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Organizational structures influencing timely recognition and acknowledgment of end-of-life in hospitals – A qualitative study of nurses' and doctors' experiences

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ABSTRACT

Purpose: Healthcare personnel's timely recognition and acknowledgment of end-of-life (EOL) is fundamental for reducing futile treatment, enabling informed decisions regarding the last days or weeks of life, and focusing on high-quality palliative care. The aim of this study is to explore and describe nurses' and doctors' experiences of how organizational structures in hospitals influence timely recognition and acknowledgment of EOL. Methods: A qualitative explorative design was applied, with data collected through 12 individual in-depth interviews using a semi-structured interview guide. A total of 6 nurses and 6 doctors were strategically recruited from medical and surgical wards in a Norwegian hospital. Qualitative content analysis was used. Results: The analysis revealed the theme The importance of hospital organizational structures in timely recognition and acknowledgment of EOL and a subtheme comprising three areas of organizational structures influencing timely recognition and acknowledgment of EOL; Challenges to and demands of continuity, collaboration, and time. Conclusions: The study's results show challenges in identifying when cancer patients approach the last weeks and days of life within hospital wards. For nurses and doctors to be able to recognize and acknowledge EOL, continuity of care, collaboration, and time is needed. A fragmented healthcare system, with a predominant focus on treatment and cure, may prevent cancer patients from receiving timely palliative, care causing unnecessary suffering.

1. Introduction

Even though current cancer treatment has become more targeted and effective, more than ten million people die from cancer each year (World Health Organization, 2022). In Western countries end-of-life (EOL) care has shifted to institutions and dying in hospitals has become more complex and medicalized (Gagnon and Duggleby, 2014; Gunasekaran et al., 2019). Healthcare personnel's (HCP) timely recognition of EOL is fundamental for reducing futile treatment, enabling informed decisions regarding the last days and weeks of life, and focusing on high-quality palliative care (Taylor et al., 2017; Temel et al., 2016; Stacey et al., 2019), helping patients to die with dignity (Brenne and Dalene, 2016; Nou, 2017; Binda et al., 2021). Recognizing EOL is challenging for nurses and doctors (Taylor et al., 2017) and differentiating between

reversible- and irreversible causes is difficult (Devery et al., 2022; Bloomer, 2015, 2019). Timely recognition of EOL requires knowledge, experience, courage, and good clinical judgment (Gunasekaran et al., 2019; Luna-Meza et al., 2021).

The economic incentive-driven organization of hospitals, with fragmented care and ill-defined responsibilities for EOL care, has an impact on how healthcare professionals communicate EOL to patients and their experiences of death and bereavement (Stacey et al., 2019). Patients are likely to encounter many experts during a hospitalization period and responsibilities are set aside when it comes to EOL conversations (Stacey et al., 2019). Additionally, hospital cultures often focus on cure and life prolongation, hence providing both curative care and EOL care can be challenging (Devery et al., 2022; Bloomer, 2019). Clinicians continue to provide curative care even when they realize that a patient is dying

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(Bloomer, 2015). Recognizing EOL depends on the collection of relevant information over a longer period (Taylor et al., 2017), in order to recognize the often gradual decline of various organ functions. Therefore, because of a lack of continuity of care, doctors are often unaware of the patient's wishes and continue to deliver futile treatment at EOL (Bloomer, 2019; Hudson et al., 2019).

Although several studies indicate that hospital organization challenges timely recognition of EOL and good EOL care (Stacey et al., 2019; Devery et al., 2022; Bloomer, 2015, 2019; Hudson et al., 2019), this still seems to be a considerable problem. Consequently, these challenges need more attention. We sought to obtain increased knowledge of nurses' and doctors' experiences using qualitative research interviews. The aim of this study is to explore and describe nurses' and doctors' experiences of how organizational structures in hospitals influence timely recognition and acknowledgment of EOL.

