

Haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies

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Masteroppgave
i avansert klinisk sykepleie med
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Tittel: Sykepleieres erfaringer med palliative forløp hos pasienter med livstruende hematologisk kreft

Bakgrunn

1. Hematologiske kreftpasienter mottar behandling til sent i sykdomsforløpet, og palliativ pleie, omsorg og behandling introduseres ofte først ved livets slutt, eller ikke i det hele tatt. Tidligere studier har undersøkt sykepleieres erfaringer med omsorg ved livets slutt, det er nødvendig med ytterligere forskning på sykepleieres erfaringer med palliative forløp fra tidlige stadier av sykdommen.
2. Vi har felles yrkesbakgrunn med intervjudeltagerne, og noen av intervjudeltakerne er våre kollegaer. Vi reflekterer rundt hvordan vår forforståelse kan påvirke datainnsamlingen i studien.

Hensikt

1. Å utforske sykepleieres erfaringer med palliative forløp hos pasienter med livstruende hematologisk kreft.
2. Refleksjon rundt forforståelsens betydning for datainnsamlingen i en kvalitativ studie.

Metode

1. Kvalitativ metode med beskrivende og utforskende design ved bruk av individuelle semistrukturerte intervju med 12 sykepleiere fra fire hematologiske avdelinger i Norge. Datamaterialet ble analysert ved hjelp av systematisk tekstkondensering. COREQ sjekkliste for rapportering av kvalitative data ble fulgt.
2. Refleksjonsoppgave.

Resultat

1. Funnene i studien deles inn i tre kategorier: fokus på å kurere forsinker integrasjon av palliativ behandling, dialog med pasienten fremmer palliativ behandling og behov for en forbedret interdisiplinær forståelse.
2. Refleksjon rundt vår forforståelse og mulige utfordringer og fordeler knyttet til datainnsamlingsprosessen. Faglige og personlige erfaringer, samt egne forventninger til funn kan både bevisst og ubevisst påvirke datainnsamlingen i en kvalitativ studie.

Konklusjon

1. Integreringen av palliativ behandling forhindres av et fokus på kurasjon. Åpenhet om døden og økt dialog med pasienter vil gi mulighet for pasientmedvirkning. Tverrfaglig samarbeid der sykepleiere deler sin innsikt om pasienters behov og bekymringer med leger kan bidra til mer helhetlige palliative forløp.
2. Refleksjon over vår forforståelse økte bevisstheten om hvordan den påvirker datainnsamlingsprosessen. Denne bevisstheten kan forhindre negative påvirkninger og bidra til å åpne for ny kunnskap.

Nøkkelord:

Hematologisk kreft, hematologi, sykepleie, palliativ pleie, kvalitativ forskning

ABSTRACT

Lovisenberg Diaconal University College
Date: 1 June 2022

Title: Haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies

Background

1. Patients with haematological malignancies receive treatment until late in their illness trajectories and palliative care is introduced late, if at all. Previous studies have investigated nurses' experiences with end-of-life care, further research is however required on nurses' experiences with palliative care trajectories from early stages of the illness.
2. We have a common professional background with the participants interviewed, as well as a collegial relationship with some. We reflect on how our preconceptions can affect the data collection in our study.

Aim

1. To explore haematology nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies.
2. Reflection around the significance of preconceptions for the data collection in a qualitative study.

Methods

1. Qualitative method with descriptive and explorative design using semi-structured interviews with 12 nurses from four haematology wards in Norway. Data was analysed using systematic text condensation. The Consolidated criteria for reporting qualitative research was followed.
2. Student reflection.

Result

1. Three categories emerged: focus on a cure delays integration of palliative care, dialogue with patients facilitate palliative care and a need for an enhanced interdisciplinary understanding.
2. Reflection around our preconceptions, as well as possible challenges and advantages related to the data collection process. Professional and personal experiences, as well as our own expectations can, consciously and unconsciously, affect the data collection in a qualitative study.

Conclusion

1. Integration of palliative care is hindered by a curative focus. Openness about death and enhanced dialogue with patients would allow for patient participation. Inter-disciplinary cooperation where nurses share their insights on patients' needs and concerns with doctors could contribute to more holistic palliative care trajectories.
2. Reflection on our preconceptions raised awareness of how this could affect the data collection process. This awareness can prevent negative effects and help to foster new knowledge.

Keywords:

haematologic malignancies, haematology, nursing care, palliative care, qualitative research

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1. Del 1: Artikkel

Title

Haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies: A qualitative study

Running title

Experiences with palliative trajectories

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Conflict of Interest Statement

The master students declare no conflict of interest.

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Author contribution

Design: SM, AKM and IS; data collection and drafting the manuscript: SM, AKM and IS; Data analysis: SM, AKM, IS and SAS; critical reviewing the manuscript: MEK and SAS. All authors approved the final version of the manuscript.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies: A qualitative study

Abstract

Aims and objectives: To explore haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies.

Background: Patients with haematological malignancies receive curative or life-prolonging treatment until late in their illness trajectories and palliative care is introduced late, if at all. Patients would benefit from earlier integration of palliative care. Previous studies have investigated nurses' experiences with end-of-life care, further research is however required on nurses' experiences with palliative care trajectories from early stages of the illness.

Design: A qualitative study with a descriptive and explorative design.

Methods: Data was collected through 12 individual semi-structured interviews with nurses working with patients with haematological malignancies from four hospitals in Norway. Data was analysed using systematic text condensation. The study was reported according to the Consolidated criteria for reporting qualitative research guidelines.

Results: Three categories emerged from the data analysis: focus on a cure delays integration of palliative care; dialogue with patients facilitates palliative care; and a need for an enhanced interdisciplinary understanding.

Conclusions: Nurses experienced that the integration of palliative care was hindered by a medical focus. The nurses described a lack of openness about death and believed that enhanced dialogue with patients would enable patient participation. Enhanced interdisciplinary cooperation between nurses and doctors could improve long-term planning and patients' palliative care trajectories.

Relevance to clinical practice: Haematologists need to be made aware of the benefits of palliative care, and how it can be applied in conjunction with standard treatment throughout the patient's illness trajectory. Arenas for the exchange of observations and assessments between haematological doctors and nurses are vital for improving palliative care planning, and establishing such arenas should be a priority. Palliative care should be included in official guidelines, and internal procedures for securing holistic palliative care trajectories must be established in the wards.

