

Original Article

A novel acute basic palliation concept for patients without specialised palliative needs

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ABSTRACT

INTRODUCTION. Among all Danish dying patients, 80% rely on non-specialised palliative care, an area lacking national and international guidelines. In this pilot study, we developed and tested an acute basic palliation concept (ABPC), a structured end-of-life (EOL) care plan for patients discharged from the emergency department to die at home compared with standard care.

METHODS. This study compared symptom scores and EOL care statement scores during a standard care period with an ABPC period using unvalidated questionnaires. Each period included 25 patients. The study was conducted across two emergency departments in Denmark and included patients aged ≥ 18 nearing EOL. Furthermore, we asked if healthcare professionals would use the ABPC again.

RESULTS. Relatives reported better symptom scores for three of four symptoms during the ABPC period. Doctors and municipal caregivers reported better scores for most EOL care statements during the ABPC period, whereas hospital nurses' scores remained unchanged between periods. All (100%, $n = 67$) healthcare professionals would use the ABPC again, and 96% provided positive free-text comments.

CONCLUSIONS. Relatives and healthcare professionals reported better symptom and EOL care scores during the ABPC period, with all healthcare professionals stating that they would use the ABPC again. Larger sample sizes and validated questionnaires are needed to verify our findings.

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TRIAL REGISTRATION. Not relevant.

Palliative care (PC), as defined by the World Health Organization, is a vital component of integrated, people-centred health services. PC is often referred to as end-of-life (EOL) or terminal care when provided in the final days or weeks of a patient's life. In Denmark, most patients want to die at home, and PC is offered at two levels: specialised and basic [1]. Specialised PC is provided by experts in the field and is available for 20% of dying Danes [2]. The other 80% receive basic PC provided by healthcare professionals without formal palliation training. Studies on basic PC and updated guidelines are sparse in Denmark and internationally.

Established guidelines rarely guide basic EOL care. Perhaps this explains why 40% of dying citizens are admitted to hospital within the last 30 days of living [3]. A study from Denmark showed that 86% of healthcare professionals in emergency departments admitted patients they knew should have been discharged to EOL care

at home [4]. They did this due to logistical and professional obstacles and despite knowing that patients wished to go home.

In a collaboration between two PC departments, two emergency medicine departments and the patient organisation DanAge Organisation, we developed a new Acute Basic Palliation Concept (ABPC) to address challenges in EOL care identified by healthcare professionals. We hypothesised that the ABPC improves EOL care for patients with a life expectancy of days and without specialised palliative needs compared with standard care. The primary objective of this study was to investigate if implementing the ABPC increased symptom control scores among relatives and healthcare professionals. Secondary objectives included evaluating healthcare professionals' inclination towards using the ABPC again and assessing if EOL care statement scores increased after implementing the ABPC.

Methods

This observational prospective pilot study was conducted in the emergency departments at Aalborg University Hospital and the North Denmark Regional Hospital, Denmark. The hospital administration approved the study (reference number: K2022-030), and the Regional Ethics Committee of Northern Denmark waived the need for approval (reference number: 2022-000764). Treatment was initiated as part of standard clinical practice in accordance with usual consent guidelines. Direct patient consent for the project was not required. As shown in Appendix A, relatives and healthcare professionals were informed, and consent was obtained. First, a standard care period was assessed, followed by a period with the implementation of the ABPC protocol. A sample group size of 25 patients was selected based on the feasibility of recruitment within the timeframe and available resources of our study. During the standard care period (Sep 2022 to Jan 2023), 26 patients were included because two patients entered simultaneously on the last day. Subsequently, 25 patients were included during the ABPC period (Jan 2023 to May 2023).

The inclusion criteria were: ≥ 18 years, discharged for EOL care, expected lifespan from days to few weeks. The exclusion criteria were: clinical conditions unsuited for home-based palliation or unfit home. If patients survived beyond 60 days, the healthcare professionals' survey data were included, but relatives' responses were unavailable and recorded as missing. Time-to-death would be reported as missing for these patients. A healthcare professional could contribute data on multiple patients during both periods and multiple times within each period. Standard care was defined as discharge to EOL care using routine practices. Notably, no formal guidelines or established protocols existed at the local or national level for basic PC during this period. The ABPC included 1) a doctor checklist inspired by the aviation industry, 2) doctor instructions, 3) a medication template, 4) a standard letter for the home including law text on EOL, 5) home nurse instructions, 6) a medication decision tool for the nurses and 7) patient information materials. A comprehensive list of the exact contents of the ABPC and materials is provided in [Appendix B](#).

