

End-of-Life Care in Chronic Respiratory Diseases. Ten Critical and Sensitive Questions

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Abstract

Getting close to death is the unique, solemn and most challenging event for all people, regardless age, gender, beliefs, religious and philosophic orientation, and health status. The longest sufferance patients encounter, the most painful waiting period they face. Advance care planning (ACP) is the process of appropriate communication between patients, health-care professionals and the patients' relatives about the preferences for end-of-life care. It became important to deliver high-quality end-of-life care, consistent with and respecting the patients' goal, values, needs and beliefs. ACP should prepare patients and the loved ones to participate with physicians in making the best possible in-the-moment medical decision, but this not always easy for the doctors, affordable to the health care system or acceptable by the patients and relatives. They are evaluated some key points of the process by addressing ten main questions.

Keywords: End-of-Life Care; Advance Care Planning; Chronic Respiratory Diseases; COPD; Lung Cancer

Abbreviations

ACP: Advance Care Planning; COPD: Chronic Obstructive Pulmonary Disease; CPR: Cardiopulmonary Resuscitation; FEV1: Forced Expiratory Volume in 1 Second; GOLD: Global Initiative for Chronic Obstructive Lung Disease; MV: Mechanical Ventilation

Introduction

Advance care planning (ACP) is the process of timely and honest communication between patients, health-care professionals and the patients' loved ones about the preferences for end-of-life care. It is important in delivering high-quality of end-of-life care [1], consistent with the patients' goal, values, needs and beliefs [2,3]. ACP should prepare patients and the relatives to participate with physicians in making the best possible in-the-moment medical decision [1,2].

ACP is frequently underutilised in chronic respiratory diseases; main information comes from chronic obstructive pulmonary disease (COPD) and lung cancer, despite the burden of sufferance that other diseases bring as well. ACP consists in the process of communication between patients and professional caregivers about options for end-of-life and palliative care (cardiopulmonary resuscitation/CPR,

invasive mechanical ventilation/MV, tube feeding before dying), options of life support and completion of advanced directives [4-6]. Palliative care is often not addressed or inadequately addressed in patients with COPD, allowing persistence of symptoms whose control or elimination would provide more comfort to the patients [5].

Even in the last 2017 GOLD recommendations for COPD, patients are asked to play an active role in the disease management through self-management, participation in rehabilitation programs, and discussions over end-of-life and prolonged care [7]. ACP can be effective in improving outcomes for the patients and their family members, providing support for advance care directives [4] and reducing suffering for all participants to healthcare process. In a study conducted by Chiu., et al. [8], one-fifth of community-dwelling older adults (75 ± 11 years) with multiple comorbidities empowered their doctors to make medical decisions for them. The rest of patients prefer to obtain information about their suffering and care options from their clinicians before taking a decision.

Critical and sensitive questions in advance care planning

When to talk about?

Timely conversations about life sustaining treatment is a crucial issue [9]; it has been suggested that talking on outpatients' premises, in a stable phase of disease, would be an appropriate moment [10]. Also, pulmonary rehabilitation programs provide opportunity to facilitate advance care and appropriate education [4]. A suggested possibility for the discussion is to be initiated after the occurrence of a disease exacerbation [9].

To improve palliative care communication, discussions should start early in the disease course or under specific clinical circumstances, like: the presence of cor pulmonale; the need for ventilation in the previous year; arterial pressure of carbon dioxide > 45 mmHg or FEV1 < 30%; recent hospital admission or consultation; oxygen dependency; weight loss or cachexia; decreased functional status; increased dependency on others; age above 70 years; and lack of additional treatment options [6,11].

Unfortunately, when discussions do happen, they often occur at an advanced stage of illness and in respiratory wards or intensive care units, when people are likely to die due to aggressive treatments. Optimally, preferences should be disclosed in early conversations with COPD patients, to have time enough to plan emergency and resuscitation decisions, palliative and hospice care interventions [11].

Most studies included in the last review of 2017 showed an undesired result: only a small percentage of patients with COPD have discussed palliative care with their clinicians. Doctors in the studies have reported several reasons like unpredictability of COPD, the fear of destroying patients' hope and the lack of understanding the need of palliative care in COPD by both patients and physicians [11]. Not talking at all with the patients about their preferences, not documenting or incorrectly documenting them in the medical records, should be viewed as "failure of communication" error or medical error [12].

