficiently structured into categories and numbers revolving around failing bodies and organisational issues, not dying persons in need of palliative care.

First, I discuss the issue of biomedicine ranking on the top of the hierarchy of modes in a hospital as the dominant narrative that constitutes the purest form of knowledge – objective results and assessments. Traditionally, science, upon which medical development is based, aimed to be about the world *as it is* (Kelly et al., 2015, p. 2). Through this medical gaze, the failing body, clinical observations, test results and treatment actions constitute the world as it is, at least in this context. Therefore, this may very well explain why the strong inclination for the EPR text to present all kinds of knowledge relevant to the treatment and care of the patient as numbers and categorises, thus submitting to the same neutral and objective language.

Presented in this way, the information appears to be more trustworthy. This is seen in the way that biomedical data constitute the foundation of the negotiations of the turning point from a

curative to a palliative treatment trajectory (Hov et al., 2020a) and how all sorts of activities concerning the patient are documented using neutral words and numbers (Hov et al., 2020b).

Secondly, Flood and Soricelli (1992) stated that refining the narrative voice in medical education implies a textual practice where the author is written out of existence 'to pretend that the document is purely objective to begin with' (p. 80). Although this study is not recent, it points to a quality of these textual practices that is still prominent in medical discourse (Hurwitz, 2017). The material analysed in the studies of this project is typically detached from both the author and the patient. This ongoing de-personalisation of voices leads to an EPR text that appears to be written on behalf of the organisation/profession about any patient. The content of the text is detached from all the involved parties and what is at stake. Moreover, when the patient is mentioned only in generic terms, which was a feature in all articles (Hov et al., 2020a, 2020b, 2021), the implication is that information about an individual patient's needs and pain (understood in palliative terms) is scarce. This indicates that the patient's individual needs cannot be met based solely on the knowledge the EPR passes on, and whether palliative care may be provided would depend on other structures of the organisation and the work of the professionals.

Taking these two aspects together, the textual practices of dying and death are submitted to strong traditions as to what the EPR text should contain, and the discourse performed by the text provides very little reflection on palliative care and very little encouragement towards implementing it.

Viewing the EPR from a Heteroglossic Perspective – Adding New Insights

Accountability, as proposed by Kline and Preston-Shoot (2012, p. 25), means that healthcare professionals in their daily duties are held accountable in two main ways. The first is by internalisation as *how to do the profession* in the course of education to becoming a nurse or physician, here referred to as professional affiliation. The second is the expectations of the organisation that the healthcare professionals conduct their job as expected. In the investigation of the 'modes of dying' (Hov et al., 2020b), one of the main findings is that the EPR proposes knowledge

about the dying patient to follow the ideals of biomedicine as being neutral and objective *and* as being efficient by focusing on documenting elements necessary to make the organisation work. The use of neutral, impersonal and efficient language imprinted by professional terminology also was a central finding in the transition from curative to palliative care (Hov et al., 2020a) and the documentation of death (Hov et al., 2021). Thus, I see that being accountable towards the profession and organisation concurs with the hegemonic discourses of biomedicine and the doings of the hospital organisation as proposed in the summary of the findings. Based on this concurrence, I want to elaborate further on what appears as layers or flows of text influenced by profession and organisation in a continuous interplay. To do so, I use the concept of *heteroglossia* to discuss how these flows influence textual practices.

Bakhtin articulated heteroglossia as a dynamic capacity in language that forces utterances in different directions. He distinguished between a centripetal force that draws the language towards what is commonly perceived to be its ideal and a centrifugal force that represents the deviations that challenge the ideal, hence making language evolve (Dentith, 1995; Andersen, 2002).

The *professional affiliation flow* comprises how healthcare professionals, as cultivated into a specific way of speech, are influenced by biomedicine, with a tendency to be impersonal, neutral, objective and categorising (Bowker & Star, 2000; Flood & Soricelli, 1992; Risse & Warner, 1992). For example, the training of physicians involves adapting to a technical perspective and mastering the specific language of medicine 'that incorporates the formulaic abbreviated linguistic patterns and expressions characteristically used to communicate within the medical establishment' (Flood & Soricelli, 1992, p. 65). Translated into the context of EPR text, the professional demands in the doings of a profession require the professionals to acquire these linguistic patterns employed by the medical establishment to qualify as a member of the group. Nurses undergo similar training through the course of becoming a nurse, inducing a common understanding in the profession of what the nurse's documentation should contain (De Groot et al., 2019; Lunney, 2005). In Norway, this is also presented in the Nurses Union guidelines on documentation (NSF, 2007).

The *organisational flow* refers to the textual practices in the EPR that are adjusted to the doings of the particular hospital organisation. I find it elucidative to add a perspective from Garfinkel (1967/2009) and his well-argued reasons for all the imperfections in both the shape and content of the medical record. The core is that the clinical record is shaped by healthcare professionals complying with the established ways of writing clinical texts (p. 46). Further, he argued that the reason for what may be seen as shortcomings in the medical record is the organisational aim of efficiency, inducing textual practices that focus on what is perceived as 'core' information. His reflections echo well the contemporary practice of documentation, although he was referring to paper records more than 50 years ago. Another aspect of this is Berg's (1996) study of medical records, where he proposed the medical texts as a device setting 'organisational routines in motion', giving direction to hospital resources (p. 510). He stated that in the medical record, 'the body is transformed into a body of manageable problems for the hospital's routines' (p. 511). This implies that the documentation of dying and death is subsumed by numerous organisational considerations and practices in becoming texts.

I view organisational flow as something that adjusts the particular context. Thus, documentation of dying and death in a palliative ward is submitted to different organisational regulations than in a medical ward, and this would influence the textual practices. Similarly, changes in diagnosis, treatment or actions would influence professional language in any context. So, the flows of the profession and the organisation are in a constant interplay, and an utterance may carry aspects of both and is shaped by both at the same time.