Outcome measures

The primary outcome was the proportion of positive scores for symptom management statements reported by relatives and municipal caregivers, defined as answers of “to a high degree” or “to a very high degree”. Secondary outcomes were the percentage of healthcare professionals who would use the ABPC again, the proportion of positive ratings for statements presented to healthcare professionals and self-reported time used by healthcare professionals. We followed the same protocol ([Appendix A](#)) and used the same questionnaires for data collection in both periods. We developed a questionnaire for the study. All questionnaires were answered on a five-point Likert scale, supplemented by an additional “don't know” option: 1) “to a very low degree”, 2) “to a low degree”, 3) “to some degree”, 4) “to a high degree” and 5) “to a very high degree”, where 4 and 5 were defined

as positive. Healthcare professionals also indicated if they would use the ABPC again ("yes", "no", or "uncertain") and ended with an open-ended comment section. The areas covered by the questionnaires are seen in **Figure 1** and **Figure 2**. Detailed survey data is provided in [Appendix C](#).

FIGURE 1 End-of-life care quality assessed by relatives (A) and municipal caregivers (B). The percentage of answers indicating "high" or "very high" agreement with the given statements is shown for the acute basic palliation concept period in grey. More peripheral answers equal a higher percentage of positive answers.

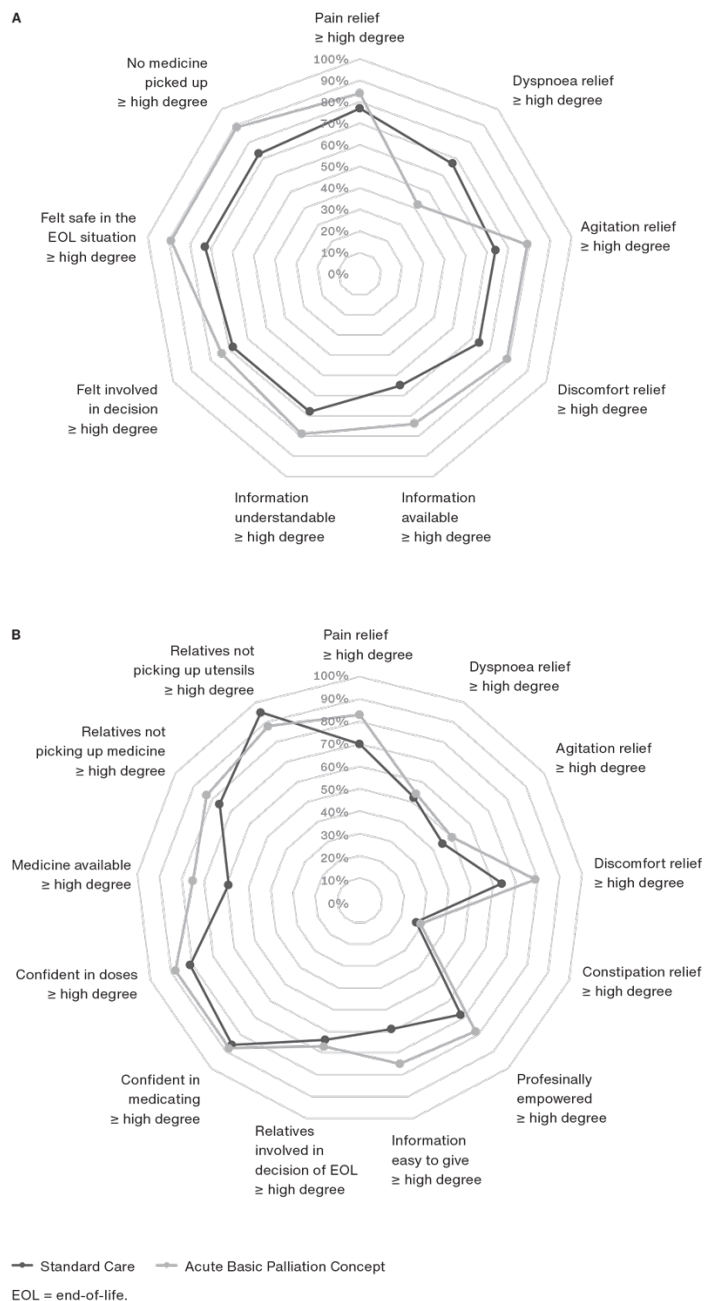
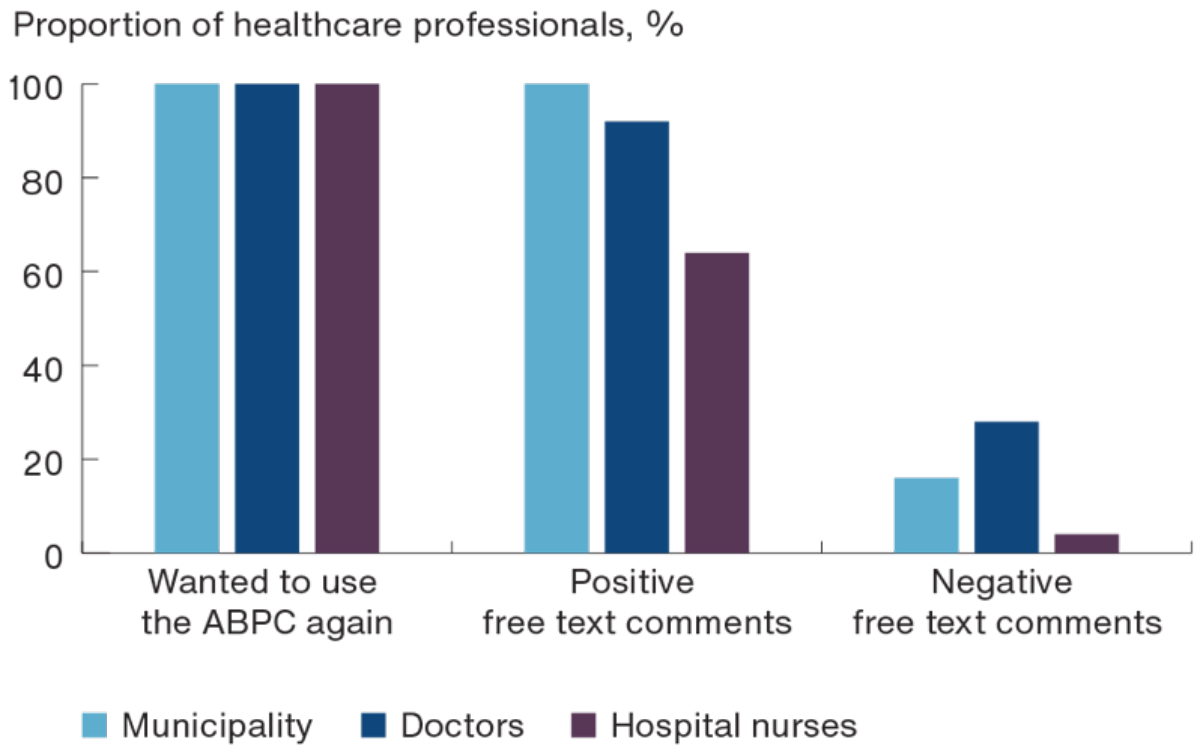


FIGURE 2 Primary and secondary sector healthcare professionals' evaluation of the acute basic palliation concept (ABPC).



Data collection and analysis

Data were collected and managed using REDCap electronic data capture tools, and data management/statistics were achieved using SAS Enterprise Guide 71 (SAS Institute Inc., Cary, NC, USA) [5, 6]. The limited sample size would potentially compromise the reliability of statistical analyses, raising the risk of type I or II errors. Therefore, results in the spider plots are reported without statistical analysis. Numerical data were reported as median and interquartile range or mean and standard deviation with differences tested by the Wilcoxon Rank Sum test or Student's T-test as appropriate. A significance level of $p < 0.05$ was selected to determine statistical significance.

