

End of life care in lung cancer patients: not at life's end?

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Abstract: Metastatic lung cancer has a poor prognosis, with a mortality of more than 80% within one year. As chemo- and radiotherapy are both effective in the palliation of symptoms, the emphasis of management is often too much put on these therapies, inducing unrealistic expectations. Since the most important aspect of caring for patients with metastatic lung cancer is to optimize or restore their quality of life (QoL), we need to integrate standard oncologic therapy with early palliative care to achieve a better understanding of the disease by the patient and his caregivers.

Keywords: Early palliative care; non-small cell lung cancer (NSCLC); communication



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Lung cancer has a poor prognosis, predominantly due to its metastatic spread at the time at diagnosis with a mortality of more than 80% within one year. The most important aspect of caring for this type of cancer patients is to optimize or restore their quality of life (QoL) by integrating early palliative care with standard oncologic therapy. As chemo- and radiotherapy are both effective in the palliation of symptoms, the emphasis of management is often too much put on these therapies, inducing unrealistic expectations. This is confirmed by Chen *et al.* in their report on patients treated with palliative radiotherapy (1). Most of them did not understand that it was not at all likely to cure their disease. Moreover a similar finding was previously reported by this group of researchers in patients receiving palliative intent chemotherapy (2).

Are these misassumptions due to bad communication by their attending physician or is it because of misinterpretation by the patients? Communication between doctor and patient is an interactive process in which the physician sends, and the patient receives the message. What are the patient-related factors which interfere with an adequate reception of the message? Maybe the patient is well informed but doesn't want to listen. Denial is considered a normal phenomenon, part of the illness process that cancer patients have to go through. Patients and their caregivers want to live their life as normal for as long as

possible (3). In most cases when bad news is broken, a part of the message is not received. Many patients do not ask for precise information when they fear that their prognosis is rather poor. Friedrichsen *et al.* observed that terminally ill patients want to know the truth but the content of the definition of this truth is variable. Although most patients say, when questioned, that they want to hear the truth by their doctor, their preferences change when they receive bad news in real life. Patients identify three types of truth they want to hear: firstly, the absolute objective truth that they are dying, secondly the partial truth about their condition including some facts but not all of the details and lastly the desired truth, originating in the patient's own beliefs about a healthy or better life (4).

What about the physicians? Since it is well known that metastatic lung cancer has a poor prognosis, an overly optimistic view on the disease course by the treating physician is presumably not the reason. Breaking bad news is always difficult and takes time. Maybe time shortage during a very busy clinic can be a fake argument not to (immediately) communicate about the palliative setting. A consultation in a palliative setting can indeed require an hour. Or is it the presumed conviction of the physician that hope must be a part of breaking bad news. Lamont *et al.* reported that only 37% of physicians gave a frank survival estimation (5).

Looking at the course of the conversation between doctor and patient, a characteristic feature is that when the patient is told that he/she has an incurable cancer, there is a rapid transition from the provision of bad news to a discussion about what can be done with chemo- and or radiotherapy. Both parties collude in focusing on “the treatment calendar” and, at the same time, in ignoring *the long term* (6). In such a dialogue it seems that a non-verbal message is sent: all these efforts and expenses involved in the therapy can’t be “useless” and patients can start switching to think about a therapy with possible curative intent. Moreover those patients live from consultation to consultation hoping for “good” news as “therapy worked”, forgetting to live their life. Whatever the reasons: this way of communication refrains the patient from advanced care planning by postponing the end of life discussion to life’s end, when death is imminent or occurs during an acute hospital admission (7). Many patients do not have a no “Do Not Resuscitate” code at admission, prompting the end of life discussion by a non-oncology embedded provider in the Emergency Department (8). This is not the way it should be.

Breaking bad news will always be unpleasant but necessary to do. There are many guidelines, recommendations, trainings and workshops using a variety of theories to improve provider skills in bringing bad news, assuming that these interventions lead to a better psychological outcome for the patient (9). The latter includes less anxiety, less depression and distress, more satisfaction with care and better QoL, but also a better understanding of the disease. There is however, presently little evidence that a bad news dialogue according to these guidelines results in an improved patient well-being (10).

The median survival of patients with metastatic lung cancer averages 10 months (11). So in fact, there is no time to lose for the patient to gain a good insight in what the goals of standard oncologic therapy are and in what he/she, as an individual may expect from the end of life. When a patient and his/her family know that he/she is going to die, the grief process starts. This process goes through five emotional stages: denial, anger, bargaining, depression and acceptance (12). In the ideal situation the patient eventually accepts his imminent death, supposing truly acceptance is ever possible. This grief period takes time, usually at least a year (13), and as patients with non-small cell lung cancer (NSCLC) have little time, they often die before completing their grief process. This is one of the psychological challenges, specific for lung cancer patients.

Integrating early and repeated palliative care visits in

ambulatory setting plays an important role in guiding the individual towards a personalized care. These visits need to focus on several topics: education and understanding of the illness, symptom management, decision-making, coping with life threatening disease, referrals to other care providers. It gives the opportunity to the patient and his/her family to think about the end of life at a stable moment in the disease. This way, they go through a process in which also the long term is in sight, even without having to tell a frank prognosis. This timeline implicates an important issue: the physician tailors the information to the needs of the patient, gradually leading to a decision in how the patient wants his/her end of life, reducing aggressive and useless therapies and avoiding discussions at acute moments by other than the attending physician. The general practitioner needs to be involved in this process as soon as possible to fine tune this communication and bringing the same message to the patient and his/her next of kin.

Early palliative care in combination with palliative chemo- and radiotherapy leads to a significant improvement in QoL, mood, and even survival in patients with advanced lung cancer (14). It should become the new standard of care. Nevertheless, as reported here, lots of patients even now a days have still unrealistic expectations and are not aware of their infaust future. The reason can be that comprehensive palliative care advice is difficult to combine with the management provided during standard outpatient clinic. For this reason, we recently started separate outpatient visits with another than the treating physician and using the general guidelines for the palliative care visits from the National Consensus Project for Quality Palliative care (15). The main goal, as stated before, is to optimize QoL with a better understanding of their disease.

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