By adding the concept of heteroglossia, I argue that these flows represent the mainstream documentation that constitutes the centripetal force, making the EPR predictable and understandable for the users. However, this is not all there is. Throughout the three studies, there were breaches that brought forward another kind of knowledge. They could be comments, phrasings, opinions and quotations that in one way or another opposed the centripetal force – the centrifugal force. The centrifugal force in the EPR is not as predictable and stable as in the centripetal

mainstream. However, by adding the examples of a centrifugal force from the three articles, there seems to be a consistent pattern in which that force challenges the established understanding of dying and death, thus showing other more nuanced and more complex aspects of the healthcare professionals' work with the dying patient. They are opposing the curative aim or weighing aspects that are more in line with the ideal of holistic palliative care and other facets of professional accountability. For example, explicit expressions of the writer's viewpoints, or by quoting the patient that, in some examples, oppose the trajectory of curative treatment (Hov et al., 2020a), or a nurse's note making visible the patient's suffering and fear of dying (Hov et al., 2020b). Another centrifugal force is especially visible in the article where I investigate the transition to death (Hov et al., 2021). It contains elements from a societal language of dying and death, such as the use of euphemisms of the moment of death.

My point is that the professional and organisational flows as centripetal forces, according to Bakhtin's terminology (Andersen, 2002), maintain the writing about dying and death as loyal towards an established 'ideal' of how to document both regarding organisation and profession. The centrifugal flow might expand the EPR's rather narrow space, to evolve over time through a process where what first appears as breaches can be reproduced by other healthcare professionals' writing. For example, the use of euphemisms to describe death might have been phrases that, at first, might have been a clear breach with the mainstream. However, because of frequent reproduction, it moves from the centrifugal to the centripetal flow. In the data analysis for this study, approximately 50% of the cases used these euphemisms across professional affiliations.

This project being a snapshot at one point in time, I do not know if this is how the use of euphemisms has developed, but since it stands out from the rest of the data, it makes for a good example.

I see this as a considerable issue because of a concern about the development towards a further rigidity in the textual practices of the EPR. Also, in nursing documentation, there is an increasing emphasis on using guided care plans based on predetermined terminology and

classifications suggested by the ICPN (DIPS, 2021a; NSF, 2021), which aims to increase the quality of nursing documentation (De Groot et al., 2019). In addition, the developers of the filing system are working to find a way to reuse, for example, the patient's sickness history (DIPS, 2021b) to shorten the time the healthcare professionals spend reading and writing in the EPR, so the patient need not repeat their sickness history several times. I see that the consequence of this is that both tendencies contribute to increasing the strength of the centripetal force.

So, my question is: at what cost? Bowker and Star (2000) stated that, although necessary, using classifications and categorisation follows a particular representation of some things at the expense of others. Thus, I am calling for an increased consciousness about what falls outside or in between categories and classifications when the patient is at the end of life. This is because the space for a centrifugal force is diminished with the increasing development towards a transition of EPRs to containing a more frequent use of pre-structured texts and the reuse of notes. Then, the voices that oppose or propose other aspects of the patient or that pass on knowledge that falls outside or in between the codes and categories would be suppressed further by the centripetal force with its inclination to be instrumental, neutral and objective.

Although the centripetal force is well intentioned regarding efficiency and transparency, my argument is that the centrifugal force in the EPR is a necessary counterweight to the mainstream documentation. Also, a development towards standardised texts and reuse of information that weakens the centrifugal flow by reducing the texts' ability to oppose would be a loss. This is because the centrifugal flow creates a space for the text to evolve and to show variations. Diminishing the centrifugal flow further would come at a risk of further strengthening a textual practise in which dying and death remain *not* manageable by the text because dying is outside the scope of the medical ward (both professional and organisational) and the category of curation.

I do not believe that the centrifugal flow alone is a guarantee for the EPR to develop into a text that is more human and sensitive to the dying patient. Nevertheless, throughout this study, it was in these exceptions, breaching with the centripetal flow, that had traces of opinion,

disagreement, deliberation, suffering and compassion that provided insight into the complexity of dying in a curative context.

Implications for Palliative Care

As a final stop in the discussion, I argue how this study may contribute to the field of palliative care. But first, throughout this project, it has been pertinent to demarcate the analysed texts from the clinical practice that made up the source of the knowledge that these EPRs let us in on. So, when addressing the implications for palliative care, I find it essential to stay within the same border, because the texts are not representations of clinical practice. Rather, the EPR text is an embedded part of the doings around dying and death in medical wards. So, by a critical investigation of the textual practices in the EPR, given its essential position at the nave of the doings of healthcare, my aim is *not* to answer how the EPR influences palliative care practices. My aim has been to show that it *can*. This is because the 'performativity' of the EPR is not just about documenting care that does happen. It is also about how the EPR encourages dealing with dying and death in specific ways.

Hence, by adding up the most predominant findings of this study, some distinctive features stand out in how the trajectory of dying and death is forwarded. Predominantly, the textual practices propose dying and death as a biomedical event seen from a curative perspective. There is a tendency by the text to solve the patient's pain and unease by medication. In addition, the text does not seem to take the patients' age or comorbidities into consideration when aiming for curation or active treatment. The text organises the patients into categories of curative *or* palliative, which are forwarded as dichotomous treatment goals. Also, deeply rooted in the EPR structure is neutrality operationalised as impersonality. The genderless 'pt.' without features or interests, appears mostly as having nothing at stake in this vulnerable situation. My argument is that these aspects of the text point to a lack of space or invitation to attend to palliative care that aims to recognise not only the patient's physical needs, but their spiritual, psychological and social needs as well.

