8024 ORAL

Lung cancer patients' quality of life during chemotherapy: comparison of patients and their partners perceptions

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Background: Quality of life (QoL) is recognized as a significant prognostic factor in lung cancer patients, most of whom have a poor prognosis. In Greece partners play a substantial role during patients' illness trajectory. The purpose of this study is the comparison of Greek patients' and their partners' perceptions about patients' QoL during chemotherapy.
Material and Methods: The sample consisted of patients diagnosed with primary lung cancer and their partners ($n = 40$) hospitalized in departments in the metropolitan area of Athens. Patients and partners completed in the same day, the same measurement instruments in separate rooms, one after the other. Measurement instruments completed at three different points during (before, in the middle and after) chemotherapy course were: European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 and LC13, and Partner Relationship Inventory. Instruments had appropriate psychometric characteristics in the study sample.
Results: Almost all of the couples were married (97.5%). The majority of patients were male (95%) with mean age 60.3 years, advanced disease (62.5%) and 59% metastasis. Partners mean age was similar to patients (55.1 years).
High attrition rate reduced sample size during chemotherapy to 25 couples at second measurement and to 10 couples at the third. The most common attrition factors were patient's death (33.3%) and partners' denial (26.7%) to participate to the study, at the second measurement and partners' denial (26.7%), chemotherapy discontinuation due to disease control (26.7%) and patient's death (20%) at the third one.
Partners evaluated sufficiently patients' QoL with EORTC scale during chemotherapy. Statistically significant differences were observed only in fatigue ($p = 0.030$) at the first measurement and emotional functioning ($p < 0.001$) at the second. Partners overestimated their responses about patients fatigue and emotional functioning during chemotherapy.
Demographic and clinical data was not related with the level of agreement between patients and partners estimations about patients' QoL. Contrary partners' perception of the quality of couple relationship ($p = 0.046$) affected negatively the level of agreement with patients.
Conclusions: This first Greek study comparing patients and partners perceptions about patients QoL recognized the significance of partnership relationship when partners are used as proxy estimators of patients QoL, despite high attrition rate of patients.

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Health-related quality of life in significant others of patients dying from lung cancer

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Background: The interconnectedness between patients and their families has previously been demonstrated; illness is consequently a family matter. The rapid disease trajectory of inoperable lung cancer stresses the importance of studying health-related quality of life (HRQOL) for significant others of patients dying from lung cancer, through the disease trajectory and in the bereavement phase. This study compares HRQOL in significant others of patients dying from lung cancer, with a general population sample. Further, it explores the course of HRQOL from diagnosis (T1), at a time point close to the patient's death (T2), and six months after the patient's death (T3).
Material and Methods: The Swedish Health-Related Quality of Life Survey, SWED-QUAL, assessing functioning and well-being in aspects of the physical, mental and social domains were selected. For group comparisons at T1 and T3, independent t-test were used including 137 and 74 significant others respectively. For these group comparisons a random sample from the Swedish population was used for composing matched groups. For longitudinal analyses repeated measures ANOVA were used including 38 significant others. In the case of statistically significant effects, patterns of change in these scales were identified.
Results: The group comparisons at T1 showed that the significant others scored significantly lower on the scales in the mental domain compared to a general population sample. These results were the same at T3, when the significant others also scored lower on most of the scales in the physical and social domains. In the longitudinal analyses there were significant changes in five scales or items, and three patterns of change were identified: a decrease-increase pattern for 'self-rated health', 'emotional well-being' and 'positive affect'; a constant decrease pattern for 'family functioning'; and a decrease-stable pattern for 'satisfaction with family functioning'.
Conclusion: Living with inoperable lung cancer in the family and then facing the death of a family member affects most of the HRQOL dimensions.