KEYWORDS

haematological malignancies, haematology, nursing care, palliative care, qualitative research

What does this paper contribute to the wider global clinical community?

- Nurses experience that openness about death and enhanced dialogue with patients are key to early integration of palliative care.
- More arenas for inter-disciplinary cooperation between nurses and doctors could improve planning and integration of palliative care.
- Nurses' insights on patients' needs and concerns should be valued as they could contribute to more holistic palliative care trajectories, as well as ensure a person-centred care approach.

INTRODUCTION

In the past few decades, there have been significant advances in the treatment of patients with haematological malignancies. However, many patients still die from their disease or from treatment complications (Wedding, 2021). Haematological malignancies are a group of blood cancers with heterogenous disease trajectories that can be broadly categorised into four subgroups: Hodgkin's lymphoma, non-Hodgkin's lymphoma, multiple myeloma and leukaemia (Krok-Schoen et al., 2018; Wedding, 2021). Haematological malignancies caused around 7% of all cancer deaths globally in 2020 (Sung et al., 2021). This number is expected to increase in the future as the world's population continues to age, and haematological malignancies have a higher prevalence and mortality in those aged 65 years or more, compared to younger adults (Krok-Schoen et al., 2018). The increasing prevalence of haematological malignancies indicates that a large proportion of these patients could have an extensive need for palliative care (Wedding, 2021). In a recent consensus-based definition, palliative care is defined as the active holistic care of individuals with serious health-related suffering because of severe illness, and aims to improve the quality of life of patients, their families and their caregivers. Palliative care is applicable throughout the course of an illness in conjunction with treatment (Radbruch et al., 2020).

Studies have shown that combining palliative care and oncological treatment gives several advantages such as improved survival and symptom control, less anxiety and depression, reduced use of futile chemotherapy at the end of life and improved family satisfaction and quality of life (Dowling et al., 2020; Elliott et al., 2021; Kaasa et al., 2018). However, research shows that patients with haematological malignancies are less likely to be referred to palliative care, and for those who are, this tends to occur later in their illness trajectory compared to patients with other types of cancer (Hui et al., 2014; Vanbutsele et al., 2019; Wedding, 2021). Patients with haematological malignancies also have a higher risk of dying in hospital due to complications from the aggressive treatment, and as a result palliative care is often provided within a haematology oncology unit (Elliott et al., 2021; Hui et al., 2014; Manitta et al., 2010).

BACKGROUND

Due to the many advantages of early palliative care in oncological treatment, both patients and healthcare services would undoubtedly benefit from this integration (Kaasa et al., 2018). There are several barriers to integrating palliative care into the care of patients with haematological malignancies, such as the patient's uncertain prognosis and unpredictable illness trajectory, clinical optimism due to new therapies and clinical trials and lack of awareness of palliative care services (Manitta et al., 2010; Wedding, 2021). However, there is little research available on palliative care to patients with haematological malignancies, and even less on their palliative care trajectories (Moreno-Alonso et al., 2018; Wedding, 2021).

As haematology nurses work closely with both patients and haematologists, they can provide valuable knowledge about these patients' palliative care trajectories. However, previous studies have investigated haematology nurses' experiences and perspectives with end-of-life care (Grech et al., 2018; McCaughan et al., 2019; McGrath & Holewa, 2006, 2007a, 2007b). One study identified that factors such as close clinician-patient bonds, delayed end-of-life discussions and barriers at discharge contributed to patients receiving end-of-life care and dying in hospital (McCaughan et al., 2019). Other studies have explored haematology nurses' experiences with an aim to develop a model for end-of-life care for patients with haematological malignancies. This model describes how factors such as openness to addressing death and an organisation open to discussing palliative care services can facilitate integration of palliative care into haematology (McGrath & Holewa, 2006, 2007a, 2007b). Findings also suggest that the lack of integration of palliative care in the medical treatment of patients with haematological malignancies, preventing a dignified end-of-life, leads to nurses reporting a high level of emotional distress and powerlessness (Grech et al., 2018; McGrath & Holewa, 2006).

To the best of our knowledge, no studies have investigated nurses' experiences with palliative care trajectories of patients with haematological malignancies from early stages of the illness. Consequently, the aim of this study was to explore haematological nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies.

METHODS

Design

This study employed an exploratory and descriptive qualitative design, which allows for flexibility to investigate and develop new knowledge on topics with limited coverage within clinical nursing research (Hunter et al., 2019). The data was collected through individual semi-structured interviews. This approach could allow nurses time to reflect and express their experiences in their own words, and make it possible to study and understand the nurses' insight on palliative care trajectories regarding patients with life-threatening haematological malignancies (Polit & Beck, 2021).

Participants and recruitment

The participants were recruited by purposeful sampling from haematological wards in four hospitals at national, regional and local levels in eastern and western regions of Norway. Purposeful sampling was chosen to gain varied and rich data about nurses' experiences (Polit & Beck, 2021). To be included in the study the participants had to be registered nurses with a minimum of two years work experience caring for patients with life-threatening haematological malignancies.

A total of 12 nurses agreed to participate in the study: three from a local hospital, four from two regional hospitals, and five from one hospital with both regional and national functions. The sample is further described in Table 1.

Data collection

The interviews took place from November 2021-January 2022 and lasted between 28 and 56 minutes (average 39 minutes). They were conducted at the participants' workplace and were audiotaped.

A semi-structured interview guide was used to facilitate reflection and dialogue with the participants. The guide covered aspects related to nurses' experiences with palliative care trajectories with focus on competency, initiative, decision-making, communication, and cooperation. The participants were encouraged to talk about their experiences with both

dignified and undignified illness trajectories, and how they were affected by working with this group of patients. A pilot interview was conducted on an experienced nurse from our workplace to ensure that the questions in the interview guide were relevant and understandable. After the pilot one additional question was included to the interview guide regarding how the nurses experienced working with patients with life-threatening illnesses.

