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ORIGINAL ARTICLE

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What amount of medicine and utensils are needed for acute, basic End-Of-Life palliation? An observational cohort study.

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Abstract

Introduction: End-of-Life (EOL) care is essential for alleviating patients' suffering in their final days. An Acute Basic Palliation Concept (ABPC) includes a checklist for doctors and nurses, patient information materials, a medication box, and a decision-making tool for municipal nurses. The concept was developed to support patients, relatives, and healthcare professionals in relieving suffering in elderly, frail, and terminally ill patients, who prefer to die at home. The aim of this study was to investigate the amount of medication and utensils necessary for EOL care when using the ABPC on patients without specialized palliative needs and a life expectancy of days.

Methods: This observational study was conducted in the North Denmark Region. Forty dying patients were discharged from the emergency departments using the ABPC, which included a pre-packed box of medicine and utensils for EOL care. When the patient had passed away, the boxes were collected, the remaining medication and utensils counted, and the used medicine calculated.

Results: The remaining contents of 32 out of 40 boxes were counted after the completion of the patient-treatment process. The last eight boxes had been sent for destruction by the healthcare staff. Median time to death was 2.0 (1;3) days, mean age was 85 (standard deviation 9.4) years, and 69% were women. Availability of 20 vials of Morphine (10 mg/mL), 18 vials of Midazolam (5 mg/mL), four vials of Haloperidol (2.5 mg/mL), six vials of Glycopyrronium (0.1 mg/mL), and six suppositories of Bisacodyl (10 mg), was sufficient for covering the needs of 95% of the patients receiving EOL care.

Conclusions: The number of medication vials needed for EOL care in 95% of patients without special needs was documented in this study of 32 patients.

Trial registration: Trial approval from the hospital administration was received (reference number: K2022-030) and the regional Ethical Committee waived the need for approval (reference number: 2022-000764).

Keywords: End-of-Life care; Palliative Care; Terminally Ill; Emergency Department; Pain; Dyspnea; Anxiety; Delirium

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Introduction

When the life expectancy is days to a few weeks, End-of-Life (EOL) care is needed to avoid suffering from, e.g., pain, dyspnea, anxiety, and delirium. Of the 52,000 patients who die each year in Denmark, 82% do not receive specialized palliative care (1). The majority of these patients will likely not need specialized palliation but rather have a need for basic palliative care. Those patients rely on basic palliative care provided by the doctor available, e.g., in the emergency medicine department. Several doctors and nurses find it challenging to provide EOL care due to a lack of systematic education and evidence in the area (2,3). This may lead to doctors setting too low maximal doses of EOL care medicine or insufficient prescriptions due to apprehension about shortening the patient's life (4). The consequence might be unnecessary suffering for the patient and their family (2). This belief is in strong contrast to results from many studies documenting that patients who receive EOL care do not die earlier than those who do not receive EOL care (5–7).

There are few studies on how to provide EOL care for acute patients without specialized palliative needs who are expected to die within days (8). In Denmark, this area has likewise received limited attention; however, in 2024, the Danish Society for General Medicine updated its clinical guideline for general practice with a focus on these patients (9).

Furthermore, no studies regarding the amount of medicine needed for at-home EOL care have been conducted. Knowledge about this will diminish the situations in which relatives are required to leave their dying relative to go to the pharmacy or situations where a lack of medicine leads to hospital admission.

A Danish quality study of EOL care in dying patients without specialized palliative needs investigated the effect of a systematized concept for EOL care: The "Acute Basic Palliation Concept" (10–12) . The concept was created in a collaboration between departments of emergency medicine, palliative teams, and the patient organization Dan-age. It consisted of 1) a guideline and checklist for the discharging doctor, 2) a guideline and a decision tool for administration of medicine for the district nurse at the patient's home, 3) written information for the patients and their relatives, and 4) medicine and utensils in a box.

The aim of this study was to estimate the amount of medication and utensils needed for EOL care in 95% of the patients without specialized palliative needs having a life expectancy of days who were treated with the Acute Basic Palliation Concept (ABPC).

Methods

This quality improvement study was conducted at Aalborg University Hospital, which had 210,208 acute hospital contacts during 2021 (13). Patients were included from two departments of emergency medicine. Data were collected from January 2023 to May 2023. Patients fulfilling the following criteria could be included in the study: age ≥ 18 years, admitted to the emergency department, expected to die within a few days (assessed by the admitting physician in consultation with a senior doctor), not needing specialized palliative care, and wanting to die at home. Patients were excluded if their clinical condition or home environment were unsuitable for palliation at home (e.g., severe vomiting or rat infestation at home).

Patients were discharged with a prepacked kit as part of the ABPC. The kit from the ABPC contained vials of Morphine, Midazolam, Haloperidol, and Glycopyrronium for s.c. injections as well as suppositories with Bisacodyl (Table 1). The kit also contained all the necessary utensils and written materials designed for patients, relatives, and healthcare professionals (Table 1). When the patient had passed away, the kits were collected, and the remaining medicine and utensils were counted. As for hygienic reasons a vial can only be used for a one-time administration outside hospitals, the number of missing vials was used as an estimate for the number of times a medication was administered to the patient.