Who should talk about?

Patients desire someone they know and who know them when discussing palliative care [11]. Skilled and trustworthy respiratory clinicians caring the patients for years are the most preferred professionals [10] [13]. Clinicians can provide specific recommendations and/or help patients and surrogates decide among available alternatives [2]. In other studies, patients transfer the trust to their general practitioner; a respiratory physician or a specialist nurse might be considered knowledgeable professionals, but generally not implicated in a personal relationship [11]. Emotional support is one of the most appreciated physicians' skill by the patients and their families [11].

The overall quality of end-of-life communication was found to be poor in many studies, especially because most topics were not discussed. When they have been indeed discussed, the quality was found quite moderate to good. It is therefore suggested that healthcare professionals should consider these conversations as part of their daily duties [11,13].

Who should participate?

Talking about ACP is a solemn and profound discussion between the patients and the medical team; the patients' relatives should be included if according to the patients' desire. Clinicians should identify the patient's preferences, share their medical opinion and propose the most suited plan of treatment. During discussions, patients might feel upset, angry, sad, worried or dominated by contradictory emotions [11]. Any disagreement identified between all parts should be debated to get to a common decision [11], but each action should be planned to the best of the patient; this is in fact the purpose of all interventions and the main outcome.

What to talk about?

ACP is a process that enables patients, family caregivers, and health professionals to make plans regarding the desired future care, including end-of-life care [9,10]. An essential part of ACP is end-of-life communication, a unique process requiring good communication skills for patients, family caregivers and health care professionals [9]. Family caregivers need such information to prepare them to cope with end-of-life arrangements and loss of the loved person [9].

As mentioned by Tavares, et al. for patients with end-stage COPD, education is an important special domain, as most of them did not recognize palliative care as an option for their disease, and did not understand the meaning of CPR and non-invasive ventilation as life-sustaining treatments [11]. The patients were not aware on the progressive and irreversible nature of COPD [11], and that they may die from this disease [6]. However, the preferences for CPR and MV changed in about two-third of patients with chronic organ failure at least once during the first year; the possibility of a negative outcome may be considerable in patients with COPD and most patients refuse to undergo such treatment options [1].

People with advanced organ failure have been assessed regarding the preference for site of death (home, hospital, care home, nursing home or hospice) [6,14]; to die at the preferred site is one of the key principles of a "good death". 61.2% of the patients changed their preference during one-year follow-up. More than half of patients (51.5%) reported they prefer to die at home, but unfortunately a higher proportion (57.6%) died in the hospital, and only 39.4% died at the preferred site [14]. Patients' preferences are influenced by vulnerability and fear, feeling the need of a safe environment, or being worried of becoming a burden for their family [14]. Discussing preferred site of death as part of the process of ACP may be a way to help families prepare for the crises moments, and to elaborate a management plan having the patient's options in mind [14].

What not to talk on?

There are some sensitive items like "talking about what dying might be like" and "asking about spiritual and religious beliefs" that were rated low both in the Netherlands and in the USA [10]. Doctors generally have reserves when talking about these items because they do not have the requested skills and because they try to avoid emotional impact generated by a terminal patient [11]. In the clinical team should be another professional addressing the case under physician coordination [6,10], e.g. a trained nurse, an allied health-care professional [6], or a clinician psychologist with some desirable characteristics: old enough to have a mature judgement, emotionally stable, empathetic and experienced, to completely understand the patients and family members sufferance, and to become a reliable support in the future. Priests are always welcome in the team for spiritual issues.

Using questionnaires and filing them in while talking to the patients, missing the eye contact and an empathetic attitude, might not be a very good idea. For the patients being close to the most terrifying moment of their lives, shortly before dying, it would mean no more than a clergy attitude in a supermarket, in a tourism agency or on a bank premise. This is an unnecessary stress, frustration and humiliation of the patient, increasing his anxiety, depression and loneliness in front of death. People did not change over centuries: they have same expectations, same few positive and especially negative emotions facing this major event. This is the complex and complicated human being, with body, soul and spirit, and high technology of the present time failed to intervene here.