Trial registration: not relevant.

Results

Demographics are shown in Table 1. The groups varied non-significantly within the variables of age, sex and having dementia or cancer between the standard care period and the ABPC period. The number of patients readmitted was comparable (1 versus 2, $p = 0.58$). Two patients did not die within 60 days after discharge during the APBC period. Discharging doctors reported a low level of experience during both periods (ABPC 1.0 (0.0-5.0) years versus 2.0 (0.3-14) years, $p = 0.45$). Nurses reported a median experience of 2.5 years (1.5-7.0 years) during the ABPC period compared to 7.0 years (1.5-22.5 years) ($p = 0.08$) in the standard care period.

TABLE 1 Patient demographics for standard care and acute basic palliation concept periods.

Patients	Standard care (N _S = 26)	Acute basic palliation concept (N _A = 25)	p value
Age at discharge, mean (± SD), yrs	81 (± 10)	86 (± 8.3)	0.08
Males, % (n)	58 (15)	32 (8)	0.07
Time to death from discharge, median (IQR), days	2.5 (1.0-6.0)	3.0 (1.0-5.0) ^a	0.85
Patients unable to walk before admission, ^b % (n)	73 (19)	64 (14) ^c	0.48
Dementia or cancer, % (n)	69 (18)	52 (13)	0.21
<i>Admission facilitated by, % (n)</i>			0.58
Primary care physician	19 (5)	24 (6)	
Emergency medical services	73 (19)	60 (15)	
Out-of-hours primary healthcare	7.7 (2)	16 (4)	
<i>Admitted from, % (n)</i>			0.40
Own home	27 (7)	12 (3)	
Nursing home	69 (18)	84 (21)	
Other	3.9 (1)	4.0 (1)	
<i>Discharged to, % (n)</i>			0.78
Own home	19 (5)	12 (3)	
Nursing home	77 (20)	84 (21)	
Other	3.9 (1)	4.0 (1)	
<i>Regular medication usage prior to inclusion, % (n)</i>			
Morphine	23 (6)	24 (6)	0.94
Benzodiazepine	23 (6)	24 (6)	0.79

IQR = 25-75 interquartile range; SD = standard deviation.

a) N_A = 23, since two patients were still alive in the acute basic palliation concept period 60 days after discharge.

b) Patient was either confined to bed, had mobility restricted to the use of a lift or wheel chair or activities of daily living were described as “low” without additional details in the medical record.

c) N_A = 22.

Primary endpoint: better symptom management was reported during the acute basic palliation concept period

