A narrative review on palliative care in the emergency department: dealing with the uncertainty of death

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Abstract

In the last decades emergency physicians have observed a steep increase in the emergency department (ED) admissions of palliative care patients who rely on the hospital for symptoms' relief and management of acute exacerbations of their chronic disease. Previous studies have suggested that palliative care interventions in the ED could prevent unnecessary admissions and reduce both the length of hospitalization and costs. However, emergency medicine physicians might have limited specialistic education and resources to provide a correct management of palliative care patients and avoid futile interventions. Thus, we aim in this narrative review to provide the reader with an introduction on the principles that should guide the emergency physician in a correct approach to palliative care patients in the ED. We will explain how to deal with the intrinsic prognostic uncertainty of palliative care patients by implementing a correct ethical approach which encompasses the understanding of both appropriateness and futility of intervention; furthermore, we will present practical tools such as scores and trials.

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Introduction

In the last decades, the median age of the world population has rapidly grown due to a steep decline in the birth rates and an increase in life expectancy.[1] The World Health Organization has estimated that between 2015 and 2050 the number of people older than 60 years old will double, and by 2050 worldwide there will be more than 400 million people over 80 years old.[1] The consequences of this demographic shift are devastating with an exponential use of the healthcare resources toward the end of life.[3,4] Emergency departments (EDs) are especially affected by this phenomenon with a growing number of patients who present to the hospital not for acute problems, but for symptom relief and management of chronic diseases.[5] Among them, palliative care patients compose a high percentage, which is slowly increasing year after year.[6,7] Even though previous studies have suggested that palliative care interventions in the ED could prevent unnecessary admissions and reduce both the length of hospitalization and costs, emergency medicine physicians, especially residents and young doctors, might have limited specialistic education and resources to provide a correct management of palliative care patients.[8] This lack of knowledge and practice has been highlighted by the COVID-19 pandemic, during which the increased demand for emergency department services resulted in limited resources and staff to provide quality palliative care. The situation clearly demonstrated that, especially during times of crisis, emergency department protocols should incorporate palliative care and seek innovative tools which can allow for better management of palliative care patients and emotional/spiritual support of families.[9,10] Thus, we aim in this narrative review to provide the reader with an introductory guide on the ethical and practical principles that should guide the emergency physician in a correct approach to these patients in the ED.[11-15]

Uncertainty and how to deal with it

Doctors are historically taught to understand patients through scientific knowledge, basing their decisions on scientific evidence alone so that subjectivity does not bias their judgment. Even though this technical approach is very efficient for disease management, it is not adequate to deal holistically with another human being, especially in situations of suffering or dealing with possible fatal outcomes. In these cases, the assembly line of the industry of healthcare fails and both the patient and the doctor find themselves impotent, especially in front of death. The difficulties of managing palliative care patients can stem from the intrinsic uncertainty of death. In fact, while centuries ago death was typically sudden and unexpected, now it is usually the delayed final event in a prolonged course of a chronic disease, during which a correct prediction can be impossible. These delicate situations require a "humane" doctor who applies the scientific evidence and skills with ethical sensitivity and insight, trying to understand the patient's biography.[16] Doctors need to combine the scientific knowledge of disease and

treatments with the understanding that each patient might need different approaches and interventions. In fact, physicians should pursue a personalization of the healing process which aim to maximize the benefits for each patient based on their own values and narratives.[17,18] In the following chapters we will explain how emergency medicine physicians can deal with the intrinsic uncertainty of death trajectories, assessing patients in a multimodal and holistic approach that encompasses both active emergency medicine and palliative care, avoiding futile interventions and providing the finest support to the patient and family. We will illustrate death trajectories and how to apply ethical reasoning, scores, and trials to navigate through the uncertainty of death. Given the aim and scope of our research, we will not present and review the use of drugs in the palliative care. However, given the great importance of the topic, we will provide the reader with some bibliographic sources which can be used as a basis for further studies.[19-21]

Death trajectories

Four common death trajectories have been identified and understanding them can help the emergency medicine physician to position every patient on the course of its disease, avoiding futile intervention and promoting correct palliative care interventions.[22] The known trajectories, as displayed in Figure 1, are: i) sudden death: instantaneous or after a brief episode of an acute illness (*e.g.,* infection, trauma, cardiac arrest, stroke). This trajectory does not allow for any planning of palliative care interventions; ii) short period of evident decline: predictable decline in physical health over a period of weeks, months, or years (*e.g.*, cancer), with a progressive reduction in the performance status especially in the last months. This trajectory allows for early palliative care interventions and, in the last months of life, a more intense palliative approach, if necessary; iii) long term limitations with intermittent serious episodes: long course of disease (*e.g.*, heart failure, chronic obstructive pulmonary disease) with occasional acute, possibly lethal, exacerbations generally associated with hospitalization and intensive treatment. After each episode, the patient experiences a deterioration in health and functional status; iv) prolonged dwindling: progressive disability from an already low baseline of cognitive or physical functioning (*e.g.*, Alzheimer's dementia, frailty), characterized by a progressive and long loss in functional capacity until a final event, which results fatal due to the declined physical reserves.