Doctors' visits are waited eagerly worldwide, with a positive attitude and even with some sort of joy. All patients hope in good news for them, in new directions of treatment, in not being abandoned and in a continuous support. What kind of flag do doctors hold in their hands for centuries? There is the white flag of their fathers in medicine, always bringing hope [11], encouragement and alleviation. Doctors are supposed to fight for surviving and for a good quality of life up to the end. Patients declared that they prefer to concentrate on staying alive [10]; doctors should support this intention with generosity and willingness to help.

Doctors should refrain from pronouncing the word “death” (e.g., “what make the death might be/look like?” [10,11]); they are promoters of life, regardless the necessary efforts. Words have energy, they can change reality into a good or bad way. By talking about death one take away all patients’ hopes [11], the possibility to live a miraculous improving and even curing. Body has an innate intelligence, it can cure itself under favourable stimuli; doctors everywhere in the world may meet patients with only 3 supposed months ahead being still alive after 10 - 15 years despite unfavourable prognosis.

What are the barriers to end-of-life communication?

There are some recognized barriers depending on the patients and clinicians as well. Here they are mentioned some of the patients’ limitations: patients with advanced disease have concerns about dying, but they do not initiate discussion of this kind with their doctor and wait for the doctor’s first step; patients’ ability to make end-of-life decisions might be compromised at a certain stage; they cannot consider all implications of treatment decisions [13]; many of them refuse to think about issues related to illness, death and may not want to participate in decision making [2].

Both patients and family caregivers might wait for the known and trustworthy doctor to initiate the end-of-life communication, and sometimes they need to receive information several times up to complete understanding of the issue [9]. The major limitation of this process is that the patients might feel abandoned from this time on and consider themselves entering in a very severe phase of disease; these feelings might take away any reasonable hope [6].

Only a small proportion of 14% patients believe that doctors understand their wishes for end-of-life care; interestingly, only 31% of patients with advanced COPD estimated their life expectancy to be less than one year [4]. Discussions about end-of-life issues should take into consideration cultural values and beliefs of different population, especially in multi-ethnic communities. Patients who are more passive will receive less information from clinicians; minorities tend to report lower satisfaction with patient-clinician communication [8].

Among US patients, a high proportion reported they are not sure which doctor would be taking care of them if they would become very sick; in this view, continuity of care by the same doctor might be the best way to ensure the quality of patient-clinician communication [10]. Other reported barriers are that patients change many times their options and doctors look down at people who used to smoke [10].

A considerable proportion of patients, even with very severe disease, reported they are not ready to talk about care they want if they become very ill [10], or they prefer to focus on staying alive instead of dying [9]. These facts are very important at a deeper look, because they reveal the natural fear, anxiety and temptation of running from death; people avoid talking and calling a certain reality in their lives if this makes them suffer (“I feel that talking about death can bring death closer”) [9]. There is an aspect doctors should reflect about: despite all interventions designed to improve frequency and quality of communication, only a modest impact was noted, maybe because patients feel uncomfortable with these kind of discussions [11].

Even in these cases, several actions can be taken in clinical practice to reduce the refuse of the patients to discuss this important topic: looking for patients’ readiness to discuss palliative care, slowly titration of information according to the patient’s own rhythm and respond when patients/relatives raise the subject on their own [11]. However, this remain a sensitive and painful issue; the most efficient way of using clinicians’ time in such situation is to educate, motivate and address barriers [2].

Clinicians reported tensions between remaining hopeful and the reality of patients’ conditions, lack of time for extensive ACP discussions and poor communication skills [2,11,13]. They are unable to accurately evaluate the patient’s individual prognosis; there are difficulties in understanding the likelihood of death in COPD and other respiratory diseases; also, death might appear unexpectedly due to intercurrent illnesses or to progression of comorbidities, without any prior ACP [13]. Patients with previous open palliative care discussions rated their medical care and clinicians’ skills higher than the patients who did not. That means that they had a discussion on personal preferences, their wishes were respected and care was adjusted accordingly [11].