One possible reason for this may be that the EPR has evolved from a cure-oriented period and perspective (Risse & Warner, 1992). Palliative care has been added to this orientation, but the

EPRs structure and use seem to suggest this has hardly found its way into the documentation practices and protocols; for even when 'palliative' possibilities enter, they are adjusted to emphasise a biomedical perspective. Therefore, the EPR seems to forward a mode of palliative care that may become increasingly out of tune with the practices and goals of contemporary care.

Another distinctive feature in the forwarding of dying and death in the EPR is textual practices that propose death as manageable by removing details, by numbering bodily functions, by classifying the patient's condition and by hiding away the dirt and the trouble (Hov et al., 2020b). Thus, the texts hide and avoid central aspects of what dying also is about. This omitting of difficult and uncomfortable details cloaks aspects of dying where I believe a more nuanced and honest text would be preferable. A text where the textual practices are 'staying with the trouble' (Haraway, 2016) that we know is a part of this work – the mess, the dirt, the suffering, the emotions, the patient's anxieties etc. Such a textual practice could provide healthcare professionals forwarding a more nuanced version rather than reproducing texts where the reader is being encouraged *not* to see. My assertion is that a more nuanced format would also help to identify the patients' sufferings, and this would be highly useful in determining that the best possible actions are taken to ease the pain. Also, more refined texts would be of use to identify a wider repertoire of patient needs that also includes psychological and existential aspects. This would create a new standard where the space to document knowledge about existential needs is not left empty in the nurse documentation. Hence, by working towards these adjustments in the textual practices, the text would become more in line with the holistic approach to patients, which is one of the core values of palliative care (WHO, 2021).

So, as long as the EPR forwards a retouched picture of dying and death, it also keeps feeding into a limited perception of palliative care. There is an urgent need to be aware of the power of the textual practices about dying and death and to start recognising the EPR text as a part of the bits and pieces that make up the care for dying and death in the curative contexts that hospitals predominantly are. Hence, I call for an increased consciousness of what the EPR forwards about

dying patients among healthcare professionals, in research and among system developers. The text

of the ERP must be recognised as having a productive capacity, and thus it should become a part of

the equation in projects that aim to improve palliative care in a curative context. In addition, the

power of the EPR must be thematised in the education of healthcare professionals by enabling them

to be critical in their own production of EPR texts, especially for those who work or plan to work in

this field of tension.

VI. Concluding remarks

This project started with an interest in exploring the documentation of dying and death in the EPR, and the overall research question was: What kind of textual practices of dying and death in medical wards are present/reflected in the EPR, and what do these practices achieve? I chose to answer this question by elaborating on three different aspects of the text, pragmatically inspired by elements from selected conceptual frameworks. Hence, I aimed to raise awareness and insight into the EPR and its role as an active contributor to the professional practice of documentation and communication of knowledge.

By synthesising the main reflections in the three articles, my argument is that the textual practices in the documentation of dying and death induce several implications on how and what knowledge about the dying patient becomes a part of the documentation. First, knowledge about dying is classified into words and phrases from a seemingly limited vocabulary that is highly influenced by biomedicine, presented through a set of textual practices that value neutrality and objectivity. Second, the text is mainly preoccupied with being *correct* regarding professional accountability in the current situation and the doings of the hospital. Therefore, dying and death are proposed in limited generic terms, where the difficult details of suffering are systematically omitted. The consequence of this rigidity of the EPR language produces a dynamic in which aspects of the dying and death of subjects cannot be addressed. My argument is that this potential imprecision in what is passed on also weakens the EPR as a source of knowledge about the patient and for assessments of the quality of both palliative care and end-of-life care, especially of qualities of care that cannot be documented in numbers, codes or categories.

Far from seeing the EPR as a neutral source of information, this study has given insight into the textual practices in the documentation of dying and death, where a strong centripetal force in both profession and organisation works against a nuanced understanding of the dying patient. This positions the text as a part of a complex web of professional considerations, political agendas and the distribution of resources regarding the patient at the end of life.

So, what can be done? I think there is a need to address this issue on a systemic or structural level. To open a dialogue with the system owners and developers of the EPR, who I worry are too occupied with making documentation easier (in terms of being more efficient) and more standardised. I also believe that healthcare professionals can gather up and add more weight to the centrifugal force of the documentation by not following the current, by putting into words what is needed to contribute to better care for the patient. Thus, I find it hard to understand what is lost by evolving the language and textual practices of the EPR in a humanising direction. I believe this can be done without jeopardising the quality of care or diminishing the quality and efficiency of the EPR. The increasing number of treatment alternatives to cure concurring with the expansion of the notion of palliative care follows an increasing need to address the negotiations at this final border of viability in the text regarding medical technical equipment and interventions to postpone death, or not. By allowing richer and more nuanced language about the cost of always aiming for cure, and by integrating palliative care as a supplement rather than a deviation from heroic medicine, I believe the biomedical discourse in the EPR must embed dying as a natural part of being human and not as a defeat of medicine. Then the trajectory of death would become more than a lost battle, uneventful or sanitised, or as a machine that has stopped working.

As a start, minor changes to the textual practices, such as referring to the patient by their name and for the author to be positioned as an 'I' in the text, would enhance the human presence in the text and become a counterweight to 'medicine's technological and business framework' (Flood & Soricelli, 1992, p. 79).

Another benefit from linguistically cultivating dying and death with nuances in the EPR would be that the complexity and difficulties both for the patient/family and the healthcare professional would become a visible part of doing the hospital organisation. This could contribute to an increased basis for assessing and developing the quality of care, adding to a greater recognition of the hardship that this work often entails for the professionals. Based on the findings presented in this study, I call for the EPR text to be included as a part of the development of palliative care, a more nuanced

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debate, recognising that everything is not solved by adding codes, categories and pre-structured

texts and templates. Thus, I call for greater recognition by professional practice, in the education of

healthcare professionals, and system developers that words matter.