Each interview was conducted by two master students. One master student interviewed the participant, whilst the other took notes and ensured that the topics in the interview guide were sufficiently covered. To build trust, the master students introduced themselves and explained what their role in the interview setting was. With an open and curious attitude the master students avoided guiding the conversation, but instead encouraged the informants to share their experiences (Brinkmann & Kvale, 2015). Probing questions such as “Could you tell us a little more? Can you give an example? How did you experience that?” were asked to encourage the participants to elaborate their answers (Polit & Beck, 2021). During the interviews the master students restated or summarized their interpretation of what the nurses expressed and then questioned the participants to determine the validity of their interpretations. At the end of the interview, the nurses were given an opportunity to speak freely, and to reflect on both the topic and any last thoughts. Immediately after each interview the master students wrote down their main impressions from the interview to grasp what was perceived as the most important themes.

Data analysis

The interviews were transcribed verbatim and analysed inductively using systematic text condensation (STC) (Malterud, 2012). STC is a descriptive and explorative method consisting of an iterative four-step process to decontextualize and analyse interview data to gain accurate recontextualized essences of participants’ experiences as they were narrated (Malterud, 2012). First the transcripts were read several times to get an overview of the material and to identify preliminary themes guided by the aim of the study. Each master student identified six to eight preliminary themes and through discussion, agreement on three preliminary themes was reached: a curative focus downgrades palliative care, a need for increased patient involvement and early integration of palliative care. The data material was re-read, and meaning units were identified and organised into three code groups. The meaning units in each code group were organised into two to three subgroups. Then, the meaning units in each subgroup were

condensed into a summarizing quote which formed the basis for the development of an analytical text. The subgroups in each code group were abstracted to a category. The categories were reviewed for consistency and grounding with the original transcripts.

The transcripts and analysis were not returned to the participants for comments or corrections.

An example of the analysis process is shown in Table 2.

Trustworthiness

The master students are registered nurses with experience in palliative care in haematology and shared a preconception that a strong focus on curative treatment leads to palliative care only being considered late in the disease trajectory. By identifying and discussing both individual and shared preconceptions, the master students maintained a conscious, critical and reflective approach to data collection and interpretation (Polit & Beck, 2021).

To further enhance credibility, the development of the interview guide, the data collection process and the data analysis were discussed with supervisors who have experience in palliative care and haematology (Graneheim & Lundman, 2004). The master students and the supervisors had regular discussions on the results of each step of the analysis process, with different perspectives on data interpretation and relevance (Malterud, 2012). Together, a shared consensus on the final analysis and categories was reached, and a logbook of important decisions was maintained for reflexivity (Polit & Beck, 2021).

The nurses were recruited from four hospitals with local, regional and national functions. This ensured that the nurses had experience with patients in all stages of their disease and shared these experiences from various perspectives. Also, the participants differed in age, work experience as a nurse, work experience in haematology and post-graduate education which gave a richer variation in responses and enhanced credibility (Graneheim & Lundman, 2004).

The master students had a professional relationship through work with five of the participants. These interviews were conducted by the master students who were least acquainted with the respective participant to enable the participants to express their thoughts more freely.

Transferability was strengthened by describing the sample, inclusion criteria and analysis process. Descriptions of the findings were supplemented with key quotations to allow the reader sufficient insight to evaluate relevance to other healthcare contexts (Graneheim & Lundman, 2004; Polit & Beck, 2021). To ensure clarity in the reporting of the study, the Consolidated criteria for reporting qualitative research checklist was followed (Tong et al., 2007).

Ethical considerations

The study was approved prior to the data collection by the Norwegian Centre of Research Data (NSD) (reference number: XXXXX) and the data protection officer at each individual hospital. To avoid nurses feeling pressured to participate in the study, participants were recruited by the ward nurse manager of the individual unit, who conveyed their contact details to the master students. All participants gave their signed consent after receiving written information about the project. This included the assurance of confidentiality, that their participation was voluntary and that they could withdraw their consent at any time without consequences (Beauchamp & Childress, 2019). Prior to beginning the interview, the master students repeated information about the voluntary participation in the study.

The data material was stored securely in accordance with the guidelines by the NSD.

FINDINGS

Three categories emerged from the data analysis: focus on a cure delays integration of palliative care, dialogue with patients facilitate palliative care and a need for an enhanced interdisciplinary understanding. Categories and subgroups are described in Table 3.

Focus on a cure delays integration of palliative care

Several nurses had worked with both oncological and haematological patients and reflected on the difference between the two groups in the way palliative care trajectories were integrated. In their experience, oncologists were more familiar with palliative care principles and palliative care was introduced earlier in oncological patients' illness trajectories. Haematologists, on the other hand, often focused on curation until the patients were dying. According to the nurses, haematologists were reluctant to introduce palliative care if there was even a slight chance that patients could recover from their cancer. Nurses expressed that haematologists often wished to try out new medications and include patients in clinical trials and that patients and relatives often expected to be offered the newest treatments. Several nurses believed that the multitude of new treatment options made it ethically difficult to introduce palliative care. As one nurse elaborated:

“It's typically brought up very close to the end when you are more or less dying, far too late, it's as if there's no knowledge that palliative care can last several years. Doctors seem unable to think of palliative care at the same time as giving treatment (...) and if we bring up the need for palliative care, we are often told that it isn't necessary, we aren't at that stage yet.”
(nurse 4)

Two nurses emphasised that it is impossible to know in advance who will survive, and that everybody should be given the opportunity to be cured. These nurses expressed that some patients are still alive because they were offered that chance. However, many nurses felt that treatment continued for too long, resulting in patients dying rapidly once the treatment ended or from treatment complications. Nurses felt that some doctors were better than others at drawing the line and deciding when enough is enough. They also admitted that nurses should take a more active part in raising doctors' awareness of the value of integrating palliative care, especially in regard to frail and older patients receiving high doses of chemotherapy, and sometimes even a bone marrow transplant. The nurses questioned whether milder treatments might be a better alternative for some patients. Although such treatment would not cure the

patients, it could give them a few more good months to live, without the heavy burden of side-effects from chemotherapy and frequent hospital stays. As one nurse put it:

“I think that we sometimes treat them a little too long (...) the boundaries have already been pushed far in respect to age and treatment, and it’s very difficult, I’m glad I’m not a doctor who needs to decide who should receive treatment and who shouldn’t (...) and maybe we give a treatment with poor prospects, in the hope of curing them, and then we end up in situations where we almost feel that we “kill” the patient with the treatment.” (nurse 8)

Dialogue with patients facilitates palliative care

Several nurses emphasised that a dialogue characterised by honest information and attentive communication was important to enable patient participation. In their opinion, this could facilitate a palliative care trajectory that was in accordance with the patient’s wishes.

