

# Illness understanding in patients with advanced lung cancer: curse or blessing?

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**Abstract:** Early palliative care (EPC) should be introduced from the start of the treatment of patients with advanced lung cancer. Unfortunately, this is often not integrated in daily oncologic care. This letter wants to emphasize the importance of offering a holistic approach, meaning EPC to optimize quality of life (QoL). Illness understanding is important because patients with better understanding of their disease choose more often for symptom control and less for an aggressive treatment at the end of life. This illness understanding should be achieved during communication with the treating oncologist. Based on the limited available literature about illness understanding, it seems that an EPC program is necessary when breaking bad news, in order to maintain or improve QoL in patients.

**Keywords:** Early palliative care (EPC); advanced lung cancer; illness understanding

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## Introduction

Lung Cancer is the most common cause of cancer death in Europe with around 354,000 deaths in 2012 (20% of the total) (1,2). Its diagnosis in advanced stage is the most obvious cause of this poor prognosis. Patients with advanced lung cancer have a median survival of 10 months (3). In view of the fact that there is no cure possible, treatment is primarily based on maintaining the quality of life (QoL). According to the World Health Organization (WHO) this means a treatment which improves the QoL of patients and their relatives, who deal with a life threatening disease, by preventing and relieving the suffering by means of early detection, careful judgment and treatment of pain and other problems of physical, psychosocial and spiritual kind (4). Informing the patient and his/her family of the consequences and prognosis of their disease is an important part of the treatment and needs to be undertaken by the treating oncologist. In daily practice, most patients start

with palliative chemotherapy (and, if needed, palliative radiotherapy) to improve survival while maintaining their QoL by improving symptom control (5). The other aspects of palliative care are often addressed in a later phase of the disease history (6). Can a patient be informed of his prognosis from the diagnosis onwards without detrimental effect on QoL? The purpose of this current review is to provide an answer on this relevant question.

## The consequences of a primarily physically-oriented treatment

When a physician brings bad news and tells the patient that he/she has an incurable disease, this part of the consultation is often quickly followed by the discussion of the treatment plan, where the main discussion is about side-effects of chemo- and/or radiotherapy. Physicians and patients are focused on the 'treatment calendar' and therefore primarily



**Figure 1** Influence of EPC on illness understanding and QoL. EPC, early palliative care; QoL, quality of life.

on the physical aspect of lung cancer. They don't address the factual goal of the treatment, which is palliation in view of a better QoL. There also seems to be a non-verbal message: all these efforts and costs cannot be 'useless', and the patient makes a mind switch where he believes that the treatment will cure him/her (7).

Although the patient should be aware of the palliative goal of the treatment, recent research has shown that most patients assume that they are still receiving a curative treatment (8-10). It hence seems that many patients and their family have no insight about the palliative setting of their disease. In 68% of the cases, the patient's family only realizes that the disease is incurable, when this has explicitly been said by the physician (11). The same authors also report that this issue is only discussed rather late in the disease history: in 24% of the cases even less than a month prior to the patient's death. This implies that these conversations are often held by a physician, other than the treating physician, during an acute hospital admission when the patient is already in the final stage of his disease evolution (12). Pardon *et al.* have shown that more than half of the patients with metastasized lung cancer were not involved in a conversation about life end, despite the fact that most patients indicated that they wanted to be involved (13). Starting with palliative care at an early stage of the disease makes this possible. This is called early palliative care (EPC) in which the treating physician plays a role in communicating about the goal of the therapy.

### What is the content of EPC?

EPC includes better symptom control, strengthening coping mechanisms, improving illness understanding, making the patient aware of the prognosis and involving the family (14). This results in a more holistic approach towards the patient in comparison with the standard oncologic outpatient contact.

### EPC and advanced lung cancer

Temel *et al.* (15) performed a randomized controlled

trial in patients with advanced lung cancer, whereby the effect of EPC, starting within 8 weeks after diagnosis in combination with the standard oncological treatment was compared to standard oncological treatment only. They showed that the intervention group experienced a better QoL and state of mind, better illness understanding and a longer survival, with less aggressive treatment at the end of life (*Figure 1*). This study and two other randomized studies (16,17) are considered 'landmark studies' for the implementation of EPC in the day-to-day care since they all showed better QoL in the EPC group (18). Is this effect on QoL primarily caused by better symptom control? Is this the effect of more attention for the other domains by more social, psychological and spiritual support? Or is it influenced by early communication on the palliative setting, with consequently a better illness understanding and less aggressive therapy? Until now, the answers are unclear and need further investigation.

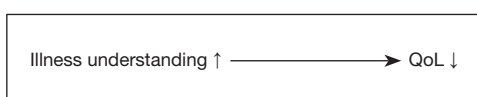
In practice, EPC has not been applied yet (6). Most likely, this has to do with operational reasons such as lack of time and insufficient resources to work out such a care pathway. Furthermore, there are hospitals without palliative units but with a palliative team having limited resources.

### Understanding the disease

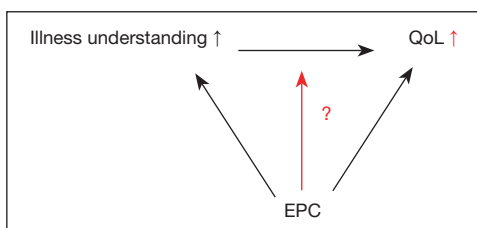
Patients with better understanding of their disease choose more often for symptom control and less for an aggressive treatment at the end of life (19). Until now, limited research has been done with regard to illness understanding in patients with lung cancer. Two recent studies have shown that in patients with either gastro-intestinal or hematological malignancies, who did not receive EPC, a better disease insight was correlated with a reduced QoL and more distress (10,20). Another study concludes that patients with advanced lung cancer, who show a certain degree of denial, have a better QoL (21,22). These data suggest that disease insight implies reduced QoL (*Figure 2*).

### Influence of illness understanding on QoL in patients with advanced lung cancer

Informing the patient and his/her family of the consequences and prognosis of their disease is an important part of EPC and needs to be undertaken by the treating oncologist. The available evidence suggests a possible negative interaction between illness understanding and QoL (*Figure 1*). On the other hand, there is a positive interaction



**Figure 2** Influence of illness understanding on QoL in patients with malignancy. QoL, quality of life.



**Figure 3** Can EPC buffer the influence of illness understanding on QoL? The red line assumes that EPC has a protective effect on the relation between illness understanding and quality of life. EPC, early palliative care; QoL, quality of life.

between EPC and Illness Understanding and between EPC and QoL (Figure 2). Figure 3 amalgamates these two previous figures and suggests that EPC has a protective effect on the relation between illness understanding and QoL. This is a relevant question for a physician. Can a patient be informed of his prognosis from the diagnosis onwards without detrimental effect on QoL? It seems that this is only possible if the necessary preconditions, namely EPC with holistic support of the patient and his/her family, are met.

## Conclusions

Illness Understanding by the treating oncologist is an important part in the treatment of patients with advanced lung cancer. Based on the limited available literature about illness understanding, it seems that an EPC program is necessary when breaking bad news, in order to maintain or improve QoL in patients. Illness Understanding seems to be a curse but can become a blessing when EPC is offered. Whether the relation between illness understanding and QoL is different in patients with or without EPC is matter of further research.

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## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

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