References

Aarseth, G. (2019). *The language of work disability: A study of medical certificates written by Norwegian general practitioners* [Doctoral dissertation, University of Oslo].

Aarseth, G., Natvig, B., Engebretsen, E., & Lie, A. K. (2017). 'Working is out of the question': A qualitative text analysis of medical certificates of disability. *BMC Family Practice, 18*(1), 55. doi:10.1186/s12875-017-0627-z

Aarseth, G., Natvig, B., Engebretsen, E., & Lie, A. K. (2019). Acting by persuasion: Values and rhetoric in medical certificates of work incapacity: A qualitative document analysis. *Medical Humanities, 45*(1), 60–66. doi:10.1136/medhum-2018-011496

Aarseth, G., Natvig, B., Engebretsen, E., Maagerø, E., & Lie, A. H. K. (2016). Writing the patient down and out: The construal of the patient in medical certificates of disability. *Sociology of Health & Illness, 38*(8), 1379–1395. doi:10.1111/1467-9566.12481

Aaslestad, P. (2016). *The patient as text: The role of the narrator in psychiatric notes, 1890–1990.* CRC Press.

Asdal, K., & Reinertsen, H. (2020). *Hvordan gjøre en dokumentanalyse. En praksisorientert metode. [How to conduct a document analysis. A practice-oriented method].* A Cappelen Damm Akademisk.

Andersen, N. M. (2002). *I en verden av fremmede ord. Bachtin som sprogbruksteoretiker [In a world of alien words: Bakhtin as a language use theorist].* Tid og tanke.

Aries, P. (2008). *The hour of our death: The classic history of Western attitudes towards death over the last one thousand years.* (2nd ed.). Vintage Books. (Original work published 1981).

Bakhtin, M. M. (1981). *The dialogic imagination: Four essays* (7th ed.). University of Texas Press.

Bakhtin, M. M. (1986). *Speech genres and other late essays.* University of Texas Press.

Bakhtin, M. M. (1998). *Spørmålet om talegenrene [The question of the speech genres].* Ariadne forlag and Rasmus T. Slaatelid.

Berg, M. (1996). Practices of reading and writing: The constitutive role of the patient record in

medical work. *Sociology of Health & Illness, 18*(4), 499–524. doi:10.1111/1467-9566.ep10939100

Bowker, G. C., & Star, S. L. (2000). *Sorting things out: Classification and its consequences*. MIT Press.

Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health, 58*(2), 257–67. https://doi.org/10.1007/s00038-012-0394-5

Cardona-Morrell, M., Kim, J. C. H., Brabrand, M., Gallego-Luxan, B., & Hillman, K. (2017). What is inappropriate hospital use for elderly people near the end of life? A systematic review. *European Journal of Internal Medicine, 42*, 39–50.

Cardona-Morrell, M., Kim, J. C. H., Turner, R. M., Anstey, M., Mitchell, I. A., & Hillman, K. (2016). Non-beneficial treatments in hospital at the end of life: A systematic review on the extent of the problem. *International Journal of Quality in Health Care, 28*(4), 456–469. doi:10.1093/intqhc/mzw060

Chapple, H. S. (2010). *No place for dying. Hospital and the ideology of rescue*. Left Coast Press.

Clark, D. (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science & Medicine, 49*(6), 727–736. doi:https://doi.org/10.1016/S0277-9536(99)00098-2

Class, M. (2014). Introduction. Medical case histories as genre: New approaches. *Literature and Medicine, 32*(1), vii–xvi. doi:10.1353/lm.2014.0007

Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE Publications.

Dahl, K. (2002). Dokumentasjon og prosess: Dilemmaer i et historisk perspektiv [Documentation and process: Dilemmas in a historical perspective]. *Sykepleien, 90*(3), 46–50. doi:https://doi.org/10.4220/sykepleiens.2002.0007

Datatilsynet. (2015). *Anonymisering av personopplysninger [Anonymization of personal information]*.

https://www.datatilsynet.no/globalassets/global/dokumenter-pdfer-skjema-

ol/regelverk/veiledere/anonymisering-veileder-041115.pdf

Davidson, S., & Gentry, T. (2013). *End of life evidence review*. Age UK.

De Groot, K., Triemstra, M., Paans, W., & Francke, A. L. (2019). Quality criteria, instruments, and

requirements for nursing documentation: A systematic review of systematic reviews. *Journal*

of Advanced Nursing, 75(7), 1379–1393. doi:10.1111/jan.13919

Dentith, S. (1995). *Bakhtinian thought: An introductory reader*. Routledge.

DIPS. (2021c, July 01) *Historien om DIPS. [The history of DIPS]*. https://www.dips.com/no/historien-

om-dips

DIPS. (2021a, April 22). *ICPN-veiledende tiltaksplaner [ICPN-indicative action plans].*

https://www.dips.com/no/tar-forste-steg-mot-strukturert-journal

DIPS. (2021b, April 22). *Tar første steg mot strukturert pasientjournal [Takes the first step towards a*

structured patient record]. https://www.dips.com/no/tar-forste-steg-mot-strukturert-journal

Ellershaw, J., & Ward, C. (2003). Care of the dying patient: The last hours or days of life. *BMJ Clinical*

Research Ed.), 326(7379), 30–34.

Emmons, K. K. (2009). Uptake and the biomedical subject. In C. Bazerman, A. Bonini & D. Figueiredo

(Eds.), *Genre in a changing world* (pp. 137–160). The WAC Clearing House, Parlor Press.

Engebretsen, E. (2005). *Barnevernet som tekst: Nærlesning av 15 utvalgte journaler fra 1950- og*

1980-tallet [Child welfare as text: Close reading of 15 selected medical records from the

1950s and 1980s]. [Doctoral dissertation, University of Oslo].

Engebretsen, E. (2007). *Hva sa klienten? Retorikken i barnevernets journaler.[What did the client say?*

Rhetoric's in child welfare records]. Cappelen Akademiske Forlag.