However, a few of the nurses admitted that the ward lacked a routine for talking to patients about their preferences from the time of diagnosis. Nurses stated that a lack of openness about the possibility of dying and alternative treatments to curative care could result in little time for planning and coordinating care. As a result the patient could sometimes be too sick to be discharged from hospital in time. Some nurses felt that patients received sufficient information that enabled them to make informed decisions about their treatment, and that when it was apparent that the patient might not survive, the nurses and doctors were competent in preparing the patient and their families for the worst outcome. Other nurses felt that the doctors typically “dragged their feet” and waited too long before discussing the patient’s prognosis, and that they should give the patient and their family realistic information about the situation at a much earlier stage. These nurses were concerned that the patients were not sufficiently informed about the possible risks and complications of treatment, and therefore did not have the knowledge to comprehend how sick they could become. As one nurse described:

“After a while we understand that they haven’t understood the consequences of what they have agreed to, and sadly we experience that when they get exhausted someone finally has the courage to ask them, and then the answer is that had I known what I know now I think I would have said no to treatment.” (nurse 4)

Nurses believed that they were highly competent at creating a dialogue about palliative care with their patients. At the same time, they described that doctors and nurses were hesitant to

talk to patients about palliative care and the possibility of dying early in the course of illness.

As illustrated by one nurse:

“In my opinion, we never think about palliative care from the beginning of treatment. We’re very focused on the fact that, yes it’s a serious illness, but we’re going to handle this. I think we rarely talk about death and say: you could die of this. OK, maybe we say it once, but then we don’t talk about it anymore.” (nurse 11)

This could lead to delayed implementation of palliative measures and patients not having the opportunity to express their end-of-life preferences. One nurse felt that the patients, deep down, were often aware of their risk of dying, and that such conversations did not necessarily have to be unpleasant. Many nurses reflected on the challenge to determine the right timing for such a conversation; on the one hand they did not want to take away the patient’s motivation for treatment and hope of survival, but on the other hand they did not want to rob them of time at home with good quality of life and a dignified death.

A need for an enhanced interdisciplinary understanding

The nurses perceived that they were a step ahead of the doctors in identifying patients who might be eligible for palliative care. Nurses expressed that they have a unique insight into the patients’ physical and mental state, and the patients’ individual preferences because they care for patients with haematological malignancies at all hours and in various situations. Many nurses pointed out that although having a specialisation or degree was an advantage, experience was just as important to be able to identify patients in need of palliative care. The nurses attempted to share their observations with the doctors and described advocating the patient’s case as an important part of their work. As one nurse described:

“We try to put forward our points of view, and kind of, speak on behalf of the patient and his or her family. We try to suggest that it might be, purposeful is maybe not the right word, but important for the patient to have a good quality of life, or if we should continue with treatment that only torments them.” (nurse 6)

Some nurses were frustrated since doctors did not seem to listen to their assessments and functioned as a gatekeeper for introducing palliative care. Many experienced nurses on the other hand felt that their voice was heard:

“I think the dialogue is complementary: we are often the ones who bring it up, and then the doctors balance it against what they have experienced can work and what can’t.” (nurse 3)

One nurse spoke of discussions between fellow nurses on how palliative care planning should be considered from the moment the patients receive their diagnosis. The nurses believed that it was their duty to take an active part in the establishment and evaluation of a treatment plan because haematology patients often experience acute changes in health status. Several nurses described frustrating situations during weekends where lack of planning often caused insecurity and decision aversion in doctors who did not have knowledge of the patient’s medical history. The nurses believed that a long-term treatment plan made by the haematologist in charge of the patient would allow for a shared understanding and prepare everyone involved. As one nurse said:

“Maybe have a plan, that if this doesn’t work, considering all the treatment, that we have a plan for when it isn’t purposeful anymore, a plan for what we should do, together with the patient. That the patient also knows, is prepared maybe, for the possibility that if this doesn’t work, then OK, we have reached a new phase.” (nurse 6)

The nurses maintained the doctor’s right to have the final say in the decision-making process, as they have the ultimate responsibility for the patient. However, they also believed that there was much to gain by nurses contributing to the decision-making process regarding palliative care, as the nurses’ input could improve palliative care planning.

Nurses argued that there was a lack of arenas for information exchange between nurses and doctors. Segregated planning meetings were perceived as a barrier to cooperation. Also, several nurses found it challenging to speak up at their daily meeting with the haematologists due to time constraints and because these meetings were dominated by doctors. Nurses stressed how important it was to understand the reason behind the doctors’ decisions regarding implementation of palliative care, given that explaining medical and treatment decisions to the patients was often a nurse responsibility. To ensure satisfactory patient trajectories the nurses expressed a need for a weekly interdisciplinary meeting where they could discuss complicated patient cases. The nurses hoped that such a meeting could contribute to a common understanding of the treatment’s objectives and expected outcome, as well as allowing for ethical reflections regarding palliative care trajectories. One nurse had

positive experiences of interdisciplinary cooperation:

“We discuss amongst ourselves since we experience things differently and have contrasting standpoints (...) the focus is on working as a team and not as separate professions, which benefits the entire ward.” (nurse 11)

DISCUSSION

This study provides insight into nurses' experiences regarding palliative care trajectories of patients with life-threatening haematological malignancies. The findings suggest that integration of palliative care was hindered by a curative focus because there may be a chance that patients can recover. The nurses experienced a lack of openness about death and believed that enhanced dialogue with patients, as well as inter-disciplinary cooperation, could improve palliative care trajectories.