2. Methods

A qualitative explorative design was applied with individual indepth interviews using a semi-structured interview guide (Appendix 1), to encourage the participants to openly reflect on their experiences. End-of-life was defined as the last days and weeks of an individual's life. This research was approved by the Norwegian agency for shared services in education and research. Personal data was properly anonymized and stored, using a secure application provided by the University of Stavanger. The participants received written information about the purpose of the study; that participation was voluntary, that they could withdraw at any time, and that full confidentiality was guaranteed. Written informed consent was obtained.

2.1. Sampling and data collection

Nurses and doctors were strategically recruited from one medical and two surgical wards to ensure relevant knowledge of the research topic. The unit managers forwarded the invitation to nurses and doctors who would serve as informants. The inclusion criteria were a minimum of 2 years of work experience in a medical or surgical ward in a hospital, and experience with caring for cancer patients at EOL. Both genders were to be represented.

In total, 7 doctors and 6 nurses accepted the invitation, 8 females and 5 males. One participant dropped out for unknown reasons. The participants were between 22 and 62 years, 4 with less than 5, and 8 with more than 5 years of practice. The interviews were conducted at the hospital by two researchers (GCW, JB), who are experienced nurses, and unknown to the participants. To make the participants comfortable the interview started with an open question about their general experiences, followed by questions from the interview guide. During the interviews, which lasted from 38 to 72 min, follow-up questions were asked to ensure correct understanding. Each interview was recorded using a secure application provided by the University of Stavanger, and was later transcribed by two researchers (GCW, JB). The COREQ checklist was followed to ensure rigor in the study (Appendix 2).

2.2. Analysis

A qualitative content analysis influenced by Graneheim & Lundman (Graneheim and Lundman, 2004; Graneheim et al., 2017; Lindgren et al., 2020) was used. The analyzing process moved between open reading, selecting meaning units, condensing, coding, creating categories, and creating themes (Table 1). An example of the analysis is shown in Table 2.

We found that the data from nurses and doctors were mainly concurrent and are therefore analyzed together. When nurses and doctors had different experiences, this is shown through quotations and in the discussion.

All investigators are HCPs with experience in cancer care. The

Table 1The analyzing process.

Open reading	The data material was read several times to gain familiarity with the text and an idea of the whole picture.
Selecting meaning units	Words, sentences, or paragraphs which contained aspects related to one another were identified.
Condensing meaning units	Shortening of text while preserving meaning and content
Coding	Labeling the condensed meaning units using codes that describe the content.
Creating categories	Interrelated codes were sorted into categories at a manifest level. A total of 3 categories were identified.
Creating subthemes and themes	The latent content was interpreted into one subtheme and one theme.

interviews were transcribed by two authors (J.B and G.C.W). All authors participated in the analysis, and each author individually read the transcribed text several times.

3. Results

We found that all the participants in this study were dedicated to their work, acknowledging their responsibility to reduce futile treatment and focus on well-being of the patient and high-quality EOL care. They related that it was, therefore, difficult to identify when it is time to withdraw from painful treatment and focus on the alleviation of pain and other symptoms. Our data showed that nurses and doctors experienced a wide range of uncertainty working with cancer patients at EOL. The uncertainty was founded on the fear of making mistakes, the complexity of noticing signs of EOL, the evaluation of when "enough is enough" regarding treatment and invasive examinations, the difficulties with predicting life expectancy, challenging EOL communication, and not knowing what the patient's wishes were.

The analysis revealed the theme *The importance of hospital organizational structures in timely recognition and acknowledgment of EOL* and the subtheme *Challenges to and demands of continuity, collaboration, and time,* comprising three areas of organizational structures influencing timely recognition and acknowledgment of EOL: *Collaboration, Continuity, and Time* (Fig. 1). The results are presented with supporting quotes where appropriate. The wording of some quotes has been carefully adjusted for the sake of readability, but without changing the meaning.

3.1. Collaboration

Most participants emphasized the importance of collaboration with colleagues in timely recognition of EOL and providing good EOL care. Poor collaboration added to the feeling of uncertainty. One nurse said: "I don't like having to be the only one who says I don't think you have long left." (nurse).