Cultivating a medical ethical approach

Since the birth of the medical job, ethics has been an integral part of the profession, serving as a moral compass which allowed the physician to sail through the uncharted waters of disease and death. With the advancement of medicine, we have started to rely more on the scientific reasoning, relegating ethics to just anecdotical cases. However, nowadays more than ever the physician must face ethical problems which stem from the modernity of medicine (*e.g.*, death, abortion, euthanasia, privacy, healthcare accessibility). This situation is especially poignant in intensive care departments, where severe complications are common, and doctors must take complex decisions regarding prognosis, death, and palliation. Thus, it is crucial to learn medical ethics to approach patients without getting lost in the rush of the "necessity to act".

Medical ethics, as explained by Beauchamp and Childress, is supported by four main principles: autonomy, beneficence, non-maleficence, and justice that every doctor should always follow to ensure proper care. The principle of autonomy asserts the right of every patient to make informed decisions about their healthcare. In the emergency department, this can be pursued by direct confrontation with the patient or, in case of unconsciousness or states not fit to make decisions for themselves, by talking with family members or legal guardians. Beneficence refers to the principle of acting in the best interest of the patient, while non-maleficence refers to the principle of doing no harm. Medical professionals need to balance the risks and benefits of treatment options, being aware of potential risks and taking appropriate measures to prevent further harm to the patient. Lastly, justice refers to the principle of fairness. Doctors need to ensure that all patients receive fair and equitable care, regardless of their socio-economic status or other factors, and need to be aware of potential systemic or personal biases and work to address them.[23,24]

Appropriateness and futility

Vergano *et al.* illustrated clearly that intensive care physicians (such as emergency medicine doctors) should always evaluate both appropriateness and futility when considering an intervention.[25] Appropriateness is defined as the degree to which a provided medical intervention is beneficial to the clinical needs, given the current best evidence. To assess the clinical adequacy of a procedure, doctors must consider both the scientific pertinence and the ethical proportionality, meaning the impact on both the patient's biology and biography. This holistic approach allows patients to be offered only clinically adequate interventions, and to decide whether these proposals are meaningful within the context of their personal life narrative and values.[25] In this perspective, the limit of acting is determined by the futility of our intervention, defined as the gap between the highest level of functioning achievable by medical care and the lowest quality of life acceptable to the patient.[26]

Surprise question

To raise concern and help identify patients who might benefit from hospice and palliative care, Dr. Joanne Lynn in 2005

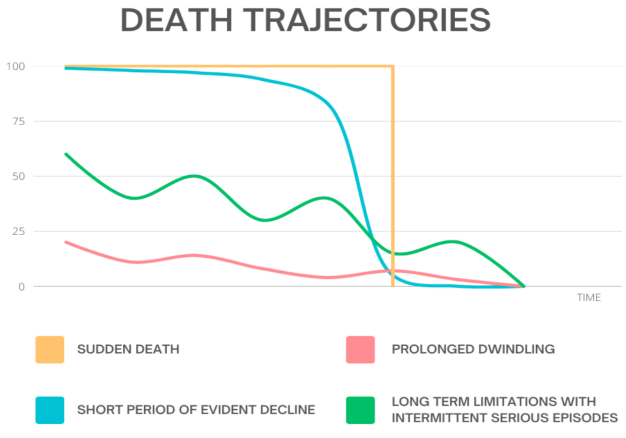

Figure 1. Death Trajectories. X axis, time; Y axis, performance status.

designed the following question every doctor can ponder on: would I be surprised if this patient died in the next 12 months? This approach has been shown to limit the physician's tendency to overestimate prognosis in all clinical settings, while being effective in identifying end-stage renal disease and patients with cancer who are at an increased risk of mortality.[27-30] Regarding the ED, the study from Zeng et al. demonstrated that trained emergency medicine physicians were able to increase their perceived ability to determine life expectancy, leading to a statistically significant increase in ED-generated palliative care consults.[31] However, the surprise question was designed for a primary care and ward settings, and mostly for neoplastic patients. Thus, its applications could be limited in the emergency medicine setting, where it could need to be modified shortening the period of time to account for the acute presentation of the patient and the possible underestimation of prognosis due to critical condition of arrival.