Fins, J. J., Guest, R. S., & Acres, C. A. (2000). Gaining insight into the care of hospitalized dying

patients: An interpretative narrative analysis. *Journal of Pain and Symptom Manage, 20*(6),

399–407. doi:10.1016/s0885-3924(00)00220-7

Flannery, L., Ramjan, L. M., & Peters, K. (2016). End-of-life decisions in the Intensive Care Unit (ICU) –

Exploring the experiences of ICU nurses and doctors – A critical literature review. *Australian Critical Care: Official Journal of the Confederation of Australian Critical Care Nurses, 29*(2), 97–103.

Flick, U. (2004). Triangulation in qualitative research. In U.Flick, E. von Kardoff & I. Steinke (Eds.), *A companion to qualitative research* (pp. 178-184). SAGE Publications.

Flood, D. H., & Soricelli, R. L. (1992). Development of the physician's narrative voice in the medical case history. *Literature and Medicine, 11*(1), p. 64–83. doi:10.1353/lm.2011.0250

Folkehelseinstituttet. (2021, January 22). *Dødsårsakregisteret. [Cause of death register].* http://statistikkbank.fhi.no/dar/

Frank, A. (2012). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds.), *Varieties of narrative analysis* (pp. 33-52). SAGE Publications.

Garfinkel, H. (2009). 'Good' organizational reasons for 'bad' clinic records. In K. Krippendorff & M. A. Bock (Eds.), The content analysis reader (pp. 45–53). SAGE Publications. (Original work published 1967)

Gholiha, A., Fransson, G., Fürst, C. J., Heedman, P. A., Lundström, S., & Axelsson, B. (2011). Stora luckor I journaler vid vård i livets slutskede. Journauppgifter saknas för data inrapporterade till Palliativeregisteret [Big gaps in documentation of end-of-life care: Incomplete medical records reported to the Swedish Registry of Palliative Care]. *Lakartidningen, 108*(16–17), 918–921.

Glaser, B. G., & Strauss, A. L. (1966). *Awareness of dying.* Weidenfeld & Nicolson.

Glaser, B. G., & Strauss, A. L. (1968). *Time for dying.* Aldine Publishing Company.

Goddu, A. P., O'Conor, K. J., Lanzkron, S., Saheed, M. O., Saha, S., Peek, M. E., Haywood C., & Beach, M. C. (2018). Do words matter? Stigmatizing language and the transmission of bias in the medical record. *Journal of General Internal Medicine, 33*(5), 685–691. doi:10.1007/s11606-017-4289-2

Goodlin, S. J., Winzelberg, G. S., Teno, J. M., Whedon, M., & Lynn, J. (1998). Death in the hospital.

Archives of Internal Medicine, 158(14), 1570–1572. doi:10.1001/archinte.158.14.1570

Greenhalgh, T., Potts, H. W., Wong, G., Bark, P., & Swinglehurst, D. (2009). Tensions and paradoxes in electronic patient record research: A systematic literature review using the meta-narrative method. *Milbank Quarterly, 87*(4), 729–788. doi:10.1111/j.1468-0009.2009.00578.x

Habeck-Fardy, A. (2019). Passing on death: An audit of the terminology utilized in discharge summaries for deceased patients. *Death Studies, 1–7*. doi:10.1080/07481187.2019.1648335

Halliday, M. A. K. (2013). *Halliday's introduction to functional grammar* (4th ed.). Taylor & Francis.

Hämäläinen, A., & Hirvonen, H. (2020). Electronic health records reshaping the socio–technical practices in long-term care of older persons. *Technology in Society, 62*, 101316. https://doi.org/10.1016/j.techsoc.2020.101316

Haraway, D. (1988). Situated Knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies, 14*(3), 575-599. https://doi.org/10.2307/3178066

Haraway, D. (2016). *Staying with the trouble: Making Kin in the Chthulucene*. Duke University Press.

Hegarty, M., Hammond, L., Parish, K., Glaetzer, K., McHugh, A., & Grbich, C. (2005). Nursing documentation: Non-physical dimensions of end-of-life care in acute wards. *International Journal of Palliative Nursing, 11*(12), 632–6. doi:10.12968/ijpn.2005.11.12.20230. PMID: 16415756

Helsedirektoratet. (2015). *Palliasjon i kreftomsorgen – Nasjonalt handlingsprogram med retingslinjer [Palliative care in cancer care: National action programme with guidelines]*. https://www.helsedirektoratet.no/retningslinjer/palliasjon-i-kreftomsorgen-handlingsprogram

Helsepersonelloven. (1999). *Lov om helsepersonell* (LOV-1999-07-02-64) [Healthcare act]. https://lovdata.no/dokument/NL/lov/1999-07-02-64?q=helsepersonelloven.

Hockey, J. (2007). Closing in on death? Reflections on research and researchers in the field of death and dying. *Health Sociology Review, 16*(5), 436–446. doi:10.5172/hesr.2007.16.5.436

Hockey, J., Komaromy, C., & Woodthorpe, K. (2010). *The matter of death: Space, place and*

materiality. Palgrave Macmillan.