Our nurses believed that patients should have the opportunity of benefitting from medical progress and new treatments, which could lead to a better chance of survival or prolonged life. Nevertheless, in line with previous studies (Grech et al., 2018; McCaughan et al., 2019; McGrath & Holewa, 2006), nurses in the present study experienced that this medical focus delayed the integration of palliative care. In haematology, where the treatment goal primarily is to cure or to prolong life, there might be insufficient knowledge of the benefits of early integration of palliative care (El-Jawahri et al., 2020; Kaasa et al., 2018). However, patients with haematological malignancies have extensive palliative care needs already from the time of diagnosis and throughout their illness trajectory, as they receive intensive treatments such as stem-cell transplants and high-dose chemotherapy regimens with a high risk of toxicity and mortality (El-Jawahri et al., 2020).

Our nurses experienced the doctors' decision on whether to continue treatment as ethically difficult and that some treatments were futile. According to Benner et al. (2011), the decision to continue or terminate treatment needs to be based on both ethical and clinical reasoning, as it is unethical to either provide futile care or not to offer patients the best available medication. Reports from the Lancet oncology commission and Lancet commission on value of death indicate that patients and doctors tend to be treatment focused in situations of uncertainty because they hope for prolonged survival (Kaasa et al., 2018; Sallnow et al., 2022). Also, offering curative therapies seems to have become synonymous with caring for patients (Benner et al., 2011). Our nurses felt that the treatment sometimes continued for too long and questioned its aggressive nature especially when administered to frail patients. The option of not treating should be actively considered (Benner et al., 2011) as new treatments

often extend life only marginally, and end-of-life chemotherapy produces more harm than good in patients aged 80 years or older (Krok-Schoen et al., 2018; Sallnow et al., 2022).

Our nurses had different experiences of how well patients were informed, and some believed that a lack of timely and honest information hindered a dialogue with patients. Honest discussions, even when the prognosis is poor, could enhance the relationship between patients and the medical team. However, avoiding prognostic discussions could lead to mistrust, anxiety, reduced quality of life and family distress (Kaasa et al., 2018). The nurses believed that explaining different scenarios prepared the patients for what was to come and gave them the possibility to participate and make informed decisions about treatment and care throughout their illness trajectory. This concurs with a study indicating that early, frank discussions with the patient and their family about likely treatment outcomes could avoid unrealistic expectations (McCaughan et al., 2019). Research indicates that prognostic outcomes when treating haematological malignancies are often hard to predict, and it is challenging for patients to decide whether aggressive treatment is worth the suffering involved (Wedding, 2021). A lack of understanding of prognosis could make patients overestimate the chance of cure and is associated with an increased willingness to accept chemotherapy (El-Jawahri et al., 2020). Even if patients have received information about their disease and prognosis, they may not be able to understand the intention of the treatment (Sallnow et al., 2022) or remember the information later (Wedding, 2021). Kaasa et al. (2018) underlined the importance of assessing what patients already know and the level of detail they want, as well as using non-technical language when explaining, encouraging questions, verifying their understanding and adapting the communication to meet the patient's needs.

Our study suggests that the nurses regarded themselves as competent in discussing palliative care with patients, however, in line with the study by McCaughan et al. (2019), they hesitated in discussing death and found it challenging to find the right time for these conversations. According to our nurses this could prevent patients from expressing their end-of-life wishes. Each patient has individual beliefs, values and needs that should be reflected in their care (Österlind & Henoeh, 2021). Through dialogue the nurse can allow the patient to express how they experience their situation and their preferences and be a co-creator of their palliative care trajectory. This person-centered care approach allows the nurse to help the patient to live as good a life as possible during their palliative care trajectory (Österlind & Henoeh, 2021). The Lancet commission on the value of death underlined that such discussions are essential and

should be seen as a professional responsibility throughout the illness trajectory (Sallnow et al., 2022). Nurses can experience a human and nursing failure in care when patients do not have time to prepare for death. Therefore, it is important that nurses work towards bridging this gap by discussing human aspects such as the patient's concerns, fears and hopes (Benner et al., 2011).

In order to meet the complex needs of patients with life-threatening diseases, palliative care is often provided by a multidisciplinary team with professionals from different disciplines (Leclerc et al., 2014; World Health Organization, 2016). In contrast, patients with haematological malignancies mainly receive palliative care by their haematology team (Wedding, 2021). Our nurses believed that an enhanced interdisciplinary approach where doctors and nurses discuss patients and share their assessments, could lead to a common understanding and more holistic palliative care trajectories. However, our nurses reported a lack of arenas to meet and discuss with doctors to allow for this exchange. Interdisciplinary cooperation entails that professional groups share knowledge and plan care together (Klarare et al., 2013; Leclerc et al., 2014).

Our nurses described that doctors and nurses had different understanding of the palliative needs of patients with haematological malignancies, and that they spend considerable amounts of time with their patients and therefore can contribute with vital medical information as well as the patient's perspective. In line with previous studies (Grech et al., 2018; McCaughan et al., 2019) our nurses described advocating the patient's needs and concerns as an important nurse responsibility. This could be explained by the fact that most of the participants were experienced nurses. According to Benner (1984), the expert nurse understands the value and responsibility of being the patient's advocate as this allows the patient to participate and have control over their treatment. In contrast, the novice nurse might have a more technical care approach where he or she mainly administers and monitors complex treatments, and therefore does not have the same holistic approach to the patient (Benner, 1984).

Because of their knowledge of the patients' needs and concerns our nurses believed they could influence and improve palliative care planning. They experienced that their engagement in establishing and updating a treatment plan was important for a common understanding in the medical team. In accordance with the study by Grech et al. (2018), our nurses saw a need

for establishing a treatment plan already from the time of diagnosis, which should be a standard approach for all oncology patients (Kaasa et al., 2018). A treatment plan containing prognostic information and guidelines for different trajectories could be beneficial to organising clinical care. Furthermore, such a plan could help patients and their families to better understand and cope with their situation (Benner et al., 2011; Kaasa et al., 2018).

Limitations

The ward manager of the different wards recruited the participants and may have recruited participants that represented their own or the ward's views regarding palliative care trajectories, or whom they knew would represent the ward in a favourable manner.

A sample of twelve nurses might be considered small. However, the participants had diversity of experiences and provided rich data related to our study's aim. We perceived that during the interviews the nurses shared their reflections and experiences openly and honestly. The sample size was therefore considered to have sufficient information power (Malterud et al., 2016). Participants were selected from eastern and western parts of Norway and the majority of the nurses had extensive clinical experience; all except three had a post-graduate degree in nursing. Nurses from other geographical parts of Norway and novice nurses could have other experiences.