8026 ORAL

Significant others' perceptions of the development in relational functioning during lung cancer

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Background: Due to a rapid disease trajectory, high symptom distress, and most patients cared for at home, significant others to lung cancer patients often take an active supportive role for the patient, emotionally and physically. The success of this support may be dependent on how the relation to the patient is perceived by the significant other and how the relation is developing over the disease trajectory. The aim of this study was therefore to study relational functioning between significant others and lung cancer patient from the perspective of the significant other, and to explore developmental patterns of relational functioning during the course of the illness on both group and individual level.
Materials and Methods: In a sample of 91 significant others to lung cancer patients, data was collected four times during the first year after diagnosis. Statistical analyses were conducted for group distribution. In addition a classification of stability and change in individual development in relational functioning was carried out. To explore patterns of change over time, individual empirical growth curves were constructed and deductively classified into four typical patterns of change.
Results: Results show that relational functioning skewed towards good functioning, even though 30% of the significant others reported problems in relational functioning at first occasion. Fifty-two percent of significant others reported change in relational functioning during disease trajectory, while 48% reported stability. Of the significant others who were stable in relational functioning, 36% reported consistently low levels of relational functioning. Four typical patterns of change were identified; two showed approximate linear changes in either a positive direction (15%) or a negative direction (49%) and two showed non-linear changes with a temporary ascending curve (11%) or descending curve (26%).
Conclusion: This study shows that lung cancer may be a trigger for changes in relational functioning, with a linear or temporary decrease as the most common pattern. This implies that changes toward a more problematic relation are most common. Those significant others as well as patients in problematic relations would most probably benefit from interventions aiming to maintain good relational functioning throughout the disease trajectory.

8027 ORAL

The professional family dialogue – a Danish approach to a dialogue with terminal ill patients

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Background: At the oncology/haematology ward O81, Roskilde Hospital, we focus on giving our dying patients the best quality of the remaining life. Therefore O81 has a special area called "section for Palliative treatment" (ALB). The visions of ALB are inspired by WHO's Definition of Palliative Care. All our patients are offered a professional family dialogue, based on the patients need and desires, life situation and conditions.
Material and Methods: This survey is based on material from 100 professional family dialogues during 2006. We help the patient to identify close relatives, and invite them to a dialogue lasting 45−60 minutes. A staff nurse and a doctor are always in attendance. We invite the patient and their relatives to the dialogue, prepare the patient and their relatives about issues that might be discussed. The professional family dialogue described here starts from a hermeneutic point of view. We have two focuses in the dialogue: the patient and the relatives. We manage the focus but the patient places the focus. We invite the family to talk, to open up on the unspoken words, to talk openly about the illness, death and where the patient wants to die. We try to help the family to solve some of the problems they have as a family living with cancer.
Results: The relatives are often not at the same level of realization, before the professional family dialogue, as the patients, or vice versa. Afterwards the family talks more openly about the future and often join the family closer together. As a result of the dialogues, we make sure that all the participants are at the same level, and we ensure all of them get the opportunity to speak, ask questions or express how they feel. The illness is now more legitimate, and we encourage the family to continue the conversation. During the dialogue the patient and relatives move to a new

level of realization. After the conversations most of the families start to plan the future, facing the upcoming death with courage from a new perspective and feels they get a better quality of life.

Conclusion: The overall results of our professional family dialogues are, that the patient's feel relieved when the unspoken has been verbalised. The patient and family now have the same recognition of the situation and therefore have better terms for quality of life.

Joint EONS/ECPC symposium

(Tue, 25 Sep, 09.15–11.15)

Meeting cancer patients' informational needs: rising to the challenge

8028 INVITED

Are patients' experiences important for nurses?

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The purpose of this abstract is to give an overview and introduction to the topic described in the title. A systematic review of literature on the types of information important to cancer patients was conducted. The review included 18 studies. A synthesis of the ranking of the importance attached to various types of information by patients in individual studies showed that information about the disease itself and information about the treatment that follows are the most important types. Information about sexual concerns and physical attractiveness was ranked least important by cancer patients overall. Also, the review indicates that highly educated patients may be similar to less educated patients in the types of information they need. As for the impact of patient situations on the need for a specific type of information, patients who prefer to be active in decision-making during illness want more information about their illness. Although some evidence existed to indicate that patients who are closer in time to their diagnosis need to understand the disease by wanting more information about their illness, the stage of cancer does not affect the type of information needed. Although it is true that not all patients wish to know the nature, cause, and treatment options for their disease, there is evidence showing that virtually all patients have a deep seated need for specific information. It has been found that having relevant information not only helps patients understand the disease but also facilitates patients' decision-making and coping. While most patients want basic information on diagnosis and treatment, not all want further information at all stages of their illness. Three overarching attitudes to their management of cancer limited patients' desire for and subsequent efforts to obtain further information: faith, hope, and charity. In descending order of use, health care professionals, medical pamphlets, and family and friends were most used information sources. Internet and support groups were least used. In descending order of helpfulness, books, health care professionals and medical pamphlets were found to be most helpful information sources. Younger patients used health care professionals and certain forms of written information sources more than older patients

Conclusions: Cancer patients' attitudes to cancer and their strategies for coping with their illness can constrain their wish for information and their efforts to obtain it. The systematic review shows that many areas of cancer patients' information source use have been either neglected or barely analysed. An in-depth understanding of cancer patients' use of information sources and the characteristics in information sources they consider to be helpful is important for developing successful interventions to better inform patients.