Hov, L. (2014). *Om døden – med andre ord. Hvordan fremstilles den døende pasienten i journaltekst [About death – in other words. How is dying presented in journal text]* [Unpublished master's thesis, University of Oslo]. http://urn.nb.no/URN:NBN:no-48433

Hov, L., Pasveer, B., & Synnes, O. (2020b). Modes of dying in the electronic patient record. *Mortality*, 1–15. doi:10.1080/13576275.2020.1865294

Hov, L., Synnes, O., & Aarseth, G. (2020a). Negotiating the turning point in the transition from curative to palliative treatment: A linguistic analysis of medical records of dying patients. *BMC Palliative Care, 19*(1), 91. doi:10.1186/s12904-020-00602-4

Hov, L., Tveit, B., & Synnes, O. (2021). Nobody dies alone in the electronic patient record: A qualitative analysis of the textual practices of documenting dying and death. *OMEGA: Journal of Death and Dying.* doi:10.1177/00302228211019197

Hurwitz, B. (2006). Form and representation in clinical case reports. *Literature and Medicine, 25*(2), 216–240. doi:http://doi.org/10.1353/lm.2007.0006

Hurwitz, B. (2017). Narrative constructs in modern clinical case reporting. *Studies in History and Philosophy of Science Part A, 62*, 65–73. doi:https://doi.org/10.1016/j.shpsa.2017.03.004

International Council of Nurses. (2021, April 22). *About ICPN*. https://www.icn.ch/what-we-do/projects/ehealth-icnptm/about-icnp

Iyer, P. W., & Camp, N. H. (1995). *Nursing documentation: A nursing process approach.* Mosby Year Book.

Joki, I. (1993). The dialogicality of grotesque realism. In D. G. Shepherd (Ed.), *Bakhtin: Carnival and other subjects: Selected papers from the Fifth International Bakhtin Conference, University of Manchester, July 1991* (pp. 80-98). Rodopi.

Jones, T., Wear, D., & Friedman, L. D. (2014). Introduction. In T. Jones, D. Wear, & L. D. Friedman (Eds.), *Health Humanities Reader* (pp. 1–9). Rutgers.

Kärkkäinen, O., Bondas, T., & Eriksson, K. (2005). Documentation of individualized patient care: A

qualitative metasynthesis. *Nursing Ethics, 12*(2), 123–132. doi:10.1191/0969733005ne769oa

Kaufman, S. R. (2005*). And a time to die. How American hospitals shape the end of life*. University of Chicago Press.

Kaufman, S. R. (2010). Time, clinic technologies, and the making of reflexive longevity: The cultural work of time left in an ageing society. *Sociology of Health & Illness, 32*(2), 225–237. doi:10.1111/j.1467-9566.2009.01200.x

Kellehear, A. (2009). Dying old – and preferably alone? Agency, resistance and dissent at the end of life. *International Journal of Ageing and Later Life, 4*(1), 5-21. doi:https://doi.org/10.3384/ijal.1652-8670.09415

Kellehear, A. (2016). Current social trends and challenges for the dying person. In N. Jakoby & M. Thönnes (Eds.), *Zur Soziologie des Sterbens* (pp. 9–25). Springer VS.

Kelly, M. P., Heath, I., Howick, J., & Greenhalgh, T. (2015). The importance of values in evidence-based medicine. *BMC Medical Ethics, 16*(1), 69. https://doi.org/10.1186/s12910-015-0063-3

Kennedy, C., Brooks-Young, P., Gray, C. B., Larkin, P., Connolly, M., Wilde-Larsson, B., & Chater, S. (2014). Diagnosing dying: An integrative literature review. *BMJ Supportive and Palliative Care, 4*(3), 263–270. doi:10.1136/bmjspcare-2013-000621

Kline, R., & Preston-Shoot, M. (2012). *Professional accountability in social care and health: Challenging unacceptable practice and its management*. SAGE Publications.

Kübler-Ross, E. (1997). *Questions and answers on death and dying: A companion volume to On death and dying* (1st ed.). Touchstone. (Original work published 1974)

Kübler-Ross, E. (2003). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. Routledge. (Original work published 1969)

Law, J. (1994). *Organizing modernity*. Blackwell.

Lawton, J. (2000). *The dying process: Patients' experiences of palliative care*. Routledge.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic enquiry*. SAGE Publishing.

Lunney, M., Delaney, C., Duffy, M., Moorhead, S., & Welton, J. (2005). Standardised nursing language

in electronic health records. *Journal of Nursing Administration, 35*(1), 1–3.

Maagerø, E. (2005). *Språket som mening: innføring i funksjonell lingvistikk for studenter og lærere [Language as meaning: An introduction to functional linguistics for students and teachers]*. Universitetsforlaget.

Malt, U. (2019). *ICD-10*. In store medisinske leksikon. https://sml.snl.no/ICD-10

Malterud, K. (2017). *Kvalitative forskningsmetoder for medisin og helsefag [Qualitative research methods for medicine and health sciences].* Universitetsforlaget.

Martin, J. R., & Rose, D. (2003). *Working with discourse: Meaning beyond the clause.* Bloomsbury Academic.

Martin, J. R., & White, P. R. R. (2007). *The language of evaluation: Appraisal in English*. Palgrave Macmillan.

Meld. St. 24 (2019–2020). *Lindrende behandling og omsorg – Vi skal alle dø en dag. Men alle andre dager skal vi leve.* Helse- og omsorgsdepartementet. [Report to the Storting: *Palliative care and care – We must all die one day. But every other day we will live*. Ministry of Health and Care Services]. https://www.regjeringen.no/no/dokumenter/meld.-st.-24-20192020/id2700942/

Meld. St. 25. (2005–2006). *Mestring, muligheter og mening*. Helse- og omsorgsdepartementet [Report to the Storting*: Coping, opportunities and meaning.* Ministery of Health and Care services]. https://www.regjeringen.no/no/dokumenter/stmeld-nr-25-2005-2006-/id200879/?ch=1

Meld. St. 29 (2012–2013). *Morgendagens omsorg*. Helse- og omsorgsdepartementet[Report to the Storting: *Tomorrow's care*. Ministry of Health and Care]. https://www.regjeringen.no/no/dokumenter/meld-st-29-20122013/id723252/?ch=1

Molander, A., & Terum, L. I. (Eds.). (2008). *Profesjonsstudier [Professional studies].* Universitetsforlaget.

Moser, I., & Law, J. (2006). Fluids or flows? Information and qualculation in medical practice.