Scores

Scores provide a standardized and objective way to assess patient needs, ensuring the most appropriate and effective care possible, however they may not capture all the nuances of a patient's clinical condition or personal preferences, and healthcare providers must always use their clinical judgment in conjunction with scores to ensure the best possible care. Among the different scores applied to palliative care, the palliative performance scale (PPS) has been demonstrated to be a useful outcome-prediction tool and its use has been widely validated to assess the functional status of seriously ill patients. The PPS rates the patient with a score from 0 to 100, based on the ability to perform activities of daily living, such as eating, dressing, and bathing, as well as their ability to ambulate and communicate (Table 1). As demonstrated by Babcock *et al*., PPS can be applied in the ED setting for risk stratification and early palliative care referral of patients.[32-35] Similar results emerged from the meta-analysis by Downing et al. that illustrated that the functional status of palliative patients in the ED correctly predict survival.[36] Another useful score in the emergency department is the Palliative Care Rapid Emergency Screening (P-CaRES) which involves identifying patients with life-limiting conditions and two or more unmet palliative care needs (Table 2). If positive, palliative care consultation is indicated. This tool has demonstrated validity, reliability, and acceptabil-

Table 1. Palliative Performance Scale (PPS), version 2.

PPS level (%)	Ambulation	Activity level and evidence of disease	Self-care	Intake	Level of consciousness
100	Full	Normal; no evidence of disease	Full	Normal	Full
90	Full	Normal; some evidence of disease	Full	Normal	Full
80	Full	Normal with effort; some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Cannot do normal job; significant disease	Full	Normal or reduced	Full
60	Reduced	Cannot do hobbies; significant disease	Occasional assistance needed	Normal or reduced	Full or confusion
50	Mainly sit/lie	Cannot do any work; extensive disease	Substantial assistance needed	Normal or reduced	Full or confusion
40	Mainly sit/lie	As above	Mainly assisted	Normal or reduced	Full or drowsy +/- confusion
30	Bed bound	As above	Total care	Normal or reduced	Full or drowsy +/- confusion
20	Bed bound	As above	Total care	Minimal to sips	Full or drowsy +/- confusion
10	Bed bound	As above	Total care	Mouth care only	Drowsy-coma +/- confusion
0	Death	-	-	-	-

Table 2. Palliative care and rapid emergency screening tool (P-CaRES).

Does the patient have a life-limiting illness?
Advanced dementia or CNS disease (*e.g.*, history of stroke, ALS, Parkinson): assistance needed for most self-care and/or minimally verbal.
Advanced cancer: metastatic or locally aggressive disease.
End stage renal disease: on dialysis or with a creatinine > 6 mg/dL.
Advanced COPD: continuous home o2 therapy or chronic dyspnea at rest.
Advanced heart failure: chronic dyspnea, chest pain or fatigue with minimal activity or rest.
End stage liver disease: history of recurrent ascites, GI bleeding or hepatic encephalopathy.
Septic shock: with the necessity of ICU admission and significant pre-existing comorbid illness.
Provider discretion – high chance of accelerated death *(e.g.*, advanced AIDS, major trauma or hip fracture in elderly).
If nothing above applies, stop screening **≥1 items above: continue screening**
Does the patient have two or more unmet palliative care needs?
Frequent visits: ≥ 2 ed visit or hospital admissions in the past 6 months.
Uncontrolled symptoms: visit prompted by uncontrol symptoms, such as dyspnea, depression, fatigue, pain etc.
Functional decline: loss of mobility, frequent falls, skin breakdown, etc.
Uncertainty about goals of care and or caregiver distress: caregiver cannot meet long-term needs; distress about goals-of-care.
Surprise question: positive answer.
<2 items above: stop screening **≥2 items above: recommend palliative care consultation**

ity by palliative care specialists and emergency medicine clinicians. Furthermore, in addition to identifying patients with unmet palliative care needs who might benefit from a palliative care consultation, the P-CaRES tool was shown to predict 6-month survival and was highly correlated with PPS values.[37-39] In the emergency department, another useful tool that can be applied is the NECPal scale, which has been extensively validated to quickly and promptly identifying patients with palliative care needs, especially in the family medicine field. The scale was developed by Carvajal et al. and has been validated in several studies, demonstrating good reliability and validity.[40] The use of the NECPal scale allows healthcare professionals to tailor symptom management interventions to individual patient needs, improving patient outcomes and satisfaction with care. A study by Gómez-Batiste et al. found that the implementation of the NECPal scale in palliative care practice led to a reduction in symptom burden and improved patient comfort.[41]