8029 INVITED

Do we know what patients need?

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Abstract not received.

8030 INVITED

Access to information – the reality for European patients today

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The main patient complaint in this new Millennium of information is precisely the lack of appropriate information and communication from and with their treating physicians. The key word is appropriate and the patient lost in the face of cancer cannot rid himself of anxiety and uncertainty in front of his physician who always seems to lack time. Information and adequate education have general and specific goals in all aspects of our civil society but are absolutely vital in guiding cancer patients through the scientific labyrinth of modern up-to-date medical diagnoses and treatment. It is virtually impossible to elucidate the complexity of optimal medical treatment in one sweeping move. This information has to come in steps to avoid overwhelming information from the internet, incomplete information from the physician and contradictory information from friends and media. It is even more difficult to exchange information on a similar wavelength in dealing with the fear and panic as part of holistic patient care. The recognized need for a multiprofessional cancer treatment enhances the problem and existing barriers should be eliminated for a timely and empathic patient journey through the emotional stages of diagnosis and decision making in cancer treatment. This process demands more than patient information and requires the adaptation and education of the care team trained to treat cancer cases with limited time to understand the individual person behind the case. This lack of access to adequate information and communication exists for all consumers of our health care system in variable degrees. Serious progress has been made in pediatric and female health care by dedicated organisations including EONS and Europa Donna. Similar efforts are provided for geriatric and male health care where patient organisations such as Europa Uomo in direct collaboration with the professional organisations work towards a well informed patient, engaged in his own and others welfare, leading to better management decisions and optimal outcomes.

8031 INVITED

Meeting patients' informational needs: a practical example

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Introduction: After diagnosis, many cancer patients will receive an abundance of information about their disease, possible treatments and its side effects. This often occurs during a relatively short period of time during which patients' are struggling to come to terms with the cancer diagnosis. Under these circumstances it is difficult for many patients to retain and understand the information given. Furthermore patients have varying information needs, while some actively avoid detailed information; others will go to great lengths to educate themselves in every aspect of their diagnosis and treatment. A CD-Rom concerning Stem Cell Transplantation was developed as it has the potential to provide comprehensive information that can be accessed according to the patient's individual requirements. The CD-Rom was produced primarily for patients, their family and relatives. However, it can also be used for training purposes by both clinical and education staff.

Subject: The CD-Rom comprises audio, video, animations, pictures and the possibility of printing relevant sections. It consists of two separate components: Part one describes detailed information regarding the whole treatment course from diagnosis through to post discharge care. The second part consists of interviews and the case history of eight different former patients lasting twenty minutes each.

The information concerning treatment of part one is divided into six modules: 1. diagnosis, 2. the hospital, 3. Stem Cell Transplantation including the preparation like chemotherapy and radiotherapy, 4. side effects and their management, 5. neutropenia and 6. discharge and home situation.

The information is sequenced in order of the patients' treatment course and can be used in that order, although it is also possible to go directly to modules which are relevant to particular patients and their particular needs. The patient case history can be used in combination with the relevant information or both sections used independently. The system used to compose the CD-Rom makes it relatively simple to utilise the information or make it suitable for other institutions or even other treatments. Although the CD-Rom is in Dutch the principles are transferable and could easily be used in other languages and even other treatments.

Results: Distribution of the CD-Rom started in the spring of 2006. The patient is given the CD-Rom to take home following consultation with the doctor or transplant coordinator. This enables them to access the information in their own environment with or without family, at a time suitable to them and with the option to repeat or skip sections as they like. These properties along with the audiovisual properties of the CD-Rom provide a method of information which is easily retained. Although a survey is running, the first responses have been very positive. Finally patients felt that information given at home is more likely to be remembered.

The interactive CD-Rom looks a promising supplement next to the existing methods of patient education.