Information Technology & People, 19(1), 55–73.

https://doi.org/10.1108/09593840610649961

Norsk Sykepleier Forbund (2007). *Dokumentasjon av sykepleie elektronisk pasientjournal. En veileder fra Norsk Sykepleierforbunds forum for IKT og Dokumentasjon [Documentation of nursing electronic patient record: A guide from the Norwegian Nurses' Association's forum for ICT and documentation].*

https://www.nsf.no/Content/852451/Veileder%20%20Sykepleiedokumentasjon.pdf

Norsk Sykepleier Forbund (2021, April 14). *Dokumentasjon og planlegging av sykepleie [Documentation and planning of nursing].*

https://www.nsf.no/sykepleiefaget/dokumentasjon-og-planlegging-av-sykepleie

Parish, K., Glaetzer, K., Grbich, C., Hammond, L., Hegarty, M., & Annie, M. (2006). Dying for attention: Palliative care in the acute setting. *Australian Journal of Advanced Nursing, 24*(2), 21–5. doi:10.1097/00000446-200609000-00016. PMID: 17285832

Patton, M. Q. (2014). *Qualitative research and evaluation methods: Integrating theory and practice.* SAGE Publications.

Poirier, S. (2004). Voice in the medical narrative. In R. Charon & M. Montello (Eds.), *Stories matter: The role of narrative in medical ethics* (pp. 48–59). Taylor & Francis.

Polit, D. F., & Beck, C. T. (2020). *Nursing Research* (11th ed.). Wolters Kluwer Law & Business.

Pollock, K. (2015). Is home always the best and preferred place of death? The *BMJ, 351*:h4855. https://doi.org/10.1136/bmj.h4855

Pomata, G. (2014). The medical case narrative: Distant reading of an epistemic genre. *Literature and Medicine, 32*(1), 1–23. doi:10.1353/lm.2014.0010

Prior, L. (2003). *Using documents in social research.* SAGE Publications.

Prior, P. (2009). From speech genre to mediated multimodal genre systems: Bakhtin, Voloshinov and the question of writing. In C. Bazerman, A. Bonini, & D. Figueiredo (Eds.), *Genre in a changing world* (pp 17–34). The WAC Clearinghouse, Parlor Press.

Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, K., Goh, C., Gomez-Garcia, W., Harding, R., Khan, Q. T., Larkin, P., Leng, M., Luyirika, E., Marston, J., Moine, S., Osman, H., Pettus, K., Puchalski, C., Rajagopal, M. R., Spence, D., Spruijt, O., Venkateswaran, C., Wee, B., Woodruff, R., Yong, J., Pastrana, T. (2020). Redefining palliative care-A new consensus-based definition. *Journal of Pain Symptom Management, 60*(4):754–764. doi: 10.1016/j.jpainsymman.2020.04.027.

Ramvi, E., & Gripsrud, B. H. (2017). Silence about encounters with dying among healthcare professionals in a society that 'de-tabooises' death. *International Practice Development Journal, 7*. doi:https://doi.org/10.19043/ipdj.7SP.009

Rashidi, N. M., Zordan, R. D., Flynn, E., & Phillip, J. A. M. (2011). The care of the very old in the last three days of life. *Journal of Palliative Medicine, 14*(12), 1339–1344. doi:10.1089/jpm.2011.0308

Rawlings, D., Tieman, J. J., Sanderson, C., Parker, D., & Miller-Lewis, L. (2017). Never say die: Death euphemisms, misunderstandings and their implications for practice. *International Journal of Palliative Nursing, 23*(7), 324–330. doi:10.12968/ijpn.2017.23.7.324

Risse, G. B., & Warner, J. H. (1992). Reconstructing clinical activities: Patient records in medical history. *Social History of Medicine, 5*(2), 183–205. doi:10.1093/shm/5.2.183

Ruyter, K. W. (2003). *Forskningsetikk: beskyttelse av enkeltpersoner og samfunn [Research ethics: Protection of individuals and society]*. Gyldendal akademisk.

Seah, S. T., Low, J. A., & Chan, Y. H. (2005). Symptoms and care of dying elderly patients in an acute hospital. *Singapore Medical Journal, 46*(5), 210–214.

Seymour, J. (2001). *Critical moments: Death and dying in intensive care.* Open University Press.

Silverman, D. (2014). *Interpreting qualitative data* (5th ed.). SAGE Publications.

Small, N., & Gott, M. (2012). The contemporary relevance of Glaser and Strauss. *Mortality, 17*(4), 355–377. doi:10.1080/13576275.2012.730683

Smith, M. C. (2013). Disciplinary perspectives linked to middle range theory. In M.J Smith & P.R Liehr

(Eds), *Middle Range Theory for Nursing* (3rd ed. pp. 3-14). Springer Publishing Company.

Star, S. L. (1999). The ethnography of infrastructure. *American Behavioral Scientist, 43*(3), 377–391.

doi:10.1177/00027649921955326

Steindal, S. A., Bredal, I. S., Ranhoff, A. H., Sørbye, L. W., & Lerdal, A. (2015). The last three days of

life: A comparison of pain management in the young old and the oldest old hospitalised

patients using the Resident Assessment Instrument for Palliative Care. *International Journal

of Older People Nursing, 10*(4), 263–272. doi:10.1111/opn.12076

Valentine, C. (2007). Methodological reflections: Attending and tending to the role of the researcher

in the construction of bereavement narratives. *Qualitative Social Work, 6*(2), 159–176.

doi:10.1177/1473325007077237

VID Specialized University (2021, May 11). PhD programme in diaconia, values and professional

practice. https://www.vid.no/en/research/research-education-1/vids-phd-programmes/

Virdun, C., Luckett, T., Davidson, P. M., & Phillips, J. (2015). Dying in the hospital setting: A systematic

review of quantitative studies identifying the elements of end-of-life care that patients and

their families rank as being most important. *Palliative Medicine, 29*(9), 774–96.

https://doi.org/10.1177/0269216315583032.