Trials

Another useful approach to palliative care patients in the ED is by implementing trials, which could be time-limited, skill-limited or event limited. Trials are an agreement between clinicians and a patient/family to use a certain level of medical therapies (skill-limited) over a defined period (time-limited) to see if the patient improves or deteriorates according to agreed-on clinical outcomes, with the possibility to prematurely shift the cure to palliative support in case of certain severe complications of which risks seem to outweigh the benefits (event-limited). Physician can resort to trials to delay the dichotomous decision between palliative and active care, securing the opportunity to evaluate in time potentially beneficial interventions, with a thorough consideration of its risks and benefits. The application of trials can allow to gather biographical data which facilitate the process of understanding the patient's limits of the ethical proportionality of interventions, avoiding futile actions, and preparing in case for a shift toward comfort-focused end-of-life care.[42]

Confusion about palliative care in the ED

Even though previous studies reported that early palliative care interventions allow not only for a better quality of life, but also for an extension in the duration of life itself, confusion and obstructionism in the ED among emergency physicians are still common.[43] In fact, palliative sedation, withdrawal of life support treatments and euthanasia are wrongly used as synonyms, when they have different meaning and intentions. Palliative sedation is the act of making a patient calm, unaware, or unconscious using pharmacological therapy to relieve suffering from symptoms that cannot be controlled with other treatments (refractory symptoms). Previous research has thoroughly demonstrated that palliative sedation neither causes acceleration in the dying process nor anticipates death.[44-48] Withdraw of life support treatment means the removal of interventions that are no longer indicated because of a lack of clinical or subjective benefit. Euthanasia is the practice of intentionally terminate life to eliminate pain and suffering. It is important to emphasize these differences not for lexical justice, but because of the distinctive aims they have. In fact, while euthanasia aims to end the patient's life and is caused actively by the physician, withdrawing and palliative sedation aim to remove burdensome interventions and relieve symptoms, following the two principles of medical ethics of beneficence and non-maleficence.[49] The emergency physician must be conscious that all the decisions regarding palliative care in the emergency department must be discussed with the patient, his/her family or caregivers, the nurses, and, in case of doubts shared with palliative care specialists. In fact, a clear communication is vital to successfully start to build the patient–physician trust and to start a palliative care plan. Furthermore, the creation of joint palliative care pathway and protocols (created by the whole emergency department together with palliative care specialists) can allow for early identification of palliative care patients, implementation of simultaneous care and better management of symptoms, and palliative care sedation, while reducing the responsibility and stress of the decision of the single physician. For what concerns communication, every component of the emergency department should be trained in a correct lexicon use, communication modality and non-verbal approach, which cannot and should not be improvised but must be obtained by following a specific learning process.

Current situation in Italy

Regarding the current situation in Italy, the emergency physician should be aware and informed of two laws which regulate the application of palliative care in healthcare: D. lgs 38/2010 and D. lgs 219/2017. The first one dictates that palliative care should be implemented in every field of healthcare, including the emergency department, considering especially diseases with chronic or fatal evolution. This law allowed for a redefinition of the assistance models, the creation of specific palliative care networks, better access to palliative care drugs and an advancement in pediatric palliative care. The second law regulates the informed consent, stating that every patient has the right to know his/her health status and be informed thoroughly of his/her conditions, including the possibility of refusing every single intervention proposed. This law allowed for the creation of a National Bank for the registration of advanced treatment instructions (Disposizioni Anticipate di Trattamento – DAT) which enable every adult person to auto-determinate him/herself by expressing his/her will on possible medical interventions. The bank grants the accessibility of the instructions, and it is compulsory for every doctor to verify the patient's directives and adhere to them.

Several organizations must be cited for their extensive work to apply palliative care in the emergency department in Italy: SICP (Società Italiana di Cure Palliative), SIAARTI (Società Italiana Anestesia, Analgesia, Rianimazione e Terapia Intensiva), SIMEU (Società Italiana Medicina d'Emergenza Urgenza) ed EUSEM (European Society for Emergency Medicine). SICP's main objective is the diffusion, application and education on palliative care in every field of medicine, conveying a holistic vision of the healing process where the patient is at the center. SIAARTI, SIMEU and EUSEM focus on the promotion and application of a correct medical expertise in the field of intensive medicine. They advocate that even in intensive care departments palliative care patients deserve to be assisted properly with the aim of preserving the patient's dignity, autonomy, and control at the end of life. A virtuous example of palliative care in the ED is the "relief room" of Piacenza Hospital, a place where end-stage patients, identified by a specific protocol[21] by emergency physicians, can receive palliative sedation or symptomatic relief while surrounded by family members who can stay all day beside their loved one, in a quiet, private environment.[15]

Conclusions

We strongly believe emergency physicians need to integrate palliative medicine more into their daily practice, embracing a more holistic approach to patients, that can be acquired through the study and application of ethics and humanities in medicine. To help this process of assimilation, palliative medicine should become part of the training for emergency medicine physicians.

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