Original-, udviklings-, og kvalitets artikler

End-of-Life Care: A Survey of Hospital Staff in Denmark

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Abstract

Background: Many patients want to die at home, but do not get their wishes fulfilled. To combat this, it is important to understand the challenges that stand in the way of healthcare professionals being able to discharge people from a department of emergency medicine to receive good quality end-of-life care (EOL) in their own homes.

Aim: The aims of this study were to 1) determine if staff at Emergency Departments experienced significant challenges related to EOL care, 2) how often this led to unnecessary hospital admissions, and 3) if a new "Acute Palliation Concept" (APC) might alleviate some of the challenges identified above.

Material and method: This was a cross-sectional survey among doctors (n=53) and nurses (n=74) working in Departments of Emergency Medicine or General Practice in the North Denmark Region. The questionnaire covered the healthcare professionals' backgrounds, their perceptions of current challenges in EOL care, and the potential effects of the APC.

Results: Among the healthcare professionals, 53% of responders found the most challenging aspect of EOL care to be "Logistic Issues" and 21% "Time consumption". Out of the responders, 64% had sometimes, often, or always felt the need to admit/maintain admission/push to admit a dying patient, because it was too challenging to start the EOL care at home. On the potential effect of APC, 74% thought it would save time. In addition, most responders thought it would give both the patient and their next of kin better EOL care.

Conclusion: This study showed that doctors and nurses in the Departments of Emergency Medicine did experience noteworthy challenges related to providing EOL care and that these challenges led to hospital admissions instead of the patient being discharged to EOL in their home. This was experienced by 86 % of the staff. This may be problematic as literature suggests that it is against many patients' wishes besides being very expensive for a health care system.

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Background

World Health Organization (WHO) defines palliative care as "*Palliative care is a crucial part of integrated, people-centered health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility*"(1).

In 2021, 56,868 citizens died in Denmark, of which 50% died at home (death at the home address or nursing home), 36% died in a hospital while the remaining deaths were distributed among hospices, or unknown (2). Among patients suffering from cancer, 71% wanted to die at home. This is contradictory to the fact that 48% of patients who suffered from cancer who preferred home death, had their preference met (3). To fulfill the patients' and their relatives' wishes about dying at home, good end-of-life (EOL) care is needed (4). Specialized palliative treatment takes place in parts of the healthcare system, whose main task is palliative care. On the other hand, basic palliative treatment occurs in numerous places in the health care system, including general practices (GP), municipality care, and hospitals which is provided by healthcare personnel whose main task is not palliative care. Furthermore, palliative care must be coordinated cross-sectoral across different professional groups, including doctors, nurses, or physiotherapists. Organizational issues arise due to a lack of sufficient computer systems, exchange of information, and formal national agreement on the division of labor (5). Studies have shown that relatives of palliative patients have experienced insufficient palliative treatment due to organizational and communicative problems between sectors (6). This had also been described previously due to both ''practical issues'' and ''educational problems''. These findings from the study by Hoefler et. Al (7) could be interpreted as that insufficient training and practical issues may lead to healthcare personnel who feel incompetent and inadequate in palliative care (7). The aims of this study were to 1) determine if the staff at Emergency Departments experienced significant challenges related to EOL-care, 2) how often this led to unnecessary hospital admissions, and 3) if a new "Acute Palliation Concept" (APC) might alleviate some of the challenges identified above.

The Acute Palliation Concept is intended for individuals who have a life expectancy of days to a few weeks and wish to die in their own homes. Before a person can be sent home with the APC, it must be assessed that the patient has a basic palliative need that can be managed in the patient's own home. The concept is aimed at those who suddenly become very ill and are brought to a hospital. This applies, among other groups, to chronically ill individuals, where deterioration can occur rapidly. The APC contains instructions for doctors, for nurses, information for patients, checklists for the process as well as necessary medication (e.g. morphine, midazolam, etc.) (8).

Methods

The Regional Ethics Committee evaluated the project as not needing ethical approval within Danish law.