Both nurses and doctors asked for regular multidisciplinary meetings to discuss patient situations to reach an agreement on life expectancy. A daily "decision meeting", which is routine for follow-up and treatment decisions for inpatients at all wards of the hospital, was described as a good arena for multidisciplinary discussions, but a core condition for this to work is doctors having the time to be present. Yet, this did not serve as a meeting for reflection, evaluation, and learning from previous experiences, for which the participants had asked. Doctors also expressed the need for collegial support and discussions with other, more experienced doctors. "I would like to have more opportunities to discuss at my level." (doctor).

Nurses from surgical wards expressed that the surgeons were often performing operations, causing collaboration challenges. A nurse said: "The surgeons are never there. We don't see them" (nurse). When the doctor did not know the patients' history and wishes well, or was less experienced, it was a challenge to make EOL decisions. " ... it's also challenging that we don't see them (patients) as much as a nurse does ... The only time we see them is when we go the rounds, and talk to them, other than

Table 2 Example of analysis.

Condensed meaning unit	Code	Category	Subtheme	Theme
I will never forget someone I got to know well. Suddenly she just became weak. She completely collapsed. The doctor was quite new, she didn't know her well. I realized that this probably wouldn't work. I thought that she was in the last phase. I think it was because I knew her so well.	Knowing the patient	Continuity	Challenges to and demands of continuity, collaboration, and time	The importance of hospital organizational structures in recognizing and acknowledging EOL
The surgeons are never there. We don't see them.	Being present			
Continuity is not easy in a fast-paced healthcare system.	Busy healthcare system			
The resident doctor starts treatment. The next day, they (the patients) are seen by a senior doctor or a new resident doctor who confers with a senior doctor	Many involved			
We are a surgical post. We try to operate as best we can. If it spreads and nothing can be done about it, the cancer ward takes over and follows up and gives chemotherapy. When they have done all they can, they come to us. We take care of the complications.	Fragmented healthcare system			
My colleague and I agreed that the patient was approaching pre-terminal, The visiting doctor on duty was like "no, we won't do anything about it".	Disagreement between doctor and nurse	Collaboration		
As nurses we notice that collaboration with the doctor is difficult. We see them (patients) more often and over a longer period of time and we get to know them. It's easier for us to see when they become worse	Difficult collaboration			
We often feel that patients are being overtreated and see that the patients are dying earlier than the doctors (surgeons), they want to fix, it is difficult to say that enough is enough. Responsibility - what if you end the treatment and could do more. Difficult then, to talk to the doctors about terminating in order to give patients a dignified death. Die with antibiotics in the arm.	Disagreement between doctor and nurse			
The doctor on the ward talks to the doctor in the outpatient clinic about their thoughts. They are better at treatment than we are at the ward. We don't do it every day	Need for advice from experienced colleagues			
You don't always have time for reflection at work. When you meet colleagues in your spare time, you talk and reflect, because you really need to do that.	Need for reflection	Time		
Participating in group supervision is extremely important. Both	Need for professional			
for learning and for processing situations.	guidance			
The final decision is fortunately a doctor's task. It's not easy, I understand that they can't or don't want to take the time to get to know the patients. But someone has to do it, so many things are postponed.	Doctors need time			
I don't like having to be the only one who comes in and says I don't think you have long left."	Standing alone			

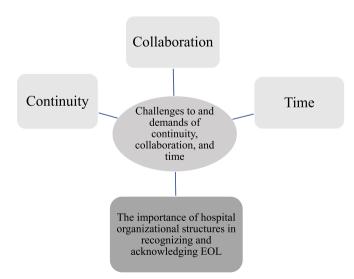


Fig. 1. Categories, subtheme, and theme.

that we don't see them much." (doctor).

The participants also expressed that nurses and doctors have different approaches, and the culture was described as a culture of treatment and cure. Nurses explained how they experienced having a holistic approach, acknowledging EOL, while some doctors focused on treatment even if the patient was dying: "As nurses, we notice that cooperation with the doctor is a little difficult ... we see them (patients) more often and over a longer period of time ... and we get to know them (patients) ... It's easier for us to see when they (patients) become worse." (nurse).