Nurses who were familiar with the master students and the established social norms at their mutual workplace, may have been hesitant to talk about sensitive topics or to challenge the institutional rules and conventions. They may also have made assumptions regarding the master student's preconceptions, goals and knowledge of various topics, which might have limited the answers they provided (McEvoy, 2002). When reviewing the interviews of the nurses in question, these nurses shared experiences that were both critical and supportive of current practices.

The interviews were conducted by two master students, which may have affected the participants' ability to relax and feel comfortable giving candid and genuine answers since they were in the minority during interviews (Polit & Beck, 2021).

CONCLUSION

The nurses experienced that integration of palliative care was hindered by a medical focus with an aim to cure or prolong life, which could lead to patients being overtreated. The nurses described a lack of openness about the possibility for palliative care and death, and believed that enhanced dialogue with patients would allow them to understand their prognosis, include them in treatment decisions and give them time to prepare for death. The nurses also believed that enhanced interdisciplinary cooperation could improve long-term planning and subsequently patients' palliative care trajectories. However, they experienced a lack of arenas where they could share their assessments and discuss patients with doctors. Nurses' insights on patients' needs and concerns could contribute to more holistic palliative care trajectories as well as ensure a person-centred care approach. Future research should therefore focus on ways to improve collaboration between nurses and doctors working in haematology wards. Based on our findings, we would also recommend further research into the development of palliative care guidelines, which incorporates knowledge from both haematologists and haematological nurses. Involving patients and relatives in the development of these guidelines can further improve patients' illness trajectories.

RELEVANCE TO CLINICAL PRACTICE

To improve palliative care trajectories of patients suffering from life-threatening haematological malignancies, there is a need for more openness and dialogue around death and palliative care already from the time of diagnosis. Haematologists need to be made aware of the benefits of palliative care, and how it can be applied in conjunction with standard treatment throughout the patient's illness trajectory. Furthermore, arenas for exchange of observations and assessments between doctors and nurses are vital for improving palliative care planning, and establishing such arenas should be a priority. To achieve this, palliative care has to be included in official guidelines to patients with haematological malignancies, and internal procedures for securing holistic palliative care trajectories must be established in the wards.

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TABLE 1 Characteristics of study participants

N=12	
Age range (mean)	30-52* (40.0)
Years of work experience as registered nurse (mean)	5.5-28.5* (14.1)
Years of experience in haematology (mean)	5-28.5* (13.6)
Bachelor of science in nursing	3
Other postgraduate education	6
Master of science in nursing	3

*Range.

TABLE 2 Example of stepwise analysis from unit of meaning to category using STC

Unit of meaning	Subgroup	Category
<p>We give input based on our observations, we also have a dialogue with the patients beyond the very limited timeframe the doctors are present for a visit, sometimes the patients express their fatigue, that they have had enough, and we have to communicate that to the doctors. (nurse 7)</p> <p>We spend a lot of time with the patient, discuss a lot with the patient and his or her relatives, and we can often get an impression of where they stand and what they want. (nurse 10)</p> <p>We see the patients many more hours than the doctors do. The patients may look ok during the visit of the doctor, but they are not. I believe the doctors are sometimes a bit surprised that we bring up palliative care, but it starts a process and after a while they agree with us. (nurse 9)</p>	<p>Nurse observations and competence is important for the patients' trajectories</p>	<p>A need for an enhanced interdisciplinary understanding</p>
<p>To think holistic at a much earlier stage, bring in more resources and make a plan that reflects what the patient's goal is – not what our goal is. (nurse 4)</p> <p>In general, I experience that we talk about palliative care at the end when the patient is terminal or preterminal. (...) it could have been initiated a little earlier, because there are many aspects both the patient and relatives have to think about at the end, if things had been clarified earlier then it might have been better for everyone. (nurse 5)</p> <p>I firmly believe the nurse should ask the doctor about the patient's outlook (...) what is the plan, is further treatment advisable? (nurse 12)</p>	<p>Planning is necessary to ensure satisfactory patient trajectories</p>	
<p>More interdisciplinary venues where we could decide together, plan and establish a treatment plan (...) containing details about what the patient's wishes are going forward. (nurse 10)</p> <p>So, I think it would be wise that the nurses are included in the decision-making process because a joint meeting would help the nurses understand the doctors' thought processes. (nurse 2)</p> <p>Patients with haematological malignancies are often very complicated cases. I think communication between us and the doctors is critical, and improvements here will benefit the patient as well. (nurse 5)</p>	<p>There is a need for interdisciplinary cooperation and platforms for information exchange</p>	

TABLE 3 Description of categories and subgroups

Category	Subgroup
Focus on a cure delays integration of palliative care	Focus on a cure prevents palliative care planning There is always new treatment to be tested, but when is enough enough?
Dialogue with patients facilitate palliative care	Lack of openness around death and palliative care Communication and information is crucial for patient participation
A need for an enhanced interdisciplinary understanding	Nurse observations and competence is important for the patients' trajectories Planning is necessary to ensure satisfactory patient trajectories There is a need for interdisciplinary cooperation and platforms for information exchange

2. Del 2: Refleksjonsoppgave

INNLEDNING

Hensikten med masterprosjektet vårt var å utforske hvilke erfaringer sykepleiere har med palliative forløp til pasienter med livstruende hematologisk kreft. I masterprosjektet benyttet vi kvalitativ metode for å utforske sykepleiernes erfaringer. Data ble samlet ved 12 individuelle semistrukturerte intervju av sykepleiere ved fire ulike sykehus som førte til rike og varierte erfaringer fra sykepleiere som jobber med hematologiske kreftpasienter.

Vi jobber i en av avdelingene som deltok i studien, og har derfor førstehåndskjennskap til temaet og personlige relasjoner til noen av intervjudeltakerne. Det var spesielt viktig å vurdere betydningen av egen forforståelse for gjennomføringen av masterprosjektet. Faglige og personlige erfaringer, og egne forventninger til funn, kan både bevisst og ubevisst påvirke hvordan data samles, leses og tolkes (Malterud, 2017). Anerkjennelse og refleksjon over egen forforståelse kan gjøre oss i stand til å gjengi informantenes historier på en lojal måte (Malterud, 2017).