Design and Population

The Danish health care system is tax-financed which entails free palliative care for all citizens in Denmark. The basic palliative treatment is provided cross-sectoral by the municipality-based home care nurses, outpatient clinics, the Department of Emergency Medicine, and doctors specializing in General Medicine (3).

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This cross-sectional survey was conducted among healthcare professionals including doctors and nurses working in 1) the Department of Emergency Medicine and Trauma Center in the Academic Hospital in Aalborg, 2) the Department of Emergency Medicine at the non-Academic Hospital in the North Denmark Regional Hospital, and 3) doctors specializing in General Medicine in the North Denmark region (NDR). The questionnaire was set up and distributed with Research Electronic Data Capture tools (Redcap, Version 9.5.6, Vanderbilt University) (Harris et al., 2009, 2019). It was sent out via the department E-mail group at both hospital wards as well as to doctors specializing in General Medicine in the NDR in June 2022 and again, in January 2023. As the questionnaire was sent out using the department E-mail group, a response rate was not calculated. This list is not updated frequently and will include some staff that do not use their email anymore e.g., previous staff, substitute nurses, staff on maternity leave. The receivers were also asked to forward emails to other people within the department who were not on the list, thus relying on the snowball effect. The number of people who make up the total sample group is left unknown. During the redistribution, it was emphasized that personnel who had previously responded to the questionnaire were not allowed to answer again. After the first distribution in June 2022, the name of the APC was changed in the questionnaire before the redistribution. For this reason, bias cannot be ruled out, but it is important to accentuate that even though the name was changed, the questionnaires still contained a description of the concept as well as a description of the content.

Table 1: Descriptive data on questionnaire responders	Responders n = 128
The responder's profession§, % of all (n)	
Nurse	58 (74)
Doctor	42 (53)
Where do you primarily work? % of all (n)	
Emergency department	84 (107)
Other	16 (21)
How far are you in your education as a doctor? % of all (n)	
Residency	21 (11)
Specializing in emergency medicine	15 (8)
Attending in emergency medicine	13 (7)
Specializing in general medicine	30 (16)
Other	21 (11)
For how long have you been fully trained? § % of all (n)	
<1 year	13 (17)
1-5 years	40 (51)
>5 years	47 (59)

Abbreviations: n: number, EOL: End-of-life, APC: Acute Palliation Concept. # missing values between 1 and 11.

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Questionnaire

A 29-item questionnaire was developed for this survey. Questions 1-6 concerned the primary place of work, how long they had been practicing medicine/nursing, how far along the physicians were in their residency, and in what specialty. Questions 7-16 concerned their experience and challenges with providing palliative care, and the knowledge of a previous initiative in EOL care at home. Question 17 concerned the thoughts on the content of the new APC and questions 18-30 about its expected efficacy. A few of the questions are specifically directed towards employees in emergency departments. These questions start with "Employee in the emergency department". Initially, a few of the questions were also directed to the on-call GP's. All doctors regardless of their professional position or level of education had the same function regarding basic palliative care. The questionnaire can be seen in Supplemental Table 1. The questionnaire has not been validated owning to local conditions.

Statistics

Descriptive statistics were given as median and range (25-75% (IQR)) for continuous variables. For categorical variables counts and percentages were displayed.

A Chi2-test was used to determine whether there was an association between experience and how challenging doctors and nurses found EOL care. Health care personnel were categorized as "experienced" if they had been fully trained for >5 years and "inexperienced" if they had been fully trained for 0-5 years. Performing EOL care was categorized as "easy" if it was rated between 0-50 and "hard" if it was rated between 51-100 on a VAS scale of 0-100, where 0 = not challenging at all and 100 = very challenging. A significance level of 0.05 was chosen. Statistics and data management was done using:

IBM SPSS Statistics Version28.0.1.1(IBM Corp.,2021,Armonk,NY:IBMCorp).