Table 1. The content of the Acute Palliation Concept

Medication	Quantity
Morphine *10 mg /ml – 1 ml per vial*	40
Midazolam *5 mg/ml – 1 ml per vial*	40
Haloperidol *5 mg/ml – 1 ml per vial*	10
Glycopyrronium *0,2 mg/ml – 1 ml per vial*	10
Bisacodyl suppositorier, *10 mg/suppository*	12
Natriumchlorid *9 mg/ml – 20 ml per flask*	20
Utensils	
Subcutaneous needles	10
Caps for needles	20
1 ml syringes	50
5 ml syringes	30
Filter cannulas	100
Swabs	100
Fixation plasters	20
Written material	
Checklist for prescribing physician	1
Short written information for patients and relatives	1
Long written information for patients and relatives	1
- Medicine information for municipal caregiver	1
Flowchart for medication administration (including potential adjustments from doctor)	1

The primary outcome was the number of vials of medication needed for EOL care in 95% of participants from the day the patient was discharged until death occurred. The secondary outcome was the number of utensils needed in the same period to cover the needs for 95% of participants.

The study was reported following the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines.

STATISTICS

Data were collected and managed using REDCap electronic data capture tools hosted at the North Denmark Region (14,15). Data were presented as median and interquartile range (IQR) as well as the 95th percentile or mean and standard deviation, as appropriate. The data management and statistics were done using SAS Enterprise Guide 7.1 (SAS Institute Inc., Cary, NC, USA) and figures using SigmaPlot 11.0 Build 11.1.0.102 (Systat Software Inc., CA, USA).

Results

Of the first 40 patients discharged with the ABPC, 32 boxes of medication were returned after the patients had passed away. Contrary to the instructions given, eight boxes had been discarded by the staff at the nursing homes due to local routine. Patients included had a mean age of 85 (standard deviation 9.4) years and died within a median of 2.0 (1;3) days. Women comprised 69% of patients.

The amount of medication used from the medicine boxes is presented in Table 2 and Figure 1.

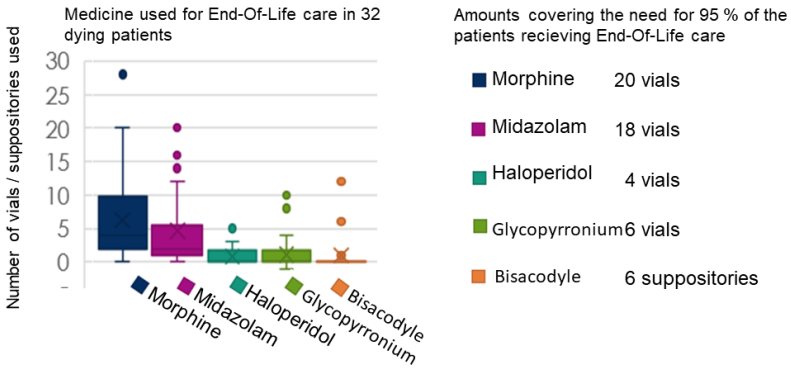

Figure 1. Medication used for End-of-Life care in the last days of life and the number of vials needed for 95% of patients.

Table 2. Use of medication and utensils in 32 patients palliated with the APC

		Median	25 % percentile	75 % percentile
Morphine	Vials	4.0	2.0	9.5
Midazolam	Vials	2.0	1.0	5.0
Haloperidol	Vials	0.0	0.0	1.5
Glycopyrronium	Vials	0.0	0.0	1.5
Bisacodyl	Suppositories	0.0	0.0	0.0
NaCl	Flasks	2.0	0.50	8.0
Subcutaneous needles	Number	0.0	0.0	1.0
Caps for needles	Number	1.0	0.0	4.0
1 ml syringes	Number	6.5	2.0	26
5 ml syringes	Number	2.0	1.0	4.0
Filter cannulas	Number	5.5	2.0	23
Swaps	Number	5.5	0.0	17
Fixation plasters	Number	0.5	0.0	2.0

Morphine and midazolam were primarily used, whereas Haloperidol, Glycopyrronium bromide, and laxatives (Bisacodyl) were used to a lesser extent. As illustrated in Figure 1, 95% of the included patients' needs for EOL care in the last days of life were covered by: 20 vials of Morphine (10 mg/mL, 1 mL vial), 18 vials of Midazolam (5 mg/mL, 1 mL vial), four vials of Haloperidol (5 mg/mL, 1 mL vial), six vials of Glycopyrronium (0.2 mg/mL, 1 mL vial), and six suppositories of Bisacodyl (10 mg/suppository).

The used utensils are outlined in Table 2 and Figure 2. In the retrieved boxes with leftover medicine and utensils, we observed that all 1 mL syringes (50 pcs) or alcohol swabs (100 pcs) were removed from the boxes in a few cases. Considering what had been used of the medication, it is highly unlikely that these were all used for the patient; this may have been caused by a culture among staff of reallocating unused utensils (but not medication) for other patients. For the utensils where this pattern was observed, we marked the results with "*" in Figure 2.