"We have to understand that it is the last phase and limit examinations and things they need to do ... It's not always easy ... we're in fix mode ..." (doctor)

Some nurses explained how they felt that they had to administer futile medication and treatment that made the patient suffer unnecessarily, instead of contributing to a peaceful death. At the same time, nurses acknowledged the difficult responsibility the doctors have regarding medical decisions, especially if they did not know the patient well. The doctors acknowledged that the nurses knew the patients well and that collaboration, therefore, was important.

3.2. Continuity

Continuity was described as crucial for recognizing and acknowledging EOL. One doctor emphasized the importance of continuity to

make EOL decisions: "In the fast-paced healthcare system with daily changes of responsibilities, there is no continuity. Continuity must be written in capital letters and underlined. It is essential. It is more difficult to assess the situation when you have nothing with which to compare." (doctor). Another participant said: "You come in and … you have no relationship with either the patient or their next of kin. … and they die an hour later. That is more difficult." (nurse).

The continuity of care was often described as challenging or non-existent due to the rotation of doctors, the specialization of medical care, and working shifts. Most participants reported that it was highly important to know the patient in order to detect the visible changes in the patient's condition over time, or just get a gut feeling when they approach EOL: "With those in nursing homes, I noticed a change in personality ... that they became ... not quite themselves in a sense ... " (nurse).

Some participants also emphasized the importance of continuity for building trust. Several participants pointed out that lack of continuity was challenging for the patients, too, seeing different nurses and doctors every day. "At first everyone said he was going home, but different times." (doctor). A reason for the lack of continuity was doctors working in different places, for example, outpatient clinics, hospital wards, and surgery. Some were satisfied with changes made to the organization, with surgeons having a week of responsibility on the ward without other assignments, which offered the possibility of continuity.

Doctor rotation and patients receiving different treatments and care in different units were explained to cause fragmented care and responsibility to be set aside. This was described as difficult, as the aim was to have a doctor with coordination responsibility for each patient. "They often come to us for examination, possibly for surgery, and then they are followed up in the outpatient clinic ... If they don't get surgery, they go to the cancer ward and are followed up there until nothing more can be done for them in a sense, and then they are sometimes transferred back to us." (doctor).

Although most participants suggested that continuity of care was of great importance, some also mentioned that it sometimes was necessary to view the situation in a different light and that someone who had not been following the patients, therefore, could contribute to making good decisions.

3.3. Time

Participants reported not having enough time to provide good palliative care as frustrating and causing a painful feeling of inadequacy. Palliative care was described as time-consuming, especially EOL conversations, this being a challenge in a busy ward: "We have intense pressure in the ward ... often we have no time to familiarize ourselves with ... different issues ... It can be difficult to decide what is the right thing to do ... there is too much postponing." (doctor).

The nurses and doctors described a feeling of responsibility to advocate for the patients in a rigid healthcare system. One doctor also explained how difficult it was to notify leaders about the need for more time: "It's never nice to be the one who does the least in the same amount of time, but you have to think about the effect this has on the patients if you don't have time for a proper conversation about palliation or the way forward. And that is important for these patients. I'll let them know. Then you are a no person in a yes system." (doctor). Another doctor said: "I wish it would be a little more natural and find ... someone who has time to talk to them properly. To sit down. It's clear, some nurses are good at it ... but they're too busy. They run from one to the next and they don't even have time to go to the bathroom." (doctor).

Nurses asked for debrief meetings with doctors to learn from different situations, and to gain a better understanding of each other's work. "I miss ... meetings where we can discuss what we think, in general, and the doctors explain why they think the way they do. It makes it easier for us to understand why they choose treatment." (nurse).

Participants also asked for time to evaluate and learn from nonoptimal situations, time for guidance through teaching and collaboration with experienced colleagues, and for multidisciplinary collaboration meetings. Some of this was offered, but often there was no time to participate. "We could have had such an interdisciplinary meeting where we could have talked together. But it is difficult to achieve, it is a very busy unit, it is difficult to find the time." (nurse).