Results

A total of 128 people filled out the questionnaire (n = 45 August 2022 and n = 83 January 2023). Of the respondents, 58% were nurses and 42% were doctors (Table 1). Out of the healthcare professionals 47% had been fully trained for >5 years while 53% had been fully trained for ≤5 years.

Logistics Were the Biggest Challenge Regarding End-Of-Life Care

When asked about what the responders perceived as their biggest challenge, 28% out of a total of 128 responders answered that they did not encounter any challenges, whereas 21% experienced time as the biggest challenge, and 14% found it professionally challenging. More than half of the responders viewed logistic issues as the biggest issue. A summary of the experience with EOL care among healthcare professionals can be seen in Supplemental Table 2.

Hospital Admission Was Often Easier than Discharging for End-Of-Life Care

Of the responders, 86% had rarely, sometimes, often, or always felt the need to admit/maintain admission/push to admit a dying patient because it was too challenging to start EOL care at home (Supplemental table 2 & Figure 1). Among the healthcare professionals, 28% had admitted >5 patients in the last year because it was too challenging to send them home (Supplemental table 2).

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Figure 1: Chart illustration of two questions from the questionnaire regarding hospitalization due to challenges of starting EOL care at home. A) Have you felt the need to admit / maintain admission / push to admit a dying patient to the hospital for "end-of-life care" because it has been too challenging to start this at home. B) How many patient processes in which you have been involved, have ended with the patient being admitted / not discharged on the basis that it is challenging to send them home for "end-of-life care" in the past year?

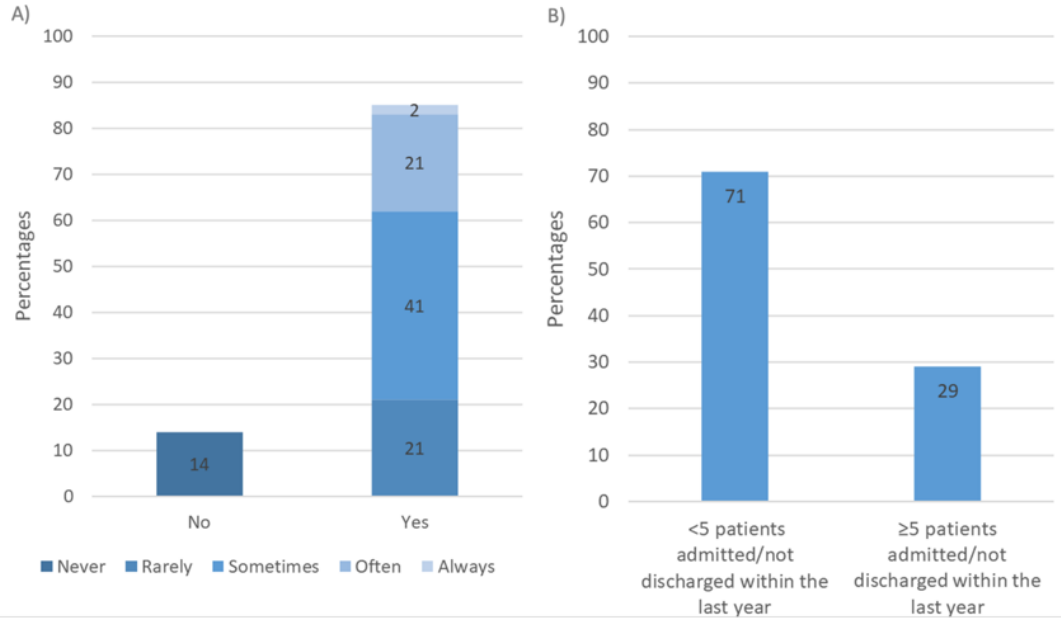
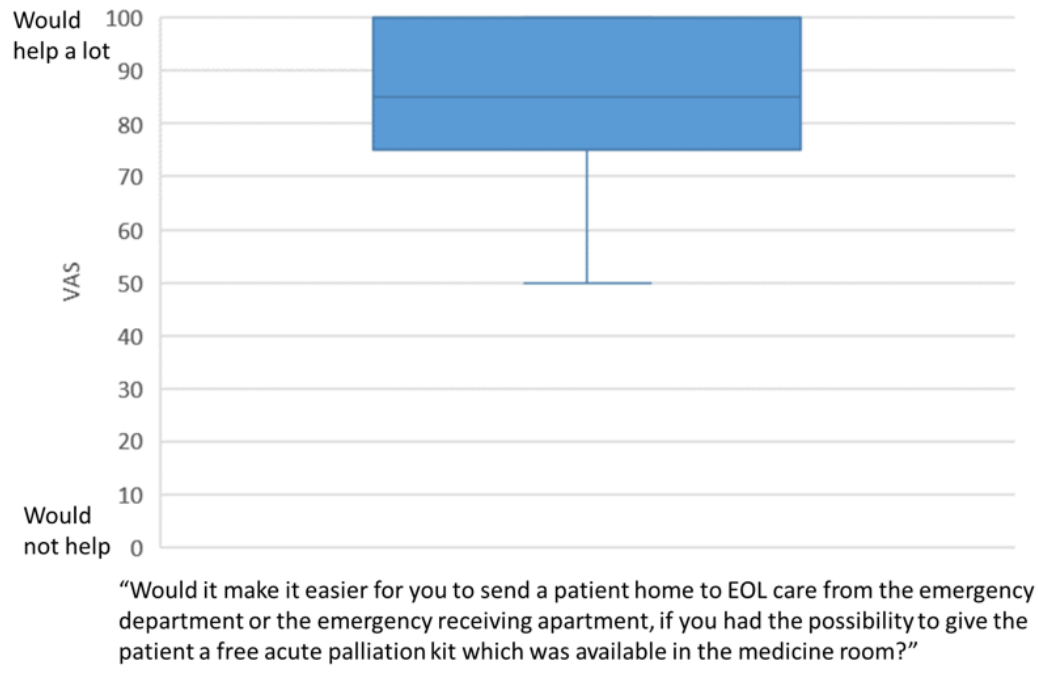