Virdun, C., Luckett, T., Lorenz, K., Davidson, P. M., & Phillips, J. (2017). Dying in the hospital setting: A

meta-synthesis identifying the elements of end-of-life care that patients and their families

describe as being important. *Palliative Medicine, 31*(7), 587–601.

Walter, T. (2017). *What death means now: Thinking critically about dying and grieving*. Policy Press.

Woodthorpe, K. (2009). Reflecting on death: The emotionality of the research encounter. *Mortality,

14(*1), 70–86. doi:10.1080/13576270802591228

World Health Organization (2021, February 22). Palliative care. https://www.who.int/health-

topics/palliative-care

Lisbeth Thoresen
Avdeling for helsefag

2016/2035 Om døden – med andre ord. En tekstanalytisk studie av journaler til pasienter som døde på sykehus

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 01.12.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: VID vitenskapelige høgskole
Prosjektleder: Lisbeth Thoresen

Prosjektbeskrivelse (revidert av REK)

Formålet med dette prosjektet er å undersøke hvordan helsepersonell dokumenterer pasientens fire siste levedøgn i pasientjournal.

Journaler er en svært viktig, men lite brukt kilde til kunnskap om eksisterende helsefaglig praksis. Å studere dokumentpraksis er særlig viktig når det gjelder alvorlig syke og døende pasienter fordi disse kan være for syke til å uttrykke egne ønsker og behov eller delta i beslutningsprosesser. Gjennom analyse av journaltekster kan man få tilgang til de kunnskapsformer som regulerer hvordan vi forstår og følgelig hvordan vi dokumenterer hva som er verdt å vite/skrive om behandling og omsorg av den døende. I prosjektet vil det belyses hva helsepersonell anser som verdt å dokumentere om behandling og omsorg i livets sluttfase.

I prosjektet skal det gjennomføres tekstanalyse av anonymiserte utdrag av pasientjournaler til 60 voksne pasienter som døde på medisinske sengeposter, med spesielt fokus på hvilke observasjoner som dokumenteres, om døden er «synlig» og om pasientens stemme er tilstede i journalen. Det skal videre undersøkes hvordan beslutningsprosesser formes i journalen.

Utdrag av pasientjournal som skal benyttes i prosjektet omfatter løpende journaltekst fra de fire siste levedøgn, inkludert epikrise og behandlingsplan.

Vurdering

Formålet med prosjektet er primært å undersøke helsepersonellets praksis og forholdet til pasientens medvirkning på beslutningsprosesser. Etter komiteens vurdering er ikke dette å forstå som forskning på helseopplysninger med tanke på å frembringe ny kunnskap om helse og sykdom som sådan. Prosjektet er av den grunn å anse som helsetjenesteforskning.

Helsetjenesteforskning er et flerfaglig vitenskapelig felt hvor man studerer hvordan sosiale faktorer,

finansieringssystemer, organisatoriske strukturer og prosesser, helseteknologi og personellatferd påvirker tilgang til helse - og omsorgstjenester, kvaliteten og kostnadene ved helse og omsorgstjenester, og endelig helse og velvære.

Helsetjenesteforskning er også forskning på forbedring av helsetjenesten og effektiv bruk av ressurser for samfunnet. I helsetjenesteforskningen studerer man blant annet hvordan helsetjenester leveres, hvordan de er utformet, og hvordan helsetjenesten fungerer som system.

Helsetjenesteforskning omfattes ikke av helseforskningslovens virkeområde, som omfatter prosjekter med det formål å skaffe ny kunnskap om helse og sykdom, jf. helseforskningsloven § 2 og § 4 a, og er dermed ikke fremleggingspliktig for REK.

Prosjektet innebærer bruk av journalopplysninger som utløser krav om dispensasjon fra taushetsplikten for uthenting og anonymisering av opplysninger. REK er gitt myndighet i henhold til delegasjonsvedtak fra Helse- og omsorgsdepartementet, til å kunne dispensere fra taushetsplikten for tilgang til helseopplysninger som er underlagt taushetsplikt, jf. helsepersonelloven § 29, helseregisterloven § 15 og forvaltningsloven § 13 d for bruk til forskning. Det følger videre av helsepersonelloven § 29 at REK kan knytte vilkår til et slikt vedtak.

Det grunnleggende etiske prinsipp som kommer til uttrykk ved kravet om samtykke for utlevering og behandling av helseopplysninger, er retten til selv å bestemme over anvendelsen av egne helseopplysninger i forskning. Hovedregelen om samtykke kan bare fravikes dersom samfunnsnytten er stor og hensynet til deltakernes velferd og integritet er ivaretatt.

Etter komiteens syn har prosjektet tilstrekkelig samfunnsnytte til at det kan gjennomføres som beskrevet i søknad og protokoll, og hensynet til deltakerne synes ivaretatt ved at journaler anonymiseres før utlevering til forsker. Basert på dette har komiteen kommet til at helseopplysningene kan innsamles fra journal og anonymiseres før utlevering til prosjektet.

Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2, og kan derfor gjennomføres uten godkjenning av REK.

Med hjemmel i helsepersonelloven § 29 første ledd, jf. forskrift «Delegering av myndighet til den regionale komiteen for medisinsk og helsefaglig forskningsetikk etter helsepersonelloven § 29 første ledd og forvaltningsloven § 13d første ledd» har komiteen besluttet å gi fritak fra lovpålagt taushetsplikt for uthenting og anonymisering av aktuelle journaler før utlevering til forsker.

Godkjenningen gjelder til 31.08.2019.

Klageadgang

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10 tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst A. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Med vennlig hilsen

Knut Engedal
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Leder

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