4. Discussion

The aim of this study was to explore and describe nurses' and doctors' experiences of how organizational structures in hospitals influence timely recognition and acknowledgment of EOL to provide good EOL care. Our findings suggest that nurses and doctors acknowledge the last days and weeks of life as being of great importance for patients and their families to be together in a peaceful environment, with a focus on alleviating pain and other symptoms. This was complicated by an experience of uncertainty in timely recognizing EOL, causing futile treatment and reduced well-being for the patient and family. Helping patients to die with dignity is a main goal of palliative care and recognizing EOL and having EOL conversations with patients and their families are essential (The Norwegian Directorate of Health, 2019). This requires clinicians to be able to recognize EOL to ensure symptom control, appropriate interventions, and good communication (Taylor et al., 2017; Haig, 2009). The unpredictable trajectory of the disease makes it difficult to anticipate when patients are in EOL. Even though there are signs that indicate impending death, there may also be signs of a potentially reversible illness (Taylor et al., 2017; Devery et al., 2022; Bloomer, 2019). The disease trajectory for cancer patients is still somehow predictable, with a decline in physical health over a period of weeks, months, or, in some cases, years (Murray et al., 2005). We, therefore, ask if a fragmented healthcare system and a hospital culture of treatment and cure play an important role in nurses' and doctors' recognition of EOL for cancer patients.

4.1. Fragmented healthcare system

In our study doctor rotation and patients receiving different treatments and care in different units were explained to cause fragmented care and responsibility to be set aside when it comes to EOL conversations. This is supported by Stacey et al. (2019) stating that patients are likely to encounter many experts during a hospitalization period, due to the specialization of medical care, so-called "siloed care", leading to weakened responsibilities (Stacey et al., 2019). The fact that many doctors feel unprepared to provide information about poor prognoses further complicates good EOL conversations (Andrews and Nathaniel, 2015).

Further, for timely recognition of EOL and making good decisions about EOL care, the participants in our study emphasized the importance of knowing the patients and their history and wishes, and thus being observant of changes and signs. This was challenged by doctors working in different places during the week and nurses working shifts. For providers of care, continuity is the "perception of having sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognized and pursued by the other providers" (Haggerty et al., 2003, p.1221). In general, continuity of care by doctors is associated with lower mortality rates (Pereira Gray et al., 2018). Continuity further provides the context on which to build individualized care plans for patients, reducing futile treatment (Hudson et al., 2019). Wilmott et al. (Willmott et al., 2016) state that futile treatment is provided in EOL due to doctors not knowing the patient's wishes and fragmented care with a lack of focus on the person as a whole. An opportune remark seems to be that fragmented care in hospitals seemingly contradicts holistic care and the goal of health services to reduce the incidence of futile treatment (Willmott et al., 2016).

The hierarchical organization of medicine in hospitals was also highlighted as a problem when the doctors who make treatment

decisions spent little time with the patients (Willmott et al., 2016). To notice small significant changes to timely recognize EOL seems to be achieved only through consistent interactions (Hudson et al., 2019). Doctor rotation, therefore, may have a negative impact on EOL care in hospitals. "A fresh pair of eyes" could sometimes still be useful, however, based on the findings that physicians found it difficult to accept the last phase of life for patients they knew well, and they feared depriving the patients of their hope (Owusuaa et al., 2021).

Our findings suggest that collaboration and support by colleagues are of high significance. Participants in our study asked for regular multidisciplinary meetings for discussion and reflection, and for attaining a deeper understanding of each other's approaches to care. A multidisciplinary approach to care is central to palliative care (World Health Organization, 2022; The Norwegian Directorate of Health, 2019). Other studies support this approach, stating that doctors failing to appreciate nurses' opinions and nurses and doctors failing to communicate with one another may lead to ambiguous messages about a patient's prognosis in EOL (Gagnon and Duggleby, 2014; Stacey et al., 2019; Devery et al., 2022; Blaževičienė et al., 2017). EOL prognostication and decisions are further leveraged from the combined expertise between nurses and doctors (Devery et al., 2022). An opportune question thus seems to be whether hospital organizations support a multidisciplinary approach to care.