Figure 2: Boxplot illustrating the staff's expectations to a prepacked acute palliation concept on a VAS scale where 0 = would not help, 100 = would help a lot"



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There was no significant association between the responders' experience and how challenging they found the admission and care of EOL care patients (p=0.28).

The Healthcare Professionals Thought the Acute Palliation Concept Would Help

Out of 114 responders, 74% thought a palliation concept would save time when performing EOL care (Table 2). This was rated as a median of 85 (75;100) on a 1-100 VAS scale (Figure 2 & Table 2). When asked if an APC would result in better EOL care respectively for terminally ill patients, relatives, and municipality nurses, over 90% of the responders replied that they expected an improvement compared to today where it is not available.

Discussion

In this cross-sectional survey, answers from 128 healthcare professionals working in the Departments of Emergency Medicine were evaluated to determine challenges regarding End-of-life care (EOL). EOL care was found logistic challenging for 53% of the responders. Current EOL care was also perceived as time-consuming and professionally challenging. A total of 72% reported that they admitted dying patients due to these challenges. This might be the background of why above 90% of the responders believed that an accessible and pre-packed Acute Palliation Concept could improve EOL care.

Strengths and Limitations

A STROBE-checklist has been used to report this study. This survey was only conducted in the NDR, but the five regions have been shown to be highly comparable in other health aspects (9). Therefore, it was assumed that the regions are comparable. Methods of admission are assumed to be comparable across the regions. When a citizen is admitted to the hospital as an emergency, it happens based on a preadmission assessment. How this preadmission assessment is obtained, depends on the situation and time of day. This has been implemented based on Sundhedsstyrelsen in all regions with only small intra-regional differences (10). Furthermore, the survey was distributed among the two largest emergency departments in an Academic as well as a Non-Academic Hospital which is expected to improve external validity. As addressed in the method section, the questionnaire has not been validated and this can thus serve as a limiting factor for this study.