Discussion

This is, to our knowledge, the first study measuring the amount of medicine and utensils needed for EOL care in patients with a basic, acute palliative need and who are expected to die within a few days. One study documented the doses of sedative medicine used in patients with cancer in the last two days of their life, but did not indicate the amount of medicine actually needed (16).

In contrast to the many studies that exist on specialized palliation for, e.g., patients with cancer, there are only very few studies on basic palliative needs for, e.g., elderly people within the last days of their lifetime. This presents a concern, as the vast majority of dying patients (>80% in Denmark) are not treated by palliative teams (1).

No studies have resulted in recommendations regarding type, dose, or administration form of either opioid or benzodiazepine. Only one study focusing on medication in basic acute EOL care was found. This was a single pilot

study with medication administered at home by family or caregivers from a prepacked kit (17).

In Denmark, healthcare professionals administer high doses of addictive medication, which should enhance the safety of handling these dependency-forming medications (18). Healthcare professionals may be concerned that prescribing and administering the necessary medication for pain relief in dying patients could hasten death. The fear of prescribing adequate medication may lead to unnecessary suffering in dying patients. However, several studies show that palliative care using opioids and benzodiazepines does not shorten expected survival time (5–7,19). Of the evaluated studies in specialized palliative settings, the majority used morphine to treat dyspnea, while fewer used fentanyl, oxycodone, or hydromorphone, which were administered parenterally, orally, in combinations, or by nebulization.

The Danish Society for General Medicine (DSAM) has updated its guideline for general palliative care in 2024, and thereby contributes knowledge that can support general practitioners in their work with non-specialised palliative care (9). Nevertheless, there may remain a need for education of healthcare professionals in both communities and hospitals to strengthen competencies in providing basic palliative care.

STRENGTHS AND LIMITATIONS

In the study, there were very broad in- and exclusion criteria to minimize selection bias and ensure good generalizability to EOL patients without specialized palliative needs. Both patients discharged to their own homes and patients discharged to nursing homes were included, which also increases the generalizability of the findings.

A potential limitation of the study is that perceived symptom relief from the medication was not reported. However, these data are presented in the following articles, which document a very high level of symptom relief with the doses of medication used (10,11). Even though eight boxes of medicine were not collected because the medicine was sent for destruction in one municipality (local rule), we do not expect the patients in that municipality to differ from the other 32 patients living in the other municipalities. Medication boxes were safely stored in locked cabinets at nursing homes until they were collected by the researchers, which increased the validity of the data. As vials can only be used for one dose (municipality rules), the number of missing vials used to estimate doses is expected to be a strong proxy for the number of doses delivered for the EOL palliative care.

The counts of utensils, on the other hand, are less certain, as some utensils were completely missing from several boxes, even though they had not been administered much medicine. We expect that these utensils were used for other patients, which is a common culture in nursing homes, contradicting the very strict rule of medicine not being allowed to be passed on to other patients.

FUTURE RESEARCH

Given the large number of dying patients who are not offered specialized palliative care, it is imperative to intensify research to ascertain requirements for delivering high-quality EOL care. This is important to ensure that these patients are spared from unnecessary suffering during the last days of their life.

Future research could benefit from focusing on the final stages of life, where needs may differ from those in longer-term palliative care. Besides that, there is also a shortage of studies on how the older population envisions their last days, and what their fears and expectations are. Lastly, from a patient perspective, there is a lack of studies examining the optimal time in a person's life to begin preparing for end-of-life care and how these plans can be effectively implemented in practice.

Conclusion

The number of medication vials and utensils needed for basic EOL care in patients without special palliative needs was documented in this study of 32 patients dying within a few days. The amounts covering the needs of 95% of patients were calculated and could be recommended to deliver to the patient's home when patients without specialized palliative needs and a life expectancy of days are prescribed EOL care.

KEY MESSAGE

The following medications were sufficient to meet the needs of 95% of patients receiving end-of-life care: 20 vials of Morphine (10 mg/mL), 18 vials of Midazolam (5 mg/mL), four vials of Haloperidol (2.5 mg/mL), six vials of Glycopyrronium (0.1 mg/mL), and six Bisacodyl suppositories (10 mg).

Ethics approval and consent to participate

The study protocol was approved by the hospital administration (reference number: K2022-030) and the regional Ethical Committee of Aalborg University Hospital waived the need for approval (reference number: 2022-000764).

Availability of data and materials

The dataset used in this study is available on reasonable request to the corresponding author (the dataset is not publicly available due to the protection of personal data).

Conflict of interest

All authors declare that they have no competing interests.

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Authors' contributions

MBA, DM, and ALK contributed substantially to the conception and design of the work; the acquisition, analysis, and interpretation of data for the work; the drafting of the work and revising of it critically for important intellectual content; and making a final approval of the version to be published; and they agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy and integrity of any part of the work were appropriately investigated and resolved. AAØB, JMB, CM, CRK, LGR, and HE contributed substantially to the analysis and interpretation of data for the work, drafted the work and revised it critically, and made a final approval of the version to be published; and they agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy and integrity of any part of the work were appropriately investigated and resolved.

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