Forforståelsen kan påvirke flere stadier av forskningsprosessen. Vi har valgt å fokusere på hvordan forforståelsen påvirker innsamling av data, da dette er en sårbar prosess der forforståelsen til masterstudenter kan påvirke datamaterialet man ender opp med. Vi reflekterer rundt følgende problemstilling:

Hvilken betydning har forforståelsen for datainnsamlingen i en kvalitativ studie?

PRESENTASJON AV EGEN FORFORSTÅELSE

Vår forforståelse er preget av at vi jobber på en hematologisk avdeling som behandler pasienter med alvorlige hematologiske kreftdiagnoser. Vi har inntrykk av at fokus på behandling med mål om kurasjon kan stå i veien for god pasientbehandling. Vår forforståelse var at fokus på kurasjon av sykdommen fører til at palliasjon blir et tema sent i forløpet, og at palliasjon kun vurderes ved livets slutt. Vår erfaring og kompetanse om hematologiske kreftpasienter var en viktig motivator i utformingen av studien (Malterud, 2017). Det var imidlertid fare for at vi tok fatt på datainnsamlingen med egne fordommer og manglende åpenhet for ny kunnskap (Malterud, 2017).

For å styrke troverdigheten til vårt masterprosjekt reflekterte vi over betydningen av vår forforståelse, og hvordan denne kunne prege forskningsarbeidet vårt (Polit & Beck, 2021; Tjora, 2021). I arbeidet med å bli mer bevisst forforståelsen har vi sammen diskutert hvilke utfordringer som eksisterer i pasientbehandlingen til denne pasientgruppen. Vi skrev ned vår felles forforståelse før vi begynte datainnsamlingen, og returnerte til denne kontinuerlig i forskningsprosessen. I tillegg ble vi bevisst vår forforståelse gjennom samtaler med veileder i løpet av prosjektet. Selv om det i litteraturen er enighet om at det er vanskelig å bli helt fri fra egen forforståelse (Brinkmann & Kvale, 2015; Malterud, 2017; Polit & Beck, 2021; Sorsa et al., 2015), bidro refleksjon rundt hvordan den påvirker oss til å ta gjennomtenkte avgjørelser i arbeidet med datainnsamlingen.

FORFORSTÅESENS BETYDNING FOR DATAINNSAMLINGEN

Vår interesse for tema og erfaringen vi har fra vår jobb som sykepleiere på hematologisk avdeling setter sitt preg på datainnsamlingen. Brinkmann og Kvale (2015) mener det er en styrke at forskere har god kjennskap til det som forskes på, da forskerne kan gå dypere ned i tematikken under innsamling av data. Det er likevel viktig at forskere har et bevisst forhold til sin subjektivitet i møte med feltet en skal forske på. Det er nødvendig å anerkjenne at våre etablerte verdier og erfaringer påvirker datainnsamlingen på ulike måter, ettersom denne bevisstgjøringen kan begrense u hensiktsmessige påvirkninger (McDermid et al., 2014).

Hensikten med kvalitative intervju er å forstå og innhente informasjon fra informantenes perspektiv (Brinkmann & Kvale, 2015; Sorsa et al., 2015). Våre erfaringer kombinert med teoretisk kunnskap gjorde det mulig for oss å utarbeide relevante spørsmål til intervjuguiden. Spørsmålene i intervjuguiden ble omhyggelig utformet, da det var viktig at de ikke var konstruert for å få svar som var i tråd med vår forforståelse. Målet med datainnsamlingen var å være åpen for det ukjente, ikke å få bekreftet det vi mente var riktig. Intervjuguiden bestod derfor av åpne spørsmål slik at informantene kunne snakke fritt under de tema som var bestemt på forhånd. Oppfølgings spørsmål som “Kan du si litt mer om det?”, og “Kan du gi eksempler på hva du mener?” ble lagt til i tilfelle det var behov for å få informantene til å uttrykke seg mer detaljert (Thagaard, 2018). Intervjuguiden ble diskutert og utarbeidet i samarbeid med veiledere som bidro til at vi fikk mulighet til å drøfte og utfordre vår forforståelse underveis i arbeidet med spørsmålene. En godt planlagt intervjuguide bidro til å unngå å stille ledende spørsmål eller spørsmål som var preget av vår forforståelse. Når man har felles kunnskap om et tema kan man også risikere å unngå å stille oppfølgings spørsmål fordi man tar svarene for gitt (Sorsa et al., 2015). Ved å være to masterstudenter tilstede i intervjuene sikret vi at alle spørsmålene i intervjuguiden ble stilt og besvart.

Hematologi er et spesialisert fagfelt som eksisterer ved få sykehus i Norge. Vi innså derfor tidlig i forskningsprosessen at det ble nødvendig å inkludere sykepleiere fra vår egen avdeling som informanter for å få rike og varierte data som kunne belyse vår problemstilling. Samtidig var det viktig å inkludere sykepleiere som jobbet ved avdelinger hvor man potensielt hadde helt andre opplevelser, slik at vi fikk avdekket ulike erfaringer som kunne gi rike beskrivelser. Løsningen ble å inkludere informanter fra fire forskjellige sykehus som sammen representerer lokalt, regionalt og nasjonalt sykehusnivå. Dette mener vi er en styrke med studien da vi fikk

med informanter med et mest mulig variert erfaringsgrunnlag, og som bidrar med ulike perspektiver på studiens hensikt. Fem av informantene var fra vårt eget arbeidssted, de resterende syv informantene hadde vi ikke noen personlig relasjon til fra tidligere, og var ansatt på de tre andre sykehusene.

Strategisk utvalg ble benyttet for å rekruttere sykepleiere som kunne belyse hensikten fra flere sider. Vi opplevde at antall års erfaring med hematologiske kreftpasienter spilte en viktig rolle, fordi vår oppfatning var at sykepleiere ofte har flere opplevelser med kompliserte pasientforløp jo lengre de har jobbet og derfor har flere erfaringer å dele. Et av inklusjonskriteriene var derfor at sykepleierne måtte ha minst 2 års erfaring ved en hematologisk avdeling. For å unngå at informanter følte press til å delta, eller at vi inkluderte informanter som vi visste ville bekrefte våre antagelser om temaet, rekrutterte vi via avdelingsledere. Alle informantene var kjent med vår felles arbeidsbakgrunn i forkant av intervjuene, så det var en risiko for at dette kunne påvirke kvaliteten på intervjuet (McDermid et al., 2014). For eksempel kunne informantene ha en forventning om hvilke svar vi ønsket, og det kunne hindre dem i å formidle andre erfaringer enn de trodde vi var åpne for. Vi understreket derfor før intervjuene at vi ønsket å få frem flest mulig synspunkt og at ingen svar var feil.