The study could have benefited from the participation of more GP's, who are the major players in EOL care in primary care. However, the number of GP doctors working in the ED was low, making this difficult. This survey was designed to explore this area and plan future research. In future studies, staff interviews may be useful for providing more in-depth and supplementary answers when describing the challenges with EOL care. Extending the survey to include a higher number of responders was also a possibility to enhance external validity. On the other hand, the responses in this study were very clear and a majority agreed on the challenges of EOL care in the ED. Hence, more responders were not expected to change results. The expectations of an APC were high, but the real-life efficacy remains to be examined in a study designed for that. At present time there are no studies of the wishes for the last days of their life when looking at patients dying within days without specialized palliative needs. Further studies are needed to explore this area as well.

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Table 2: The rated value of a palliation concept

Do you think a free APC for use at home would improve end of life care experienced by these groups compared to today where this offer is not available? # % of all (n)			
	Patients	Relatives	Municipality nurse
Yes, % (n)	79 (99)	74 (92)	79 (99)
Possibly % (n)	15 (19)	21 (26)	14 (18)
No % (n)	1 (1)	2 (2)	1 (1)
I don't have an opinion % (n)	6 (7)	4 (5)	6 (8)
How much time do you think you could save admitting a patient to EOL care at home or start the care in the home if you could have a free APC at hand to give to the patient immediately? # % of all (n)			
It would take longer			4 (5)
It would take the same amount of time			22 (26)
It would take less time			54 (63)
It would take much less time			20 (23)
How much less time? # % of all (n)			
< half an hour			22 (18)
Approximately half an hour			21 (17)
Approximately 1 hour			31 (15)
Approximately 1,5 hours			10 (8)
Approximately 2 hours			12 (10)
Approximately 3 hours			1 (1)
> 3 hours			2 (2)
Employee in the emergency department: Would it make it easier for you to send a patient home to EOL care from the emergency department or the emergency receiving apartment, if you had the possibility to give the patient a free APC which was available in the medicine room? Respond at a scale, 0 = would not help, 100 = would help a lot (pull the button to move around on the scale)			
Median (IQR)			85 (75;100)
Employee in the emergency department: if you had access to a free APC in the emergency department and emergency receiving department, do you think you would use it? # % of all (n)			
Yes, to all relevant patients			57 (59)
Yes, to some relevant patients			27 (28)
Yes, to a few patients			11 (11)
I am not sure			5 (5)
No			1 (1)

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End-Of-Life Care Was Challenging Primarily Due to Logistics

This study identified three main problems: logistics, time consumption, and lack of professional competency. This might partly explain the discrepancies between the patients' wishes of dying at home and actual events. In this study, it was found that about half of the healthcare professionals identified logistic issues as the greatest problem concerning EOL care. This resulted in many hospital admissions, where staff believed the patient could have been palliated in their own home. This happened despite knowing that patients often wished to die at home, which ties well with a previous study by Winthereik et al. The conditions in the hospital sector can be linked to those in the primary sector, where issues regarding EOL care also occur. The study showed that no more than 9% of GPs kept a register of patients with palliative needs and 19% had specific procedures for EOL care when asked in a study exploring GPs' self-reported competence concerning EOL care. This left the GPs unprepared for fulfilling their patients' EOL care needs and therefore the easier option was to admit patients when acute palliation was needed (11). Additionally, a group interview study by Neergaard et al. identified logistics as being one of the main categories of problems in basic palliative home care including the distribution of tasks, exchange of information, and availability (12). Another study by Gorlén et al., which was based on a group interview of nurses working in Danish nursing homes, found problems hindering good EOL care similar to this study. Several also pointed towards challenges with cooperation with other sectors, e.g., in emergency situations where important decisions had to be made. However, the nurses and nurse assistants who had received palliative education were more confident in EOL care (13). In continuation with the identified challenges regarding EOL care, one could consider if this was just indicative of a lack of experience among the health care professionals. This was not the case in this current study. However, another study by Winthereik et al. that aimed to examine EOL care among Danish GPs, demonstrated contradictory results (11). They found that the oldest GPs reported higher confidence regarding being a key worker compared to the younger GPs. The different results may be due to different settings. Doctors in the study by Winthereik et al. generally had a larger experience span compared to the staff at the Departments of Emergency Medicine (11). The study also found problems regarding professional competency in relation to EOL care. There was a variation in how confident the GPs felt across different palliative skills including medical treatment (11). A similar pattern of results was obtained in this current study

Hvad ved vi?

