case report

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Palliative care: patient's autonomy in the end-of-life situation

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Summary Palliative care has evolved over the past five decades as an interprofessional specialty to improve quality of life and quality of care for patients with cancer and their families. The main objective in an end-of-life (EOL) situation is to maintain the autonomy and the dignity of the patient as much as possible. Due to the severity of progressive diseases and as a result of the poor general condition of the patient, their autonomy is often endangered. This case report presents a 70-year-old woman who suffered from hepatic and bone metastases from cancer of unknown primary (CUP) in a palliative setting and discusses the supportive treatment opportunities as well as the ethical thoughts about her autonomy.

Keywords Ascites · Cancer of unknown primary · Communication · Physician–patient relationship · Self-determination

Introduction

The World Health Organization (WHO) [1] defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and the relief of suffering by means of early identification and impeccable assessment and treatment of pain and other issues of physical, psychosocial as well as spiritual nature [2]. Palliative care affirms life and regards dying as a normal process and intends neither to hasten nor postpone death.

In addition to providing symptom management to patients, an important goal of palliative care is to assist patients with advanced care planning. Communication is a fundamental pillar of palliative care and good communication skills are important in discussions of advance directives and goals of care [3]. Studies show that patients with chronic illness want to talk about their choices and goals of care, as well as have frank discussions about prognosis in the disease trajectory [4]. Aside from this, respect for the patient's autonomy is the second key principle in contemporary medical ethics [5–8]. However, relational autonomy in EOL care is far from being clearly conceptualized or practically operationalized [9]. It can be rather challenging for the physician, the patient and/or their relatives in particular if the decision is a therapeutic and/or a diagnostic retreat.

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Case description

We admitted a 70-year-old woman with hepatic and bone metastases caused by cancer of unknown primary (CUP) for further palliative care in our palliative unit. She came in as an emergency transferred from the outpatient oncology department of the local university clinic due to a decrease of her general condition, abdominalgia and ascites. After palliative radiotherapy of her bone metastases for supportive pain treatment a year ago, further oncological therapy was neither planned nor possible. The development of ascites was profound and highly symptomatic; the result was sonographically verified and an indication for paracentesis [10].

Due to her liver failure her coagulation parameters were low, but also with a coagulation restriction it was possible to perform paracentesis in this setting. Studies show there is no higher risk of bleeding by patients with coagulation restriction and therefore no need of prophylactic substitution of clotting factors [11]. After a detailed explanation of the procedure to

the patient, the first attempt of paracentesis was unfortunately unsuccessful. A second attempt a couple days later was declined by the patient because she felt too weak in general even though the paracentesis was still indicated.

The decision of the patient had to be respected and new strategies had to be taken into consideration. A conservative strategy was established with intravenous administration of spironolactone and furosemide diuretics [12]; this was accompanied by optimization of supportive therapy with antiemetics and analgesics. Moreover, the new situation was discussed in detail with her husband and son.

Furthermore, studies of intensive specialists from Beth Israel Deaconess Medical Center show that the reduction in the use of invasive treatments over time in patients with very poor prognosis did not shorten the time-to-death [13].

The patient's symptoms were adequately managed but her general condition progressively worsened. It was impossible for her to swallow and all per os medications had to be discontinued in this preterminal phase. In the end, she died a peaceful death from the consequences of her underlying disease.

Discussion

In an EOL situation the autonomy of the patient stands for some stability in their fleeting life and this rather hopeless situation. It often gives the patient physical and emotional strength, satisfying their need for information and the desire for control [14, 15].

In order to grant our patients as much autonomy as possible it is important to support them in a professional manner. Helpful communication skills and tools like the SPIKES model (Table 1), first described by Baile et al. [16], help to find a suitable way in establishing a connection to the patient and also to the relatives.

The described situation is a challenging task for professionals to fulfill adequately, especially if the patient's request is a retreat of a helpful intervention. Each patient's case must be individually considered, particularly in an EOL situation. Furthermore, every patient has individual needs and an attending physician should cater to those. Emanuel et al. [17] described four models of physician–patient relationship according to these needs (Fig. 1).

Table 1 SPIKES model—a communication tool for delivering bad news [16]

Set up	Know the standards for learners at this stage. Consider the setting and timing
Perception	Ask for learner reflection
Invitation	Be sure feedback is expected and its purpose is clear
Knowledge	Give specific, non-evaluative comments that relate directly to the situation
Emotions	Attend to emotions evoked by the situation or by the feedback given
Strategize	Develop an action plan addressing the learning goals and providing follow-up to ensure progress is monitored

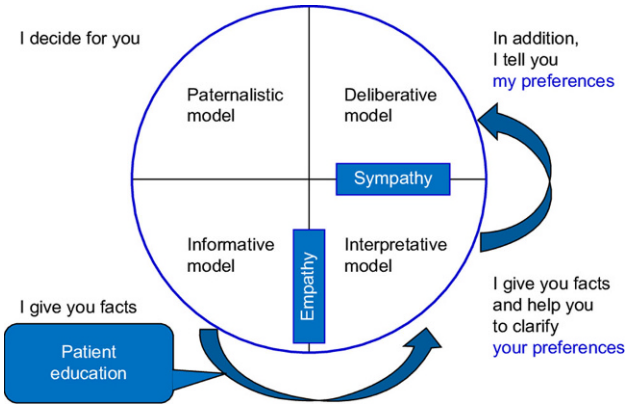

Fig. 1 Four models of physician–patient relationship [17]

With these models in mind, our case is applicable to three of these models and we are moving around to guide as best as possible for the wellbeing of the patient and the patient's autonomy. We told her that paracentesis would be the best option from our point of view (deliberative), she decided otherwise and rejected the intervention (informative), we clarified her needs and presented her new options via conservative procedure (interpretive), she accepted and retained her autonomy and with it control of her own life.

Studies show a desire for control over the dying process and the desire for autonomy in the form of self-determination in EOL processes. Common to these patients was a belief in the right to choose how they would die and what treatments they would accept or refuse. These patients, being able to maintain their autonomy and the control, were able to interpret a way of rising above their circumstances, particularly their imminent death [18].

A different and also important point of view which is discussed in a paper by Roeland et al. is that the tension between autonomy and paternalism is both an ethical and practical issue. Autonomy is the current gold standard approach to patient communication and has grown to the point that patient preference dictates care, even when their choices are not possible or are medically nonbeneficial. Furthermore, we have observed a trend among physicians to avoid making difficult medical decisions by hiding behind a shield of patient autonomy. With this in mind paternalism, characterized as the antithesis of autonomy, still has a role in medicine in certain circumstances [19].

As important and obvious as conversations and patient's autonomy are in the EOL situation and in palliative care, the more important these are for every patient in any medical field. The lack of conversations with our patients as well as the lack of preservation of their autonomy are highly underrated facts that especially for conservative methods is often missing. For example, for surgery every patient has to fill in a consent form, but for treatment with antibiotics this is

not the case. The patient's will and autonomy is the highest good that should be respected.

Conclusions

With the right communication and consideration of the patient's autonomy as well as the described communication tools, not only can physicians do the patient a great favor in guiding a difficult palliative setting, but the physicians are doing themselves an important favor to align and follow their own ethical compass, so that physicians are not left with questions about whether they did the right thing.

Conflict of interest B. Engelhardt declares that he has no competing interests.

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