Intervjusituasjonen er en dialog mellom informantene og forskeren om et tema av felles interesse, der begge er med og påvirker datainnsamlingen (Brinkmann & Kvale, 2015). En risiko var at vår forforståelse kunne stå i veien for å være lyttende og undrende til informantenes historier og at vi tolket det informantene sa i lys av vår egen forforståelse (Brinkmann & Kvale, 2015; Sorsa et al., 2015). For å unngå å bli styrt av vår forforståelse strebet vi etter å være aktivt lyttende og åpne for det informantene formidlet i intervjuene. Det var derfor viktig at vi slapp informantene til og unngikk å avbryte dem. Vi ga informantene god tid til å svare, og snakket selv så lite som mulig under intervjuene, dette for å hindre at informantenes svar ble unødig påvirket (McDermid et al., 2014). En strategi var å unngå å ta ordet selv om det ble stille en stund; vi opplevde at dette oppmuntret informantene til å komme med ytterligere refleksjoner rundt det de allerede hadde svart. Vi søkte ofte bekreftelse fra informantene underveis i intervjuet på om vi hadde oppfattet de riktig ved å stille spørsmål for å avklare svarene deres. Det var samtidig viktig å være følsomme for ny innsikt. Vi var bevisste på å ikke stille ledende spørsmål for å unngå å påvirke informantenes svar, og unngå å argumentere for det vi mente var riktig (Sorsa et al., 2015).

Forforståelsen kan være en styrke for forskerne, i den grad at forskerens rolle og kompetanse er et viktig redskap i forskningsprosessen som kan bidra til å bedre forstå informantenes situasjon på grunnlag av egne erfaringer (Thagaard, 2018). Vår felles faglige bakgrunn med informantene gjorde at vi gjenkjente det informantene fortalte. Det var sjelden de trengte å forklare ord og begreper, fordi vi hadde kjennskap til disse fra før og delte mange av de samme erfaringene som informantene, noe som kunne bidra til økt tillit oss imellom (Thagaard, 2018). Tillitt mellom forsker og informant er nødvendig for å skape en trygg atmosfære der informantene tørr å dele sine personlige erfaringer, som igjen kan gi forskeren rike data (Brinkmann & Kvale, 2015; Sorsa et al., 2015). Vår felles faglige bakgrunn kunne også ha negativ påvirkning ved at informantene følte seg gransket når de visste de ble intervjuet av en faglig likemann (Chew-Graham et al., 2002). I tillegg kunne vår kjennskap til feltet føre til at vi overså nyanser som ikke var i samsvar med egne erfaringer (Thagaard, 2018), og det var derfor viktig at vi som forskere kunne erkjenne at informantene kunne komme med andre svar enn vi forventet. Etter vår mening fungerte vår felles erfaring som en katalysator som bidro til å gå i dybden av temaet, og anerkjennelse av gjensidig forståelse bidro til økt kvalitet i datainnsamlingen (McDermid et al., 2014; McEvoy, 2002).

Intervju av kollegaer kan by på utfordringer på grunn av en eksisterende relasjon som kan påvirke svarene man får (Chew-Graham et al., 2002). For eksempel kan sosiale regler og hierarki på avdelingen fungere som en barriere for at informanten deler fritt av sine personlige erfaringer og refleksjoner. For å unngå dette organiserte vi oss slik at den som kjente informanten minst var den som ledet intervjuet, mens den andre masterstudenten tok notater og sikret at alle spørsmål ble besvart. Siden informanter i kvalitative intervju kan oppleve det som utfordrende å snakke om sensitive tema med personer de kjenner, valgte vi derfor intervjuere med minst tilknytning til informanten (McEvoy, 2002). Vår forforståelse var at intervjuene med våre kollegaer kunne gi ensidige data uten ny kunnskap. Siden vi jobber ved samme avdeling og kjenner pasientgruppen godt, antok vi at de fleste delte de samme oppfatningene og erfaringene som vi selv hadde. Derimot kom det frem flere ulike erfaringer og individuelle synspunkt under disse intervjuene som bidro til ny innsikt. Dette kan forklares med at til tross for at man har jobbet på samme arbeidssted over flere år, vil kollegaers ulike alder, bakgrunn, utdanningsnivå og tidligere erfaring påvirke synspunkter og opplevelser, og en kan derfor ikke ta for gitt hvilken innsikt de kan bidra med (McEvoy, 2002).

OPPSUMMERING

I arbeidet med masteroppgaven har forforståelsen vår utviklet seg. Vi fikk anledning til å dykke ned i et fagfelt som vi kjente godt til fra før, men har tilegnet oss ny kunnskap underveis i prosjektet. Gjennom denne refleksjonsoppgaven har vi blitt mer bevisst på betydningen av å reflektere over og redegjøre for egen forforståelse underveis i datainnsamlingen i en kvalitativ studie. Det har vært en styrke å være tre masterstudenter da vi sammen har reflektert over hvordan vår forforståelse påvirker datainnsamlingen. Veiledning har også vært av stor betydning for å reflektere over valgene som ble gjort og har bidratt til bevisstgjøring av vår forforståelse. For å få tak i informantenes erfaringer var det viktig å være aktivt lyttende i intervjuet samt være åpen for det informantene formidlet. Det var fare for at forforståelsen var for styrende og at vi bevisst eller ubevisst påvirket datainnsamlingen, men ved å møte feltet med en reflektert holdning til egen forforståelse kan det åpne for ny kunnskap.

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Vedlegg

Vedlegg 1: Godkjenning NSD

Vedlegg 2: Intervjuguide

Vedlegg 3: Beskrivelse av bidrag for masteroppgave i gruppe

Vedlegg 4: Forfatterveiledning