- Vi ved, at mange patienter ønsker at dø i eget hjem, men at det ikke er alle patienter, der får dette ønske opfyldt.

Hvordan kan det bruges i danske akutmodtagelser/perspektivering?

- Det bør undersøges om systematisering af udskrivelse til udelukkende lindrende behandling giver bedre lindring af døende i eget hjem dette ønske opfyldt.

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where 14% identified lack of professional competency as one of the biggest challenges.

Hospital Admission Was Easier than Discharging for End-Of-Life Care in Own Home

It was concerning, that 86% of the professionals in the study experienced the need to admit dying patients due to problems with establishing good EOL care at home. It was furthermore concerning, that this issue did not decrease with increased experience in the field. These findings fit in well with previous research showing that less than half of cancer patients in Denmark have their preference for place of death met (3). It is highly problematic that EOL care is regarded as a reason to admit patients who do not want to, especially when the costs are higher at hospitals. It highlights the need to simplify logistics for providing EOL care at the patient's own home.

The Healthcare Professionals Thought an Acute Palliation Concept Would Help

A study by Neergaard et al. showed that patients and relatives experienced insufficient palliative care mainly due to organizational and cultural problems among professionals (6). This was a known fact in the clinical field and was possibly one of the reasons that 96% of the responders in this study wanted to use a palliation concept if they had access. The willingness to use a pre-packed concept is consistent with results from another previous study by Perusse et al. In that study, the evaluation of a similar Symptom Management Kit (SMK) demonstrated a positive impact on patients, caregivers, and providers due to the advantages of improvement in timely access to medication and management of symptoms. Overall, the SMK reduced ED visits, hospital admissions, and increased patient deaths in their preferred location. This is in line with the results of this current study where healthcare professionals expected the APC to be timesaving concerning EOL care (14). As the proposed APC from the questionnaire in this study contains information material for nurses as well as all medication and utensils to administer it, there is a chance that the APC could yield similar results. However, a pre-packed kit may not be enough, as a study by Healy et al. found that the use of a palliation concept in a home required education and support of the health care professionals (15). The current study was the first step in understanding how the concept can help improve EOL care. Further research could investigate the opinions of GPs and

Hvad tilføjer denne artikel til vores viden?

- Mere end 8 ud af 10 ansatte i akutmodtagelserne i Region Nordjylland havde det seneste år indlagt uafvendeligt døende patienter til udelukkende lindrende behandling fordi det var for logistisk og tidsmæssigt udfordrende at lade patienterne komme hjem at dø.
- 1 ud af 3 af disse ansatte indlagde alle de uafvendeligt døende patienter de så i akutmodtagelserne
- Ansatte i akutmodtagelserne troede, at en systematisering af udskrivning til udelukkende lindrende behandling med en tjekliste, informationsmateriale og forud pakket plaster og medicin ville gøre det lettere for at udskrive døende til eget hjem

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municipality nurses on EOL care and APC and thereafter investigate the actual effect of the concept on patients in a dedicated study.

Conclusion

This study showed that healthcare professionals in the Departments of Emergency Medicine did experience noteworthy challenges related to providing EOL care and that these challenges led to hospital admissions instead of the patient being discharged to EOL in their home. This may be problematic as the literature suggests that it is against many patients' wishes besides being very expensive for a healthcare system currently under pressure. In the future, the logistics of EOL care would benefit from being simplified for hospital staff if fewer patients were to be admitted to die. A pre-packed EOL care concept might reduce logistics but needs evaluation in dedicated studies.

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