4.2. Curative-focused and fast-paced care

The findings in our study reveal the challenge of timely recognition and providing good EOL care in a culture of treatment and cure. Participants also emphasized the significance of having enough time in a busy ward to provide good EOL care, conduct EOL conversations, and for doctors to be present at decision meetings. Similar results have been reported in other studies. The acute care environment of hospitals with a fast pace, and a biomedical culture focused on life prolongation and cure, is recognized as less optimal for EOL care (Bloomer, 2019; Friedrichsen et al., 2021). Caring for curative and palliative patients at the same time is thus a challenge, and establishing a meaningful relationship with dying patients in a task-oriented culture of medical units is difficult (Gagnon and Duggleby, 2014). In addition, lack of space and time limits the possibility of good EOL care. A constant work overload is a major hindrance to providing a dignified death (Bloomer, 2015). Nurses express a feeling of helplessness and of being torn between competing demands (Gagnon and Duggleby, 2014; Blaževičienė et al., 2017; Friedrichsen et al., 2021), not having the time for complex issues like conversations about death and dying (Willmott et al., 2016; Owusuaa et al., 2021). Stacey et al. (2019) further argue that institutional culture has a role in shaping awareness of EOL (Stacey et al., 2019). Body language and use of words have an impact, for example, when professionals speak about the future to terminal patients to imply recovery. Rigid professional hierarchies and a strict focus on curative care are organizational realities that contribute to low awareness. Nurses refer to doctors for discussion of prognosis, and doctors are part of a "curative culture" (Stacey et al., 2019).

4.3. Implication to practice

Increased attention is needed to the consequences of fragmented specialist care in hospitals. This fragmentation may be countered by a different model for decision-making, focusing on the needs of the patient, asking "What matters to you?" instead of "What's the matter", thus putting the person, not the disease, at the center of healthcare. At an organizational level, we suggest that nurses and doctors should be given enough time to spend with the patients and their families to ensure good EOL conversations and decisions. For many acute care organizations, strong leadership and significant cultural change will be necessary.

4.4. Methodological considerations

Rich data materials and the diversity of included departments and respondents are strengths of this study. The respondents were both nurses and doctors from different surgical and medical departments, with experience in EOL care. The sample included both experienced and inexperienced HCPs representing both genders. The research team consisted of experienced researchers and clinicians. To ensure trustworthiness a detailed description of the strategies used for the method, process, and results is included. Feedback was not provided by participants during or after the analysis process, but participant checking was continuously carried out during the interviews to avoid misunderstandings. The semi-structured interview guide was not piloted, but the interviewers were experienced with in-depth interviews, and the interview guide was evaluated, without being changed, after the first two interviews. Our data are based on nurses and doctors recruited from one hospital, which causes a possibility of selection bias. One participant had only one year of relevant practice, this became known to the authors when the interview began. The participant was still included because of relevant experience in cancer care and the ability to thoroughly reflect on the theme in question. In hindsight, the inclusion criteria of a minimum of two years of work experience were unnecessary since nurses and doctors with less experience may also have had sufficiently relevant practice to participate in the study.

5. Conclusions

This study reveals challenges in identifying cancer patients approaching the last weeks and days of life in hospital wards. Hospital organizations with fragmented care, lack of continuity, fast pace, and a predominant focus on treatment and cure seem to influence timely recognition of EOL and EOL decision-making more than anticipated. This may cause a lack of EOL awareness, futile treatment, and inadequate preparation for death. Nurses and doctors have high ethical standards and seek to meet patients' and relatives' needs for palliative care in the last part of life. Continuity of care, multidisciplinary collaboration, and enough time seem to be important for noticing the signs of EOL and making decisions that lead to good palliative care. To achieve this, an environment for active planning and caring for patients at EOL needs to be created in hospital wards.

Author contributions

J.B. was responsible for drafting the manuscript. JB and G.C.W was conducting the Investigation. J.B, G.C.W, B.F, V.U and H.K contributed to the Conceptualization, Funding acquisition, Methodology, Formal analysis, Writing – original draft, Writing – review & editing., and provided critical reflections throughout the writing process.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2023.102420.

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