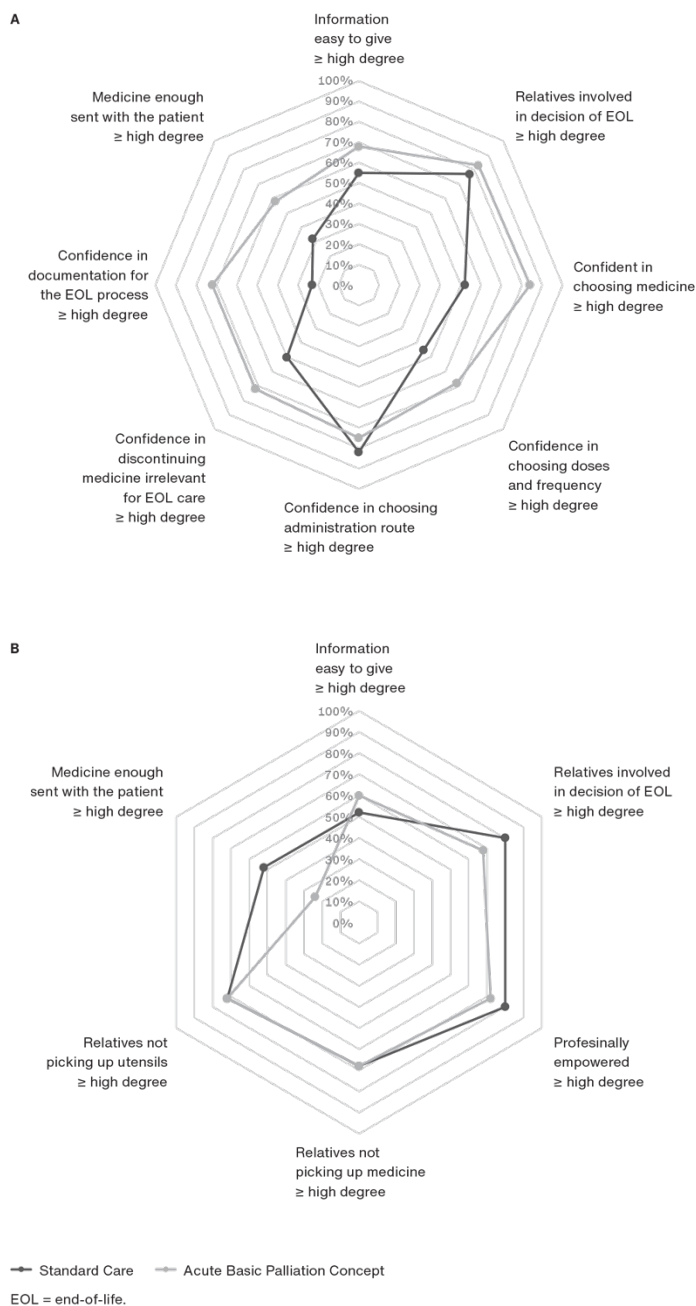
Figure 1 shows the percentage of positive scores for symptom control, with most peripheral scores being the best. Approximately 75% of relatives answered the questions of the survey. Figure 1A shows that relatives scored higher on three of four symptom management statements and lower on one statement during the ABPC period. In Figure 1B, municipal caregivers scored higher on two of five symptom management statements and similar for the remaining three statements during the ABPC period. Furthermore, they reported that enough medicine was provided at discharge 75% of the time during the ABPC period compared to 59% during the standard care period.

Secondary endpoint: healthcare professionals’ opinion of the acute basic palliation concept

All (n = 67) participating healthcare professionals responded "yes" to wanting to use the ABPC again (21

municipal caregivers, 25 discharging doctors and 21 hospital nurses). In free text, 100% (25/25) of the municipal caregivers provided a positive comment, with 4/25 also providing a negative comment. Among the discharging doctors, 92% (23/25) added a positive statement about the ABPC, and 7/25 also commented negatively. The comments can be seen in [Appendix D](#) (in Danish). **Figure 3** presents the results for discharging doctors (A) and nurses (B), with peripheral scores indicating more favourable outcomes. Discharging doctors reported higher scores during the ABPC than the standard care period for their confidence in the choice of medication type (88% versus 52%) and necessary documents (72% versus 24%). During the ABPC period, the doctors used a median of 60 (60-90) minutes to discharge a patient compared to 90 (60-120) minutes during the standard care period. Hospital nurses and municipal caregivers used a median of 60 minutes during both periods.

FIGURE 3 End-of-life care quality assessed by discharging doctors (A) and nurses (B). The percentage of answers indicating a "high" or "very high" agreement with the given statements are shown in grey for the acute basic palliation concept period. More peripheral answers equal a higher percentage of positive answers.



Discussion

Primary outcome

Overall scores during both periods indicated adequate symptom control with room for improvement and slightly higher numerical scores during the ABPC period. There are few studies on EOL care in the non-specialised setting [7]. Our results compare well to a 2022 Danish study where 70% of cancer patients received adequate relief in non-specialised EOL care during their final three months [1]. Specialised PC has been shown to improve symptom management and quality of life for non-cancer patients [8]. However, with demand outpacing supply from the specialised palliative teams, there is an urgent need for all healthcare professionals to be equipped with EOL care skills. We lack updated national and international EOL care guidelines in non-specialised settings, although they have been proven to increase the quality of EOL care, even in emergency departments [9]. Furthermore, a qualitative study from 2015 found that family relatives require more information about the EOL drugs used [10]. Relatives reported increased scores for symptom control during the ABPC period. This might indicate that the information provided with the ABPC was useful to them. However, the authors noted a risk of bias as nearly 25% of relatives did not answer their questions.