What are the facilitators of end-of-life communication?

They have been noticed some factors facilitating communication: doctor seems to care about the patient as a person; the patient is worried about the quality of life in the future and do not wish to become a burden for the family and friends; repeated questions from the doctor about end-of-life care and talking with another person but the doctor about the desired care [9,10]. COPD patients reported as important the clinician communication skills; competence of their physician and earlier experience with death in their environment are also helpful [9,10].

Patients who are uncomfortable talking about these issues may be indirectly approached; using structured formats to guide end-of-life discussions might be a useful idea [9]. Conversations directed to self-efficacy around disease management and quality of life concerns may enable patients to actively participate to future treatment plans [9,10].

What are the benefits from talking about?

The first to benefit are the patients, receiving educational topics on their disease, prognosis and end-of-life care. When patients informed their physicians that they would like to receive all available treatments, regardless of limited benefits and invasiveness, Quill, et al. cited by [11], found that the most appropriate response was to provide accurate information about the illness, prognosis and possible outcomes of life-sustaining treatments. Conversely, some patients might prefer comfort instead of life extension, to maintain dignity or to be free of pain, so doctors should be careful to the patients' wishes [2].

Second, the family caregivers, deeply involved in the practical care and emotional support of the patients, are helped to participate to the decision-making process in medical care and have an acceptable bereavement [9]. Moreover, Detering, et al. found a reduction in stress, anxiety and depression in family caregivers through the ACP process [15]; that could also improve satisfaction with end-of-life care in family members of deceased patients [13]. It is important therefore to discuss the uncertainty of prognosis and the possibility of unexpected death with closest relatives of patients with advanced chronic organ failure [14].

It should be taken into consideration that patients and family caregivers often have divergent hopes, desires, needs and beliefs about end-of-life care, and require different levels and types of information [2,9]; for example, family caregivers may want detailed end-of-life care information and may feel more comfortable to make plans [9]. In opposition, the end-of-life care information is an issue frequently avoided by the patients on directly approach [10]; therefore, most patients want their loved ones to have freeway in making decisions [2].

Unlike people with COPD, the cancer sufferers expect conversations regarding ultimate prognosis and the impact of treatment and care; the main difference is that cancer brings the terrible expectation of death. In COPD, the variable and unpredictable progression over time make discussions on care planning not expected or requested [11]. Difficult to believe, but many COPD patients and their relatives declared that they didn't expect this disease to be the cause of death [6]. Moreover, patients with advanced illness seem to adapt to their deteriorating state of health, which may affect the willingness to accept life-sustaining treatments [1].

What are the risks of open talking?

Initiation of ACP discussions should not be perceived by both patients and doctors as a transition to cessation of life-prolonging treatments; more than that, the patients should not feel abandoned [6]. Affirming non-abandonment of patients and families is important to be included in end-of-life conversations and it is associated with increased family satisfaction [6]. The amount of information and details might overwhelm the patients, contributing to the instability of preferences for end-of-life care [1]. ACP should be a continuous process for all parts, in which preferences for specific situations are discussed and regularly evaluated to deliver high-quality end-of-life care [1].

Is ACP available everywhere in the world?

Janssen, et al. have mentioned the Cartwright study showing that Dutch clinicians were more likely to discuss purpose of treatment and palliative care compared with clinicians from other European countries. Moreover, the Netherlands have legalized euthanasia and it is premature to determine the consequence over communication on end-of-life care; it is still unclear if the findings from this study are applicable to other European countries [10].

ACP and the importance of improving end-of-life care is supported by legislation in Australia, the USA and the UK [15]. Similar programs have been implemented in other health care systems as in Canada, Germany, Spain, Singapore [15] and in the Netherlands [10]. In other less developed European countries lack the legal, financial and material conditions, palliative care being reserved to cancer patients.

Conclusions

End-of-life communication and care is a unique and complex process requiring financial and technical possibilities, a legislation frame and deep empathy for the patient. Looking to the patient as to a person, understanding his fear in confrontation with the sufferance and death, and identification of all obvious or hidden mechanisms to intervene, will bring the much-desired peace and courage in front of his last journey and inherent passage.

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