Secondary outcome

Healthcare professionals in and out of hospital provided positive feedback on the ABPC. Doctor scores in the ABPC period were considerably increased. The increase in scores aligns with former qualitative and quantitative studies that identified logistics, bureaucracy, low confidence, ineffective communication and lack of standardised workflows as barriers to the provision of EOL care for emergency department staff [4, 11]. These were items that the ABPC aimed at improving.

Municipal caregivers face problems when they provide EOL care in patients' homes, especially during inter-sector transitions, such as moving from hospital to home [12]. Our questionnaires did not include questions investigating sector changes, quality of palliation plans, prescriptions and documentation for discharged patients to die at home. Therefore, the municipal caregivers commented on these issues in the free text (all had solid plans, all relatives were informed, all paperwork was in order, time was spent on care instead of finding medicine/utensils). This shows that EOL care tools, like the ABPC, were needed. These tools are also endorsed by the World Health Organization, Danish health organisations and emergency departments [13-15]. The significance of our developed checklist for the ABPC, which addresses logistical and bureaucratic elements of EOL care, resonates with findings in a Belgian study highlighting collaboration among healthcare professionals across sectors to uplift the quality of EOL care [16].

Our study did not observe a shorter survival time in the ABPC period, which is consistent with several international studies [17]. In the context of the ABPC period, the survival of two patients beyond 60 days after inclusion suggests that adherence to the ABPC protocol does not inevitably lead to immediate death. This indicates the importance of ongoing post-discharge monitoring, allowing for potential changes in patients' conditions, which is included in the ABPC standard discharge text.

Our study found that the discharging doctors and nurses in both the ABPC and standard care periods had similar median years of experience but a broader range in the standard care period. Therefore, experience alone may not equip healthcare professionals with the confidence or skills needed for basic EOL care decisions. The findings highlight the importance of targeted training supported by an American study investigating EOL care in the emergency department setting [18]. This raises a dilemma. Although targeted training for basic EOL care is crucial, the rarity of such cases among daily patient encounters in an ED makes it difficult to prioritise this training over more common patient needs and to maintain these acquired skills.

Strengths and limitations

The ABPC was developed by an expert panel involving patient representatives (the DanAge Organisation), specialised PC physicians and emergency medicine physicians. The expert panel used clinical experiences of negative patient trajectories in combination with learnings from a previous Danish project (“tryghedskassen”), showing that a box of medicine alone was a poor solution [19]. This ensured an approach addressing the diverse needs of patients, their relatives and healthcare professionals. The broad inclusion criteria of our study strengthened the generalisability of the study results.

A main limitation of our study was using unvalidated questionnaires, which need validation in future studies. Furthermore, the study design introduced potential confounding bias as data were gathered continuously without controlled group randomisation. Due to data access limitations, we could not analyse if there was variation in the frequency of patient discharges to EOL care between the two observation periods, which may have biased our results. In our study, most patients were discharged to nursing homes, raising the question of whether the impact of ABPC is the same for patients in nursing homes as for those not living in a nursing home. Our findings, based on a relatively small sample size, need confirmation in more extensive studies with more patients to enable relevant subgroup analysis. The results may not apply to specialised care settings as we focused on EOL care for patients without specialised needs.

Conclusions

This observational study investigated the experiences of relatives and healthcare professionals before and after implementing an acute basic palliation concept (ABPC). Relatives and healthcare professionals reported better symptom and EOL care scores during the ABPC period, and all healthcare professionals stated that they would use the ABPC again. Future studies with larger sample sizes and validated questionnaires are needed to verify our findings. Integrating basic PC models, such as the ABPC, into general practice further offers a promising pathway for initiating treatment pre-emptively, thereby mitigating the need for hospital admissions.

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Conflicts of interest Potential conflicts of interest have been declared. Disclosure forms provided by the authors are available with the article at ugeskriftet.dk/dmj

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<https://content.ugeskriftet.dk/sites/default/files/2024-09/a10230621-supplementary.pdf>

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